

# BIOETHICS



PRINCIPLES, ISSUES, AND CASES

LEWIS VAUGHN

OXFORD  
UNIVERSITY PRESS

FIFTH EDITION

# Bioethics

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Lewis Vaughn

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UNIVERSITY PRESS

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## PREFACE

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This fifth edition of *Bioethics* embodies all the features that have made it a best-selling textbook and includes all the most important changes and improvements that dozens of teachers have asked for recently and over the years. The book is, therefore, better than ever. And if it isn't, let even more good teachers say so and let the corrections and enhancements continue. And may the book remain, as so many teachers have said, exactly suitable to their teaching approach.

*Bioethics* provides in-depth discussions of the philosophical, medical, scientific, social, and legal aspects of controversial bioethical issues and combines this material with a varied collection of thought-provoking readings. But on this foundation are laid elements that other texts sometimes forgo:

1. An extensive introduction to ethics, bioethics, moral principles, critical thinking, and moral reasoning
2. Full coverage of influential moral theories, including criteria and guidelines for evaluating them (the focus is on utilitarianism, Kantian ethics, natural law theory, Rawls's contract theory, principlism, virtue ethics, the ethics of care, and feminist ethics)
3. Detailed examinations of the classic cases that have helped shape debate in major issues
4. Collections of current, news-making cases for evaluation
5. Many pedagogical features to engage students and reinforce lessons in the main text

6. Writing that strives hard for clarity and concision to convey both the excitement and complexity of issues without sacrificing accuracy

### TOPICS AND READINGS

Eleven chapters cover many of the most controversial issues in bioethics, detailing the main arguments and filling out the discussions with background on the latest medical, legal, and social developments. The main issues include paternalism and patient autonomy, truth-telling, confidentiality, informed consent, research ethics, clinical trials, abortion, assisted reproduction, surrogacy, cloning, genetic testing, gene therapy, stem cells, euthanasia, physician-assisted suicide, the just allocation of health care, pandemic ethics, and racial bias in health and medicine.

Every issues chapter contains one to twelve readings, with each selection prefaced by a brief summary. The articles—old standards as well as new ones—reflect the major arguments and latest thinking in each debate. They present a diversity of perspectives on each topic, with pro and con positions well represented. In most cases, the relevant court rulings are also included.

### SPECIAL FEATURES

A two-chapter introduction to bioethics, moral reasoning, moral theories, and critical thinking. These chapters are designed not only to introduce the subject matter of bioethics but also to add coherence to subsequent chapter material and to provide the student with a framework for thinking critically about issues and cases.

Chapter 1 is an introduction to basic ethical concepts, the field of bioethics, moral principles and judgments, moral reasoning and arguments, the challenges of relativism, and the relationship between ethics and both religion and the law. Chapter 2 explores moral theory, shows how theories relate to moral principles and judgments, examines influential theories (including virtue ethics, the ethics of care, and feminist ethics), and demonstrates how they can be applied to moral problems. It also explains how to evaluate moral theories using plausible criteria of adequacy.

**Helpful chapter elements.** Each issues chapter contains:

1. Analyses of the most important arguments offered by the various parties to the debate. They reinforce and illustrate the lessons on moral reasoning in Chapter 1.
2. A section called “Applying Major Theories” showing how the moral theories can be applied to the issues. It ties the discussions of moral theories in Chapter 2 to the moral problems and illustrates the theories’ relevance.
3. A section labeled “Classic Case File” that examines in detail a famous bioethics case. The stories covered in these sections include those of Elizabeth Bouvia, Jerry Canterbury, Nancy Klein, Baby M, Nancy Cruzan, the Kingsburys, Christine deMeurers, and the UCLA Schizophrenia Study. These are in addition to many other controversial cases covered elsewhere in the book—for example, the Terri Schiavo controversy, the Tuskegee tragedy, the Willowbrook experiments, and the U.S. government’s human radiation studies.
4. A bank of “Cases for Evaluation” at the end of each chapter. These are recent news stories followed by discussion questions. They give students the chance to test their moral reasoning on challenging new scenarios that range across a broad spectrum of current topics.

A diverse package of pedagogical aids. Each issues chapter contains a chapter summary, suggestions for further reading, and a variety of text boxes. The boxes are mainly of three types:

1. “In Depth”—additional information, illustrations, or analyses of matters touched on in the main text.
2. “Fact File”—statistics on the social, medical, and scientific aspects of the chapter’s topic.
3. “Legal Brief”—summaries of important court rulings or updates on the status of legislation.

#### NEW TO THIS EDITION

##### *A Chapter on Pandemic Ethics*

Chapter 12 covers many of the most important life-and-death issues and moral debates that have occurred during the COVID-19 pandemic: emergency triage and the allocation of scarce medical resources (ICU beds, ventilators, medications, vaccines), the safety and welfare of health care workers, disparities in health care for racial and ethnic minorities, personal morality (whether to wear a mask, practice social distancing, get vaccinated, and self-isolate), the spreading of pandemic misinformation, cutting corners in coronavirus research, and contact tracing versus privacy rights.

##### *A Chapter on Race, Racial Bias, and Health Care*

Chapter 13 delves into the insidious effects of racial and ethnic bias on the health status of minorities and on nearly every facet of health care. It discusses prevailing misconceptions about race and provides philosophically sound definitions of racism (both individual and structural), racial prejudice, and racial discrimination. It debunks the myth that racism and racial discrimination are things of the past, shows how structural racism has caused large-scale racial inequalities in society, and documents the health disparities—the differences in mortality and disease—between Whites and minorities.

It examines the evidence of widespread racial and ethnic bias in health care, explores the powerful effects of implicit bias in clinical practice, and surveys the problem of racial profiling in diagnosis and treatment.

### **Updates**

- Abortion and public opinion (survey)
- Abortions performed later in pregnancy
- Statistics on assisted reproduction
- “Savior siblings”
- New developments in gene therapy
- The five main ways to do gene therapy
- Genetic testing for cancer risk
- Euthanasia and assisted suicide: major developments
- Oregon’s Death with Dignity Act
- U.S. health care: the uninsured, per capita spending, and health care quality
- Comparing health care systems: U.S., Canada, and Germany

### **New Readings**

- Michael Sandel with Colleen Walsh, “Why Some Americans Refuse to Social Distance and Wear Masks”
- Ezekiel J. Emanuel, Govind Persad, Ross Upshur, et al., “Fair Allocation of Scarce Medical Resources in the Time of Covid-19”
- Angela Ballantyne, “ICU Triage: How Many Lives or Whose Lives?”
- Michael Root, “Racial Profiling in Medicine”

### **ANCILLARIES**

The Oxford University Press Learning Link houses a wealth of instructor and student resources, including an Instructor’s Manual, Test Bank, and both Lecture and Art PowerPoint Presentations for instructor use. The site also includes Self-Quizzes, Videos and Video Quizzes, and Flashcards for student use. Please visit [www.oup.com/he/vaughn-bioethics5e](http://www.oup.com/he/vaughn-bioethics5e) to access these resources.

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# Principles and Theories

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# Moral Reasoning in Bioethics

Any serious and rewarding exploration of bioethics is bound to be a challenging journey. What makes the trip worthwhile? As you might expect, this entire text is a long answer to that question. You therefore may not fully appreciate the trek until you have already hiked far along the trail. The short answer comes in three parts.

First, bioethics—like ethics, its parent discipline—is about morality, and morality is about life. Morality is part of the unavoidable, bittersweet drama of being persons who think and feel and choose. Morality concerns beliefs regarding morally right and wrong actions and morally good and bad persons or character. Whether we like it or not, we seem confronted continually with the necessity to deliberate about right and wrong, to judge someone morally good or bad, to agree or disagree with the moral pronouncements of others, to accept or reject the moral outlook of our culture or community, and even to doubt or affirm the existence or nature of moral concepts themselves. Moral issues are thus inescapable—including (or especially) those that are the focus of bioethics. In the twenty-first century, few can remain entirely untouched by the pressing moral questions of fair distribution of health care resources, abortion and infanticide, euthanasia and assisted suicide, exploitative research on children and populations in developing countries, human cloning and genetic engineering, assisted reproduction and surrogate parenting, prevention and treatment of HIV/AIDS, the confidentiality and consent of patients, the refusal of medical treatment on religious grounds, experimentation on human embryos and fetuses, and the just allocation of scarce life-saving organs.

Second, it would be difficult to imagine moral issues more important—more closely gathered around the line between life and death, health and illness, pain and relief, hope and despair—than those addressed by bioethics. Whatever our view of these questions, there is little doubt that they matter immensely. Whatever answers we give will surely have weight, however they fall.

Third, as a systematic study of such questions, bioethics holds out the possibility of answers. The answers may or may not be to our liking; they may confirm or confute our preconceived notions; they may take us far or not far enough. But, as the following pages will show, the trail has more light than shadow—and thinking critically and carefully about the problems can help us see our way forward.

## ETHICS AND BIOETHICS

Morality is about people's moral judgments, principles, rules, standards, and theories—all of which help direct conduct, mark out moral practices, and provide the yardsticks for measuring moral worth. We use *morality* to refer generally to these aspects of our lives (as in “Morality is essential”) or more specifically to the beliefs or practices of particular groups or persons (as in “American morality” or “Kant’s morality”). *Moral*, of course, pertains to morality as just defined, though it is also sometimes employed as a synonym for right or good, just as *immoral* is often meant to be equivalent to wrong or bad. *Ethics*, as used in this text, is not synonymous with *morality*. *Ethics* is the study of morality using the tools and methods of

philosophy. Philosophy is a discipline that systematically examines life's big questions through critical reasoning, logical argument, and careful reflection. Thus, ethics—also known as *moral philosophy*—is a reasoned way of delving into the meaning and import of moral concepts and issues and of evaluating the merits of moral judgments and standards. (As with *morality* and *moral*, we may use *ethics* to say such things as “Kant’s ethics” or may use *ethical* or *unethical* to mean right or wrong, good or bad.) Ethics seeks to know whether an action is right or wrong, what moral standards should guide our conduct, whether moral principles can be justified, what moral virtues are worth cultivating and why, what ultimate ends people should pursue in life, whether there are good reasons for accepting a particular moral theory, and what the meaning is of such notions as *right*, *wrong*, *good*, and *bad*. Whenever we try to reason carefully about such things, we enter the realm of ethics: We *do* ethics.

Science offers another way to study morality, and we must carefully distinguish this approach from that of moral philosophy. **Descriptive ethics** is the study of morality using the methodology of science. Its purpose is to investigate the *empirical* facts of morality—the actual beliefs, behaviors, and practices that constitute people’s moral experience. Those who carry out these inquiries (usually anthropologists, sociologists, historians, and psychologists) want to know, among other things, what moral beliefs a person or group has, what caused the subjects to have them, and how the beliefs influence behavior or social interaction. Very generally, the difference between ethics and descriptive ethics is this: In ethics we ask, as Socrates did, *How ought we to live?* In descriptive ethics we ask, *How do we in fact live?*

Ethics is a big subject, so we should not be surprised that it has three main branches, each dealing with more or less separate but related sets of ethical questions. **Normative ethics** is the search for, and justification of, moral standards, or norms. Most often the standards are moral

principles, rules, virtues, and theories, and the lofty aim of this branch is to establish rationally some or all of these as proper guides for our actions and judgments. In normative ethics, we ask questions like these: What moral principles, if any, should inform our moral judgments? What role should virtues play in our lives? Is the principle of autonomy justified? Are there any exceptions to the moral principle of “do not kill”? How should we resolve conflicts between moral norms? Is contractarianism a good moral theory? Is utilitarianism a better theory?

A branch that deals with much deeper ethical issues is metaethics. **Metaethics** is the study of the meaning and justification of basic moral beliefs. In normative ethics we might ask whether an action is right or whether a person is good, but in metaethics we would more likely ask *what it means* for an action to be right or for a person to be good. For example, does *right* mean *has the best consequences*, or *produces the most happiness*, or *commanded by God*? It is the business of metaethics to explore these and other equally fundamental questions: What, if anything, is the difference between moral and nonmoral beliefs? Are there such things as moral facts? If so, what sort of things are they, and how can they be known? Can moral statements be true or false—or are they just expressions of emotions or attitudes without any truth value? Can moral norms be justified or proven?

The third main branch is **applied ethics**, the use of moral norms and concepts to resolve practical moral issues. Here, the usual challenge is to employ moral principles, theories, arguments, or analyses to try to answer moral questions that confront people every day. Many such questions relate to a particular professional field such as law, business, or journalism, so we have specialized subfields of applied ethics like legal ethics, business ethics, and journalistic ethics. Probably the largest and most energetic subfield is bioethics.

**Bioethics** is applied ethics focused on health care, medical science, and medical technology. (*Biomedical ethics* is often used as a synonym,

and *medical ethics* is a related but narrower term used most often to refer to ethical problems in medical practice.) Ranging far and wide, bioethics seeks answers to a vast array of tough ethical questions: Is abortion ever morally permissible? Is a woman justified in having an abortion if prenatal genetic testing reveals that her fetus has a developmental defect? Should people be allowed to select embryos by the embryos' sex or other genetic characteristics? Should human embryos be used in medical research? Should human cloning be prohibited? Should physicians, nurses, physicians' assistants, and other health care professionals always be truthful with patients whatever the consequences? Should severely impaired newborns be given life-prolonging treatment or be allowed to die? Should people in persistent vegetative states be removed from life support? Should physicians help terminally ill patients commit suicide? Is it morally right to conduct medical research on patients without their consent if the research would save lives? Should human stem-cell research be banned? How should we decide who gets life-saving organ transplants when usable organs are scarce and many patients who do not get transplants will die? Should animals be used in biomedical research?

The ethical and technical scope of bioethics is wide. Bioethical questions and deliberations now fall to nonexpert and expert alike—to patients, families, and others as well as to philosophers, health care professionals, lawyers, judges, scientists, clergy, and public policy specialists. Though the heart of bioethics is moral philosophy, fully informed bioethics cannot be done without a good understanding of the relevant nonmoral facts and issues, especially the medical, scientific, technological, and legal ones.

### **ETHICS AND THE MORAL LIFE**

Morality, then, is a normative, or evaluative, enterprise. It concerns moral norms or standards that help us decide the rightness of actions, judge the goodness of persons or character, and

prescribe the form of moral conduct. There are, of course, other sorts of norms we apply in life—*nonmoral* norms. Aesthetic norms help us make value judgments about art; norms of etiquette about polite social behavior; grammatical norms about correct use of language; prudential norms about what is in one's interests; and legal norms about lawful and unlawful acts. But moral norms differ from these non-moral kinds. Some of the features they are thought to possess include the following.

**Normative Dominance.** In our moral practice, moral norms are presumed to dominate other kinds of norms, to take precedence over them. Philosophers call this characteristic of moral norms *overridingness* because moral considerations so often seem to override other factors. A maxim of prudence, for example, may suggest that you should steal if you can avoid getting caught, but a moral prohibition against stealing would overrule such a principle. An aesthetic (or pragmatic) norm implying that homeless people should be thrown in jail for blocking the view of a beautiful public mural would have to yield to moral principles demanding more humane treatment of the homeless. A law mandating brutal actions against a minority group would conflict with moral principles of justice and would therefore be deemed illegitimate. We usually think that immoral laws are defective, that they need to be changed, or that, in rare cases, they should be defied through acts of civil disobedience.

**Universality.** Moral norms (but not *exclusively* moral norms) have universality: Moral principles or judgments apply in all relevantly similar situations. If it is wrong for you to tell a lie in a particular circumstance, then it is wrong for everyone in relevantly similar circumstances to tell a lie. Logic demands this sort of consistency. It makes no sense to say that Maria's doing action A in circumstances C is morally wrong, but John's doing A in circumstances relevantly similar to C is morally right. Universality,

however, is not unique to moral norms; it's a characteristic of all normative spheres.

**Impartiality.** Implicit in moral norms is the notion of impartiality—the idea that everyone should be considered equal, that everyone's interests should count the same. From the perspective of morality, no person is any better than any other. Everyone should be treated the same unless there is a morally relevant difference between persons. We probably would be completely baffled if someone seriously said something like “murder is wrong . . . except when committed by myself,” when there was no morally relevant difference between that person and the rest of the world. If we took such a statement seriously at all, we would likely not only reject it but also would not even consider it a bona fide moral statement.

The requirement of moral impartiality prohibits discrimination against people merely because they are different—different in ways that are not morally relevant. Two people can be different in many ways: skin color, weight, gender, income, age, occupation, and so forth. But these are not differences relevant to the way they should be treated as persons. However, if there are morally relevant differences between people, then we may have good reasons to treat them differently, and this treatment would not be a violation of impartiality. This is how philosopher James Rachels explains the point:

The requirement of impartiality, then, is at bottom nothing more than a proscription against arbitrariness in dealing with people. It is a rule that forbids us from treating one person differently from another *when there is no good reason to do so*. But if this explains what is wrong with racism, it also explains why, in some special kinds of cases, it is not racist to treat people differently. Suppose a film director was making a movie about the life of Martin Luther King, Jr. He would have a perfectly good reason for ruling out Tom Cruise for the starring role. Obviously, such casting would make no sense. Because there would be a good reason for it,

the director's “discrimination” would not be arbitrary and so would not be open to criticism.<sup>1</sup>

**Reasonableness.** To participate in morality—to engage in the essential, unavoidable practices of the moral life—is to do moral reasoning. If our moral judgments are to have any weight at all, if they are to be anything more than mere personal taste or knee-jerk emotional response, they must be backed by the best of reasons. They must be the result of careful reflection in which we arrive at good reasons for accepting them, reasons that could be acknowledged as such by any other reasoning persons.

Both logic and our commonsense moral experience demand that the thorough sifting of reasons constitutes the main work of our moral deliberations—regardless of our particular moral outlook or theory. We would think it odd, perhaps even perverse, if someone asserted that physician-assisted suicide is always morally wrong—and then said she has no reasons at all for believing such a judgment but *just does*. Whatever our views on physician-assisted suicide, we would be justified in ignoring her judgment, for we would have no way to distinguish it from personal whim or wishful thinking. Likewise she herself (if she genuinely had no good reasons for her assertion) would be in the same boat, adrift with a firm opinion moored to nothing solid.

Our feelings, of course, are also part of our moral experience. When we ponder a moral issue we care about (abortion, for example), we may feel anger, sadness, disgust, fear, irritation, or sympathy. Such strong emotions are normal and often useful, helping us empathize with others, deepening our understanding of human suffering, and sharpening our insight into the consequences of our moral decisions. But our feelings can mislead us by reflecting not moral truth but our own psychological needs, our own personal or cultural biases, or our concern for personal advantage. Throughout history, some people's feelings led them to conclude that women should be burned for witchcraft, that

## IN DEPTH

### MORALITY AND THE LAW

Some people confuse morality with the law, or identify the one with the other, but the two are distinct though they may often coincide. Laws are norms enacted or enforced by the state to protect or promote the public good. They specify which actions are *legally* right or wrong. But these same actions can also be judged *morally* right or wrong, and these two kinds of judgments will not necessarily agree. Lying to a friend about a personal matter, deliberately trying to destroy yourself through reckless living, or failing to save a drowning child (when you easily could have) may be immoral—but not illegal. Racial bias, discrimination based on gender or sexual orientation, slavery, spousal rape, and unequal treatment of minority groups are immoral—but, depending on the society, they may not be illegal.

Much of the time, however, morality and the law overlap. Often what is immoral also turns out to be illegal. This is usually the case when immoral actions cause substantial harm to others, whether physical or

whole races should be exterminated, that Black men should be lynched, and that adherents of a different religion were evil. Critical reasoning can help restrain such terrible impulses. It can help us put our feelings in proper perspective and achieve a measure of impartiality. Most of all, it can guide us to moral judgments that are trustworthy because they are supported by the best of reasons.

The moral life, then, is about grappling with a distinctive class of norms marked by normative dominance, universality, impartiality, and reasonableness. As we saw earlier, these norms can include moral principles, rules, theories, and judgments. We should notice that we commonly apply these norms to two distinct spheres of our moral experience—to both moral *obligations* and moral *values*.

economic. Thus, murder and embezzlement are both immoral and illegal, backed by social disapproval and severe sanctions imposed by law. Controversy often arises when an action is not obviously or seriously harmful but is considered immoral by some who want the practice prohibited by law. The contentious notion at work is that something may be made illegal solely on the grounds that it is immoral, regardless of any physical or economic harm involved. This view of the law is known as *legal moralism*, and it sometimes underlies debates about the legalization of abortion, euthanasia, reproductive technology, contraception, and other practices.

Many issues in bioethics have both a moral and legal dimension, and it is important not to confuse the two. Sometimes the question at hand is a moral one (whether, for example, euthanasia is ever morally permissible); whether a practice should be legal or illegal then is beside the point. Sometimes the question is about legality. And sometimes the discussion concerns both. A person may consider physician-assisted suicide morally acceptable but argue that it should nevertheless be illegal because allowing the practice to become widespread would harm both patients and the medical profession.

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Moral obligations concern our duty, what we are obligated to do. That is, obligations are about conduct, how we ought or ought not to behave. In this sphere, we talk primarily about *actions*. We may look to moral principles or rules to guide our actions, or study a moral theory that purports to explain right actions, or make judgments about right or wrong actions.

Moral values, however, generally concern those things that we judge to be morally good, bad, praiseworthy, or blameworthy. Normally we use such words to describe persons (as in “He is a good person” or “She is to blame for hurting them”), their character (“He is virtuous”; “She is honest”), or their motives (“She did wrong but did not mean to”). Note that we also attribute *nonmoral* value to things. If we say that a book or bicycle or vacation is good, we mean good in

a nonmoral sense. Such things in themselves cannot have *moral* value.

Strictly speaking, only actions are morally *right* or *wrong*, but persons are morally *good* or *bad* (or some degree of goodness or badness). With this distinction we can acknowledge a simple fact of the moral life: A good person can do something wrong, and a bad person can do something right. A Gandhi can tell a lie, and a Hitler can save a drowning man.

In addition, we may judge an action right or wrong depending on the motive behind it. If John knocks a stranger down in the street to prevent her from being hit by a car, we would deem his action right (and might judge him a good person). But if he knocks her down because he dislikes the color of her skin, we would believe his action wrong (and likely think him evil).

The general meaning of *right* and *wrong* seems clear to just about everyone. But we should be careful to differentiate degrees of meaning in these moral terms. *Right* can mean either “obligatory” or “permissible.” An obligatory action is one that would be wrong *not to* perform. We are obligated or required to do it. A permissible action is one that is permitted. It is not wrong to perform it. *Wrong* means “prohibited.” A prohibited action is one that would be wrong to perform. We are obligated or required *not to* do it. A *supererogatory* action is one that is “above and beyond” our duty. It is praiseworthy—a good thing to do—but not required. Giving all your possessions to the poor is generally considered a supererogatory act.

### MORAL PRINCIPLES IN BIOETHICS

As noted earlier, the main work of bioethics is trying to solve bioethical problems using the potent resources and methods of moral philosophy, which include, at a minimum, critical reasoning, logical argument, and conceptual analysis. Many, perhaps most, moral philosophers would be quick to point out that beyond these tools of reason we also have the considerable help of moral principles. (The same could be

said about moral theories, which we explore in the next chapter.) Certainly to be useful, moral principles must be interpreted, often filled out with specifics, and balanced with other moral concerns. But both in everyday life and in bioethics, moral principles are widely thought to be indispensable to moral decision-making.

We can see appeals to moral principles in countless cases. Confronted by a pain-racked, terminally ill patient who demands to have his life ended, his physician refuses to comply, relying on the principle that “it is wrong to intentionally take a life.” Another physician makes a different choice in similar circumstances, insisting that the relevant principle is “ending the suffering of a hopelessly ill patient is morally permissible.” An infant is born anencephalic (without a brain); it will never have a conscious life and will die in a few days. The parents decide to donate the infant’s organs to other children so they might live, which involves taking the organs right away before they deteriorate. A critic of the parents’ decision argues that “it is unethical to kill in order to save.” But someone else appeals to the principle “save as many children as possible.”<sup>2</sup> In such ways moral principles help guide our actions and inform our judgments about right and wrong, good and evil.

As discussed in Chapter 2, moral principles are often drawn from a moral theory, which is a moral standard on the most general level. The principles are derived from or supported by the theory. Many times we simply appeal directly to a plausible moral principle without thinking much about its theoretical underpinnings.

Philosophers make a distinction between absolute and *prima facie* principles (or duties). An *absolute* principle applies without exceptions. An absolute principle that we should not lie demands that we never lie regardless of the circumstances or the consequences. In contrast, a *prima facie* principle applies in all cases unless an exception is warranted. Exceptions are justified when the principle conflicts with other principles and is thereby overridden. W. D. Ross is given credit for drawing this distinction in his

1930 book *The Right and the Good*.<sup>3</sup> It is essential to his account of ethics, which has a core of several moral principles or duties, any of which might come into conflict.

Physicians have a *prima facie* duty to be truthful to their patients as well as a *prima facie* duty to promote their welfare. But if these duties come in conflict—if, for example, telling a patient the truth about his condition would somehow result in his death—a physician might decide that the duty of truthfulness should yield to the weightier duty to do good for the patient.

Moral principles are many and varied, but in bioethics the following have traditionally been extremely influential and particularly relevant to the kinds of moral issues that arise in health care, medical research, and biotechnology. In fact, many—perhaps most—of the thorniest issues in bioethics arise from conflicts among these basic principles. In one formulation or another, each one has been integral to major moral theories, providing evidence that the principles capture something essential in our moral experience. The principles are (1) autonomy, (2) non-maleficence, (3) beneficence, (4) utility, and (5) justice.<sup>4</sup>

### **Autonomy**

*Autonomy* refers to a person's rational capacity for self-governance or self-determination—the ability to direct one's own life and choose for oneself. The principle of autonomy insists on full respect for autonomy. One way to express the principle is: *Autonomous persons should be allowed to exercise their capacity for self-determination*. According to one major ethical tradition, autonomous persons have intrinsic worth precisely because they have the power to make rational decisions and moral choices. They therefore must be treated with respect, which means not violating their autonomy by ignoring or thwarting their ability to choose their own paths and make their own judgments.

The principle of respect for autonomy places severe restraints on what can be done to an autonomous person. There are exceptions, but in

general we are not permitted to violate people's autonomy just because we disagree with their decisions, or because society might benefit, or because the violation is for their own good. We cannot legitimately impair someone's autonomy without strong justification for doing so. Conducting medical experiments on patients without their consent, treating competent patients against their will, physically restraining or confining patients for no medical reason—such practices constitute obvious violations of personal autonomy.

Not all restrictions on autonomy, however, are of the physical kind. Autonomy involves the capacity to make personal choices, but choices cannot be considered entirely autonomous unless they are fully informed. When we make decisions in ignorance—without relevant information or blinded by misinformation—our autonomy is diminished just as surely as if someone physically manipulated us. If this is correct, then we have a plausible explanation of why lying is generally prohibited: Lying is wrong because it undermines personal autonomy. Enshrined in bioethics and in the law, then, is the precept of *informed consent*, which demands that patients be allowed to freely consent to or decline treatments and that they receive the information they need to make informed judgments about them.

In many ways, autonomy is a delicate thing, easily compromised and readily thwarted. Often a person's autonomy is severely undermined not by other people but by nature, nurture, or his or her own actions. Some drug addicts and alcoholics, people with serious psychiatric illness, and those with severe mental impairment are thought to have drastically diminished autonomy (or to be essentially nonautonomous). Bioethical questions then arise about what is permissible to do to them and who will represent their interests or make decisions regarding their care. Infants and children are also not fully autonomous, and the same sorts of questions are forced on parents, guardians, and health care workers.

Like all the other major principles discussed here, respect for autonomy is thought to be *prima facie*. It can sometimes be overridden by considerations that seem more important or compelling—considerations that philosophers and other thinkers have formulated as principles of autonomy restriction. The principles are articulated in various ways, are applied widely to all sorts of social and moral issues, and are themselves the subject of debate. Chief among these is the harm principle: a person's autonomy may be curtailed to prevent harm to others. To prevent people from being victimized by thieves and murderers, we have a justice system that prosecutes and imprisons the perpetrators. To discourage hospitals and health care workers from hurting patients through carelessness or fraud, laws and regulations limit what they can do to people in their care. To stop someone from spreading a deadly, contagious disease, health officials may quarantine him against his will.

Another principle of autonomy restriction is paternalism. **Paternalism** is the overriding of a person's actions or decision-making for her own good. Some cases of paternalism (sometimes called *weak paternalism*) seem permissible to many people—when, for example, seriously depressed or psychotic patients are temporarily restrained to prevent them from injuring or killing themselves. Other cases are more controversial. Researchers hoping to develop a life-saving treatment give an experimental drug to someone without his knowledge or consent. Or a physician tries to spare the feelings of a competent, terminally ill patient by telling her that she will eventually get better, even though she insists on being told the truth. The paternalism in such scenarios (known as *strong paternalism*) is usually thought to be morally objectionable. Many controversies in bioethics center on the morality of strong paternalism.

### **Nonmaleficence**

The principle of **nonmaleficence** asks us not to intentionally or unintentionally inflict harm on others. In bioethics, nonmaleficence is the most

widely recognized moral principle. Its aphoristic expression has been embraced by practitioners of medicine for centuries: “Above all, do no harm.” A more precise formulation of the principle is: *We should not cause unnecessary injury or harm to those in our care.* In whatever form, nonmaleficence is the bedrock precept of countless codes of professional conduct, institutional regulations, and governmental rules and laws designed to protect the welfare of patients.

A health care professional violates this principle if he or she deliberately performs an action that harms or injures a patient. If a physician intentionally administers a drug that she knows will induce a heart attack in a patient, she obviously violates the principle—she clearly does something that is morally (and legally) wrong. But she also violates it if she injures a patient through recklessness, negligence, or inexcusable ignorance. She may not intend to hurt anyone, but she is guilty of the violation just the same.

Implicit in the principle of nonmaleficence is the notion that health professionals must exercise “due care.” The possibility of causing some pain, suffering, or injury is inherent in the care and treatment of patients, so we cannot realistically expect health professionals never to harm anyone. But we do expect them to use due care—to act reasonably and responsibly to minimize the harm or the chances of causing harm. If a physician must cause patients some harm to effect a cure, we expect her to try to produce the least amount of harm possible to achieve the results. And even if her treatments cause no actual pain or injury in a particular instance, we expect her not to use treatments that have a higher chance of causing harm than necessary. By the lights of the nonmaleficence principle, subjecting patients to unnecessary risks is wrong even if no damage is done.

### **Beneficence**

The principle of **beneficence** has seemed to many to constitute the very soul of morality—or very close to it. In its most general form, it says that *we should do good to others.* (*Benevolence* is

different, referring more to an attitude of good-will toward others than to a principle of right action.) *Beneficence* enjoins us to advance the welfare of others and prevent or remove harm to them.

Beneficence demands that we do more than just avoid inflicting pain and suffering. It says that *we should actively promote the well-being of others and prevent or remove harm to them*. In bioethics, there is little doubt that physicians, nurses, researchers, and other professionals have such a duty. After all, helping others, promoting their good, is a large part of what these professionals are obliged to do.

But not everyone thinks that *we all* have a duty of active beneficence. Some argue that though there is a general (applicable to all) duty not to harm others, there is no general duty to help others. They say we are not obligated to aid the poor, feed the hungry, or tend to the sick. Such acts are not required, but are supererogatory, beyond the call of duty. Others contend that though we do not have a general duty of active beneficence, we are at least sometimes obligated to look to the welfare of people we care about most—such as our parents, children, spouses, and friends. In any case, it is clear that in certain professions—particularly medicine, law, and nursing—benefiting others is often not just supererogatory but obligatory and basic.

### **Utility**

The principle of *utility* says that *we should produce the most favorable balance of good over bad (or benefit over harm) for all concerned*. The principle acknowledges that in the real world, we cannot always *just* benefit others or *just* avoid harming them. Often we cannot do good for people without also bringing them some harm, or we cannot help everyone who needs to be helped, or we cannot help some without also hurting or neglecting others. In such situations, the principle says, we should do what yields the best overall outcome—the maximum good and minimum evil, everyone considered. The utility principle, then, is a supplement to, not a

substitute for, the principles of autonomy, beneficence, and justice.

In ethics this maxim comes into play in several ways. Most famously it is the defining precept of the moral theory known as utilitarianism (discussed in Chapter 2). But it is also a stand-alone moral principle applied everywhere in bioethics to help resolve the kind of dilemmas just mentioned. A physician, for example, must decide whether a treatment is right for a patient, and that decision often hinges on whether the possible benefits of the treatment outweigh its risks by an acceptable margin. Suppose a man's clogged artery can be successfully treated with open-heart surgery, a procedure that carries a considerable risk of injury and death. But imagine that the artery can also be successfully opened with a regimen of cholesterol-lowering drugs and a low-fat diet, both of which have a much lower chance of serious complications. The principle of utility seems to suggest that the latter course is best and that the former is morally impermissible.

The principle also plays a major role in the creation and evaluation of the health policies of institutions and society. In these large arenas, most people aspire to fulfill the requirements of beneficence and maleficence, but they recognize that perfect beneficence or maleficence is impossible: Trade-offs and compromises must be made, scarce resources must be allotted, help and harm must be balanced, life and death must be weighed—tasks almost always informed by the principle of utility.

Suppose, for example, we want to mandate the immunization of all schoolchildren to prevent the spread of deadly communicable diseases. The cost in time and money will be great, but such a program could save many lives. There is a down side, however: A small number of children—perhaps as many as 2 for every 400,000 immunizations—will die because of a rare allergic reaction to the vaccine. It is impossible to predict who will have such a reaction (and impossible to prevent it), but it is almost certain to occur in a few cases. If our goal is

social beneficence, what should we do? Children are likely to die whether we institute the program or not. Guided by the principle of utility (as well as other principles), we may decide to proceed with the program since many more lives would likely be saved by it than lost because of its implementation.

Again, suppose governmental health agencies have enough knowledge and resources to develop fully a cure for only one disease—either a rare heart disorder or a common form of skin cancer. Trying to split resources between these two is sure to prevent development of any cure at all. The heart disorder kills 200 adults each year; the cancer occurs in thousands of people, causing them great pain and distress, but it is rarely fatal. How best to maximize the good? On which disease should the government spend its time and treasure? Answering this question (and others like it) requires trying to apply the utility principle—a job often involving complex calculations of costs and benefits and frequently generating controversy.

### **Justice**

In its broadest sense, *justice* refers to people getting what is fair or what is their due. In practice, most of us seem to have a rough idea of what justice entails in many situations, even if we cannot articulate exactly what it is. We know, for example, that it is unjust for a bus driver to make a woman sit in the back of the bus because of her religious beliefs, or for a judicial system to arbitrarily treat one group of citizens more harshly than others, or for a doctor to care for some patients but refuse to treat others just because he dislikes them.

Questions of justice arise in different spheres of human endeavor. *Retributive justice*, for example, concerns the fair meting out of punishment for wrongdoing. On this matter, some argue that justice is served only when people are punished for past wrongs, when they get their just deserts. Others insist that justice demands that people be punished not because they deserve punishment, but because the punishment

will deter further unacceptable behavior. *Distributive justice* concerns the fair distribution of society's advantages and disadvantages—for example, jobs, income, welfare aid, health care, rights, taxes, and public service. Distributive justice is a major issue in bioethics, where many of the most intensely debated questions are about who gets health care, what or how much they should get, and who should pay for it.

Distributive justice is a vast topic, and many theories have been proposed to identify and justify the properties, or traits, of just distributions. A basic precept of most of these theories is what may plausibly be regarded as the core of the principle of justice: *Equals should be treated equally*. (Recall that this is one of the defining elements of ethics itself, impartiality.) The idea is that people should be treated the same unless there is a morally relevant reason for treating them differently. We would think it unjust for a physician or nurse to treat his White diabetic patients more carefully than he does his Black diabetic patients—and to do so without a sound medical reason. We would think it unfair to award the only available kidney to the transplant candidate who belongs to the “right” political party or has the best personal relationship with hospital administrators.

The principle of justice has been at the heart of debates about just distribution of benefits and burdens (including health care) for society as a whole. The disagreements have generally not been about the legitimacy of the principle, but about how it should be interpreted. Different theories of justice try to explain *in what respects* equals should be treated equally.

*Libertarian* theories emphasize personal freedoms and the right to pursue one's own social and economic well-being in a free market without interference from others. Ideally the role of government is limited to night-watchman functions—the protection of society and free economic systems from coercion and fraud. All other social or economic benefits are the responsibility of individuals. Government should not be in the business of

helping the socially or economically disadvantaged, for that would require violating people's liberty by taking resources from the haves to give to the have-nots. So universal health care is out of the question. For the libertarian, then, people have equal intrinsic worth, but this does not entitle them to an equal distribution of economic advantages. Individuals are entitled only to what they can acquire through their own hard work and ingenuity.

*Egalitarian* theories maintain that a just distribution is an *equal* distribution. Ideally, social benefits—whether jobs, food, health care, or something else—should be allotted so that everyone has an equal share. Treating people equally means making sure everyone has equal access to certain minimal goods and services. To achieve this level of equality, individual liberties will have to be restricted, measures that libertarians would never countenance. In a pure egalitarian society, universal health care would be guaranteed.

Between strict libertarian and egalitarian views of justice lie some theories that try to achieve a plausible fusion of both perspectives. With a nod toward libertarianism, these theories may exhibit a healthy respect for individual liberty and limit governmental interference in economic enterprises. But leaning toward egalitarianism, they may also mandate that the basic needs of the least well-off citizens be met.

In bioethics, the principle of justice and the theories used to explain it are constantly being marshaled to support or reject health care policies of all kinds. They are frequently used—along with other moral principles—to evaluate, design, and challenge a wide range of health care programs and strategies. They are, in other words, far from being merely academic.

### ETHICAL RELATIVISM

The commonsense view of morality and moral standards is this: There are moral norms or principles that are valid or true for everyone. This claim is known as **moral objectivism**, the

idea that at least some moral standards are objective. Moral objectivism, however, is distinct from **moral absolutism**, the belief that objective moral principles allow no exceptions or must be applied the same way in all cases and cultures. A moral objectivist can be absolutist about moral principles, or she can avoid absolutism by accepting that moral principles are *prima facie*. In any case, most people probably assume some form of moral objectivism and would not take seriously any claim implying that valid moral norms can be whatever we want them to be.

But moral objectivism is directly challenged by a doctrine that some find extremely appealing and that, if true, would undermine ethics itself: **ethical relativism**. According to this view, moral standards are not objective but are relative to what individuals or cultures believe. There simply are no *objective* moral truths, only *relative* ones. An action is morally right if endorsed by a person or culture and morally wrong if condemned by a person or culture. So euthanasia is right for person A if he approves of it but wrong for person B if she disapproves of it, and the same would go for cultures with similarly diverging views on the subject. In this way, moral norms are not discovered but made; the individual or culture makes right and wrong. Ethical relativism pertaining to individuals is known as **subjective relativism**, more precisely stated as the view that right actions are those sanctioned by a person. Ethical relativism regarding cultures is called **cultural relativism**, the view that right actions are those sanctioned by one's culture.

In some ways, subjective relativism is a comforting position. It relieves individuals of the burden of serious critical reasoning about morality. After all, determining right and wrong is a matter of inventorying one's beliefs, and any sincerely held beliefs will do. Morality is essentially a matter of personal taste, which is an extremely easy thing to establish. Determining what one's moral views are may indeed involve deliberation and analysis—but neither of these is a necessary requirement for the job.

## IN DEPTH

### ANTHROPOLOGY AND MORAL DIVERSITY

Many moral philosophers have been quick to point out that differences in moral judgments from culture to culture do not in themselves prove a difference in moral standards. Some anthropologists have made the same argument. Solomon Asch, for example, says,

We consider it wrong to take food away from a hungry child, but not if he is overeating. We consider it right to fulfill a promise, but not if it

is a promise to commit a crime. . . . It has been customary to hold that diverse evaluations of the same act are automatic evidence for the presence of different principles of evaluation. The preceding examples point to an error in this interpretation. Indeed, an examination of the relational factors points to the operation of constant principles in situations that differ in concrete details. . . . Anthropological evidence does not furnish proof of relativism. We do not know of societies in which bravery is despised and cowardice held up to honor, in which generosity is considered a vice and ingratititude a virtue. It seems rather that the relations between valuation and meaning are invariant.<sup>5</sup>

Subjective relativism also helps people short-circuit the unpleasantness of moral debate. The subjective relativist's familiar refrain—"That may be *your* truth, but it's not *my* truth"—has a way of stopping conversations and putting an end to reasoned arguments.

The doctrine, however, is difficult to maintain consistently. On issues that the relativist cares little about (the moral rightness of gambling, say), she may be content to point out that moral norms are relative to each individual and that "to each his own." But on more momentous topics (such as genocide in Africa or the Middle East), she may slip back into objectivism and declare that genocide is morally wrong—not just wrong for her but wrong *period*.

Such inconsistencies hint that there may be something amiss with subjective relativism, and indeed there is: It seems to conflict violently with commonsense realities of the moral life. For one thing, the doctrine implies that each person is morally infallible. An action is morally right for someone if he approves of it—if he sincerely believes it to be right. His approval makes the action right, and—if his approval is genuine—he cannot be mistaken. His believing it to be right makes it right, and that's the end

of it. If he endorses infanticide as a method of population control, then infanticide is morally permissible. His sincere approval settles the issue, and he cannot be in error. But our commonsense moral experience suggests that this relativist account is absurd. Our judgments about moral matters—actions, principles, and people—are often wide of the mark. We are morally fallible, and we are rightly suspicious of anyone who claims to be otherwise.

There is a more disturbing way to frame this point. Suppose former Iraqi leader Saddam Hussein approved of slaughtering thousands of Iraqis during his reign. Suppose Hitler approved of killing millions of Jews during World War II. Suppose American serial killer and cannibal Jeffrey Dahmer approved of his murdering 17 men and boys. Then by the lights of subjective relativism, all these mass killings were morally right because their perpetrators deemed them so. But we would find this conclusion almost impossible to swallow. We would think these actions morally wrong whether the killers approved of their own actions or not.

Subjective relativism also implies that another commonplace of the moral life is an illusion: moral disagreement. Consider: Hernando tells

Sophia that allowing seriously impaired infants to die is morally right. Sophia replies that allowing seriously impaired infants to die is morally wrong. We may think that Hernando and Sophia are having a straightforward disagreement over an important moral issue. But according to subjective relativism, no such disagreement is happening or could ever happen. In stating his approval of the actions in question, Hernando is essentially expressing his personal taste on the issue, and Sophia is expressing her personal taste. He is saying he likes something; she says she does not like it—and they could both be correct. Subjective relativism implies that they are not uttering conflicting claims at all—they are discussing different subjects, their own personal feelings or preferences. But this strange dance is not at all what we think we are doing when we have a moral disagreement. Because subjective relativism conflicts with what we take to be a basic fact of the moral life, we have good reason to doubt it.

Cultural relativism seems to many to be a much more plausible doctrine. In fact, many people think it obviously true, supported as it is by a convincing argument and the common conviction that it is admirably consistent with social tolerance and understanding in a pluralistic world. The argument in its favor goes like this:

1. If people's moral judgments differ from culture to culture, moral norms are relative to culture (there are no objective moral standards).
2. People's moral judgments do differ from culture to culture.
3. Therefore, moral norms are relative to culture (there are no objective moral standards).

Is this a good argument? That is, does it provide us with good reason to accept the conclusion (statement 3)? For an argument to be good, its conclusion must follow logically from the premises, and the premises must be true. In this case, the conclusion does indeed follow logically from the premises (statements 1 and 2). The truth of the premises is another matter.

Let us look first at premise 2. All sorts of empirical evidence—including a trove of anthropological and sociological data—show that the premise is in fact true. Clearly, the moral beliefs of people from diverse cultures often do differ drastically on the same moral issue. Some societies condone infanticide; others condemn it. Some approve of the killing of wives and daughters to protect a family's honor; others think this tradition evil. Some bury their dead; others cremate them. Some judge the killing of one's elders to be a kindly act; others say it is cold-hearted murder. Some think polygamy morally permissible; others believe it deplorable. Some consider it a solemn duty to surgically remove the clitorises of young girls; others say this is immoral and cruel. Some commend the killing of people who practice a different religion; others believe such intolerance is morally reprehensible. We are forced to conclude that diversity of moral judgments among cultures is a reality.

But what of premise 1—is it also true? It says that because cultures have different moral beliefs, they must also have different moral standards, which means morality is relative to cultures. If diverse moral standards arise from each culture, then morality cannot be objective, applying to all people everywhere. There is no objective morality, just *morali*ties.

Premise 1, however, is false. First, from the fact that cultures have divergent moral beliefs on an issue, it does not logically follow that there is no objective moral truth to be sought, that there is no opinion that is objectively correct. People may disagree about the existence of biological life on Mars, but the disagreement does not demonstrate that there is no fact of the matter or that no statement on the subject could be objectively true. Disagreements on a moral question may simply indicate that there is an objective fact of the matter but that someone (or everyone) is wrong about it.

Second, a conflict between moral beliefs does not necessarily indicate a fundamental conflict between basic moral norms. Moral disagreements between cultures can arise not just

because their basic moral principles clash, but because they have differing nonmoral beliefs that put those principles in a very different light. From the annals of anthropology, for example, we have the classic story of a culture that sanctions the killing of parents when they become elderly but not yet enfeebled. Our society would condemn such a practice, no doubt appealing to moral precepts urging respect for parents and for human life. But consider: This strange (to us) culture believes that people enter heaven when they die and spend eternity in the same physical condition they were in when they passed away. Those who kill their parents are doing so because they do not want their elders to spend eternity in a state of senility but rather in good health. This culture's way is not our way; we are unlikely to share these people's nonmoral beliefs. But it is probable that they embrace the same moral principles of respect for parents and life that we do. According to some anthropologists, diverse cultures often share basic moral standards while seeming to have little or nothing in common.

The argument we are considering, then, fails to support cultural relativism. Moreover, many considerations count strongly against the view. Specifically, the logical implications of the doctrine give us substantial reasons to doubt it.

Like subjective relativism, cultural relativism implies moral infallibility, a very hard implication to take seriously. As the doctrine would have it, if a culture genuinely approves of an action, then there can be no question about the action's moral rightness: It is right, and that's that. Cultures make moral rightness, so they cannot be mistaken about it. But is it at all plausible that cultures cannot be wrong about morality? Throughout history, cultures have approved of ethnic cleansing, slavery, racism, holocausts, massacres, mass rape, torture of innocents, burning of heretics, and much more. Is it reasonable to conclude that the cultures that approved of such deeds could not have been mistaken?

Related to the infallibility problem is this difficulty: Cultural relativism implies that we

cannot legitimately criticize other cultures. If a culture approves of its actions, then those actions are morally right—and it does not matter one bit whether another culture disapproves of them. Remember, there is no objective moral code to appeal to. Each society is its own maker of the moral law. It makes no sense for society X to accuse society Y of immorality, for what society Y approves of *is* moral. Some may be willing to accept this consequence of cultural relativism, but look at what it would mean. What if the people of Germany approved of the extermination of millions of Jews, Gypsies, and others during World War II? Then the extermination was morally right. Suppose the people of Libya approved of the terrorist bombing of Pan Am flight 103 over Lockerbie, Scotland, killing 270 people (a tragedy for which the Libyan government eventually took responsibility). Then the bombing was morally right, and those who placed the bomb on board did no wrong. But all this seems very much at odds with our moral experience. We think it makes perfect sense sometimes to condemn other cultures for morally wrong actions.

Now consider the notion of moral progress. We sometimes compare what people did in the past with what they do now, noting that current practices are morally better than they used to be. We no longer countenance such horrors as massacres of native peoples, slavery, and lynchings, and we think that these changes are signs of moral progress. But cultural relativism implies that there cannot be any such thing as moral progress. To claim legitimately that there has been moral progress, there must be an objective, transcultural standard for comparing cultures of the past and present. But according to cultural relativism, there are no objective moral standards, just norms relative to each culture. However, if there is moral progress as we think there is, then there must be objective moral standards.

Cultural relativism also has a difficult time explaining the moral status of social reformers. We tend to believe they are at least sometimes

right and society is wrong. When we contemplate social reform, we think of such moral exemplars as Martin Luther King, Jr., Mahatma Gandhi, and Susan B. Anthony, all of whom agitated for justice and moral progress. But one of the consequences of cultural relativism is that social reformers could *never* be morally right. By definition, what society judges to be morally right is morally right, and since social reformers disagree with society, they could not be right—ever. But surely on occasion it's the reformers who are right and society is wrong.

There is also the serious difficulty of using cultural relativism to make moral decisions. Cultural relativism says that moral rightness is whatever a culture or society approves of, but determining which culture or society one truly belongs to seems almost impossible. The problem is that we each belong to many social groups, and there is no fact of the matter regarding which one is our “true” society. Suppose you are an African American Catholic Republican living in an artists’ colony in Alabama and enjoying the advantages of membership in an extremely large extended family. What is your true society? If you cannot identify your proper society, you cannot tell which cultural norms apply to you.

Some people may be willing to overlook these problems of cultural relativism because they believe it promotes cultural tolerance, an attitude that seems both morally praiseworthy and increasingly necessary in a pluralistic world. After all, human history has been darkened repeatedly by the intolerance of one society toward another, engendering vast measures of bloodshed, pain, oppression, injustice, and ignorance. The thought is that because all cultures are morally equal, there is no objective reason for criticizing any of them. Tolerance is then the best policy.

Cultural relativism, however, does not necessarily lead to tolerance and certainly does not logically entail it. In fact, cultural relativism can easily justify either tolerance or intolerance. It says that if a society sanctions tolerance, then

tolerance is morally right for that society. But if a society approves of intolerance, then *intolerance* is morally right for that society—and the society cannot be legitimately criticized for endorsing such an attitude. According to cultural relativism, intolerance can be morally permissible just as tolerance can. In addition, though moral relativists may want to advocate universal tolerance, they cannot consistently do so. To say that all cultures should be tolerant is to endorse an objective moral norm, but cultural relativists insist that there are no objective moral norms. To endorse universal tolerance is to abandon cultural relativism.

## ETHICS AND RELIGION

How is ethics related to religion? One obvious connection is that historically religion has always had moral content—mostly in the form of moral precepts, codes, or commandments to guide the conduct of adherents. In Western civilization, this content has been so influential in moral (and legal) matters that many now take for granted that religion is the fundamental basis of morality. Secular or nontheistic systems of ethics (for example, the ethics of Stoicism, Confucianism, Buddhism, utilitarianism, and contractarianism) have also shaped how we think about morality. But for millions of people, religion is the fountainhead of the moral law.

Many religious people, however, do not embrace a moral theory related to a religious tradition. They are comfortable being guided by one of the nontheistic systems. Others prefer the very influential moral perspective known as *natural law theory* (discussed in Chapter 2)—a view that comes in both secular and religious versions but has been nurtured and adopted by the Roman Catholic Church. Still others accept the pervasive idea that morality itself comes from God.

An important query in ethics is whether this latter view of morality is correct: whether morality depends fundamentally on religion, whether—to state the question in its traditional

form—the moral law is constituted by the will of God. The view that morality does have this kind of dependence is known as the **divine command theory**. It says that right actions are those commanded by God, and wrong actions are those forbidden by God. God is the author of the moral law, making right and wrong by his will.

But many people—both religious and nonreligious—have found this doctrine troubling. Philosophers have generally rejected it, including some famous theistic thinkers such as Thomas Aquinas (1225–1274), Gottfried Leibniz (1646–1710), and Immanuel Kant (1724–1804).

The problem is that the theory presents us with a disconcerting dilemma first spelled out in Plato's *Euthyphro*. In this dialogue, Socrates asks a penetrating question that is often expressed like this: Are actions morally right because God commands them, or does God command them because they are morally right? In the first option, God creates the moral law (the divine command theory); in the second, the moral law is independent of God's will so that even God is subject to it. Critics of the divine command theory have argued that the first option implies the moral law is entirely arbitrary. The second option denies the theory.

The arbitrariness is thought to arise like this: If actions are morally right just because God commands them to be so, then it is possible that any actions whatsoever could be morally right. The murder and rape of innocents, the oppression of the weak, the abuse of the poor—these and many other awful deeds would be morally permissible if God so willed. There would be no independent standard to judge that these acts are wrong, no moral reasons apart from God's will to suggest that such deeds are evil. God would be free to establish arbitrarily any actions whatsoever as morally right.

Defenders of the divine command theory have replied to the arbitrariness charge by saying that God would never command something evil because God is all-good. But critics point out that if the theory is true, the assertion that God is all-good would be meaningless, and

the traditional religious idea of the goodness of God would become an empty notion. If God makes the moral law, then the moral term *good* would mean “commanded by God.” But then “God is good” would mean something like “God does what God commands” or even “God is what God is,” which tells us nothing about the goodness of God. Likewise, “God's commands are good” would translate as “God's commands are God's commands.” This attempt to escape the charge of arbitrariness seems to have intolerable implications.

Theists and nontheists alike find this horn of Socrates's dilemma—the idea of an arbitrary, divinely ordained morality—incredible. They therefore reject the divine command theory and embrace the other horn, the view that right and wrong are independent of God's will. Moral standards are external to God, binding on both God and mortals. If there are divine commands, they will conform to these independent moral norms. The religious may then claim that God is good—good because he abides perfectly by the moral law and guides the conduct of believers accordingly.

If moral standards are not grounded in the divine will, if they are logically independent of religion, then morality is a legitimate concern for the religious and nonreligious alike, and everyone has equal access to moral reflection and the moral life. The best evidence for the latter is ethics itself. The fact is that people *do ethics*. They use critical reasoning and experience to determine moral norms, explore ethical issues, test moral theories, and live a good life. The results of these explorations are moral outlooks and standards founded on good reasons and arguments and assented to by reflective people everywhere.

In bioethics, the informed opinions of religious people are as relevant as those of secularists. But all parties must be willing to submit their views to the tests and criteria of critical reasoning and evidence.

But even if ethics does not have this independent status, there are still good reasons for religious believers to know how to use the critical

tools that ethics offers. First, like many secular moral rules, religious moral codes are often vague and difficult to apply to conflicts and issues, especially in complex fields such as bioethics. Getting around this problem requires interpreting the codes, and this task involves consideration of broader norms or theories, a typical job for ethics. Second, like everyone else, believers must deal with moral conflicts of all sorts—including clashes between the moral beliefs of religious adherents, religious leaders, and religious traditions. What is often needed is a neutral standard and critical analyses to arrive at a resolution—tools that ethics can easily provide. Third, public debate on ethical issues in a diverse society requires ground rules—chief among them being that positions must be explained and reasons must be given in their support. Unexplained assertions without supporting reasons or arguments are likely to be ignored. In this arena, ethics is essential.

### MORAL ARGUMENTS

Critical reasoning is something we employ every time we carefully and systematically assess the truth of a statement or the merits of a logical argument. We ask: Are there good reasons for believing this statement? Is this a good argument—does it prove its case? These sorts of questions are asked in every academic field and in every serious human endeavor. Wherever there is a need to acquire knowledge, to separate truth from falsity, and to come to a reliable understanding of how the world works, these questions are asked and answers are sought. Ethics is no exception. Critical reasoning in ethics—called *moral reasoning*—employs the same general principles of logic and evidence that guide the search for truth in every other field. So we need not wonder whether we use critical reasoning in ethics but whether we use it well.

### Argument Fundamentals

Most critical reasoning is concerned in one way or another with the construction or evaluation

of arguments. As you may have guessed, here *argument* denotes not an altercation but a patterned set of assertions: at least one statement providing support for another statement. We have an argument when one or more statements give us reasons for believing another one. The supporting statements are *premises*, and the supported statement is the *conclusion*. In critical reasoning, the term *statement* also has a technical meaning. A statement (or claim) is an assertion that something is or is not the case and is therefore the kind of utterance that is either true or false.

You need to understand at the outset that *argument* in this sense is not synonymous with *persuasion*. An argument provides us with reasons for accepting a claim; it is an attempted “proof” for an assertion. But persuasion does not necessarily involve giving any reasons at all for accepting a claim. To persuade is to influence people’s opinions, which can be accomplished by offering a good argument but also by misleading with logical fallacies, exploiting emotions and prejudices, dazzling with rhetorical gimmicks, hiding or distorting the facts, threatening or coercing people—the list is long. Good arguments prove something whether or not they persuade. Persuasive ploys can change minds but do not necessarily prove anything.

So we formulate an argument to try to show that a particular claim (the conclusion) should be believed, and we analyze an argument to see if it really does show what it purports to show. If the argument is good, we are entitled to believe its conclusion. If it is bad, we are not entitled to believe it.

Consider these two simple arguments:

#### ARGUMENT 1

Law enforcement in the city is a complete failure. Incidents of serious crime have doubled.

#### ARGUMENT 2

It’s wrong to take the life of an innocent person. Abortion takes the life of an innocent person. So abortion is wrong.

In Argument 1, the conclusion is “Law enforcement in the city is a complete failure,” which is supported by the premise “Incidents of serious crime have doubled.” The conclusion of Argument 2 is “abortion is wrong,” and it is backed by two premises: “It’s wrong to take the life of an innocent person” and “Abortion takes the life of an innocent person.” Despite the differences between these two passages (differences in content, the number of premises, and the order of their parts), they are both arguments because they exemplify basic argument structure: a conclusion supported by at least one premise.

Though the components of an argument seem clear enough, people often fail to distinguish between arguments and strong statements that contain no arguments at all. Suppose we change Argument 1 into this:

Law enforcement in the city is a complete failure. Nothing seems to work anymore.  
This situation is intolerable.

Now there is no argument, just an expression of annoyance or anger. There are no statements giving us reasons to believe a conclusion. What we have are some unsupported assertions that may merely *appear* to make a case. If we ignore the distinction between genuine arguments and nonargumentative material, critical reasoning is undone.

Assuming we can recognize an argument when we see it, how can we tell if it is a good one? Fortunately, the general criteria for judging the merits of an argument are simple and clear. A good argument—one that gives us good reasons for believing a claim—must have (1) solid logic and (2) true premises. Requirement (1) means that the conclusion should follow logically from the premises, that there must be a proper logical connection between supporting statements and the statement supported. Requirement (2) says that what the premises assert must in fact be the case. An argument that fails in either respect is a bad argument.

There are two basic kinds of arguments—deductive and inductive—and our two

requirements hold for both of them, even though the logical connections in each type are distinct. **Deductive arguments** are intended to give *logically conclusive* support to their conclusions so that if the premises are true, the conclusion absolutely must be true. Argument 2 is a deductive argument and is therefore supposed to be constructed so that if the two premises are true, its conclusion cannot possibly be false. Here it is with its structure laid bare:

#### ARGUMENT 2

1. It’s wrong to take the life of an innocent person.
2. Abortion takes the life of an innocent person.
3. Therefore, abortion is wrong.

Do you see that, given the form or structure of this argument, if the premises are true, then the conclusion *has to be true*? It would be very strange—illogical, in fact—to agree that the two premises are true but that the conclusion is false.

Now look at this one:

#### ARGUMENT 3

1. All dogs are mammals.
2. Rex is a dog.
3. Therefore, Rex is a mammal.

Again, there is no way for the premises to be true while the conclusion is false. The deductive form of the argument guarantees this.

So a deductive argument is intended to have this sort of airtight structure. If it actually does have this structure, it is said to be *valid*. Argument 2 is deductive because it is intended to provide logically conclusive support to its conclusion. It is valid because, as a matter of fact, it does offer this kind of support. A deductive argument that fails to provide conclusive support to its conclusion is said to be *invalid*. In such an argument, it is possible for the premises to be true and the conclusion false. Argument 3 is intended to have a deductive form, and because it actually does have this form, the argument is also valid.

An elementary fact about deductive arguments is that their validity (or lack thereof) is a

separate issue from the truth of the premises. Validity is a structural matter, depending entirely on how an argument is put together. Truth concerns the nature of the claims made in the premises and conclusion. A deductive argument is supposed to be built so that if the premises are true, the conclusion must be true—but in a particular case, the premises might *not* be true. A valid argument can have true or false premises and a true or false conclusion. (By definition, of course, it cannot have true premises and a false conclusion.) In any case, being invalid or having false premises dooms a deductive argument.

**Inductive arguments** are supposed to give *probable* support to their conclusions. Unlike deductive arguments, they are not designed to support their conclusions decisively. They can establish only that, if their premises are true, their conclusions are probably true (more likely to be true than not). Argument 1 is an inductive argument meant to demonstrate the probable truth that “law enforcement in the city is a complete failure.” Like all inductive arguments (and unlike deductive ones), it can have true premises and a false conclusion. So the sole premise—“incidents of serious crime have doubled”—can be true while the conclusion is false.

If inductive arguments succeed in lending very probable support to their conclusions, they are said to be *strong*. Strong arguments are such that if their premises are true, their conclusions are very probably true. If they fail to provide this very probable support, they are termed *weak*. Argument 1 is a weak argument because its premise, even if true, does not show that more likely than not law enforcement in the city is a complete failure. After all, even if incidents of serious crime have doubled, law enforcement may be successful in other ways, or incidents of serious crime may be up for reasons unrelated to the effectiveness of law enforcement.

But consider this inductive argument:

#### ARGUMENT 4

1. Eighty-five percent of the students at this university are Republicans.

2. Sonia is a student at this university.
3. Therefore, Sonia is probably a Republican.

This argument is strong. If its premises are true, its conclusion is likely to be true. If 85 percent of the university’s students are Republicans, and Sonia is a university student, she is more likely than not to be a Republican, too.

When a valid (deductive) argument has true premises, it is a good argument. A good deductive argument is said to be *sound*. Argument 2 is valid, but we cannot say whether it is sound until we determine the truth of the premises. Argument 3 is valid, and if its premises are true, it is sound. When a strong (inductive) argument has true premises, it is also a good argument. A good inductive argument is said to be *cogent*. Argument 1 is weak, so there is no way it can be cogent. Argument 4 is strong, and if its premises are true, it is cogent.

Checking the validity or strength of an argument is often a plain, commonsense undertaking. Using our natural reasoning ability, we can examine how the premises are linked to the conclusion and can see quickly whether the conclusion follows from the premises. We are most likely to make an easy job of it when the arguments are simple. Many times, however, we need some help, and help is available in the form of methods and guidelines for evaluating arguments.

Having a familiarity with common argument patterns, or forms, is especially useful when assessing the validity of deductive arguments. We are likely to encounter these forms again and again in bioethics as well as in everyday life.

Here is a prime example:

#### ARGUMENT 5

1. If the surgeon operates, then the patient will be cured.
2. The surgeon is operating.
3. Therefore, the patient will be cured.

This argument form contains a *conditional* premise—that is, a premise consisting of a conditional, or if-then, statement (actually a compound statement composed of two constituent

statements). Premise 1 is a conditional statement. A conditional statement has two parts: the part beginning with *if* (called the *antecedent*) and the part beginning with *then* (known as the *consequent*). So the antecedent of premise 1 is “If the surgeon operates,” and the consequent is “then the patient will be cured.”

The best way to appreciate the structure of such an argument (or any deductive argument, for that matter) is to translate it into traditional argument symbols in which each statement is symbolized by a letter. Here is the symbolization for Argument 5:

1. If  $p$ , then  $q$ .
2.  $p$ .
3. Therefore,  $q$ .

We can see that  $p$  represents “the surgeon operates,” and  $q$  represents “the patient will be cured.” But notice that we can use this same symbolized argument form to represent countless other arguments—arguments with different statements but having the same basic structure.

It just so happens that the underlying argument form for Argument 5 is extremely common—common enough to have a name, *modus ponens* (or affirming the antecedent). The truly useful fact about modus ponens is that any argument having this form is valid. We can plug any statements we want into the formula and the result will be a valid argument, a circumstance in which if the premises are true, the conclusion must be true.

Another common argument form is *modus tollens* (or denying the consequent). For example:

#### ARGUMENT 6

1. If the dose is low, then the healing is slow.
2. The healing is not slow.
3. Therefore, the dose is not low.
  
1. If  $p$ , then  $q$ .
2. Not  $q$ .
3. Therefore, not  $p$ .

Modus tollens is also a valid form, and any argument using this form must also be valid.

There are also common argument forms that are *invalid*. Here are two of them:

#### AFFIRMING THE CONSEQUENT

##### ARGUMENT 7

1. If the patient is getting better, then drugs are unnecessary.
2. Drugs are unnecessary.
3. Therefore, the patient is getting better.
  
1. If  $p$ , then  $q$ .
2.  $q$ .
3. Therefore,  $p$ .

#### DENYING THE ANTECEDENT

##### ARGUMENT 8

1. If the rate of infection is increasing, then the patients will die.
2. The rate of infection is not increasing.
3. Therefore, the patients will not die.
  
1. If  $p$ , then  $q$ .
2. Not  $p$ .
3. Therefore, not  $q$ .

The advantage of being able to recognize these and other common argument forms is that you can use that skill to determine readily the validity of many deductive arguments. You know, for example, that any argument having the same form as modus ponens or modus tollens must be valid, and any argument in one of the common invalid forms must be invalid.

#### Patterns of Moral Arguments

All that you have learned about argument fundamentals thus far applies directly to that sub-species of argument we are most interested in: moral argument. A **moral argument** is an argument whose conclusion is a moral statement, an assertion that an action is right or wrong or that a person or motive is good or bad. We utter a moral statement when we say such things as “Physician-assisted suicide is wrong,” or “Maria should not have had an abortion,” or “Dr. Jones is a good person.” We are constantly making moral statements and including them in our moral arguments, which we frequently devise and hold up for inspection and evaluation.

## Review: Valid and Invalid Argument Forms

### Valid Forms

Affirming the Antecedent (Modus Ponens)

If  $p$ , then  $q$ .

$p$ .

Therefore,  $q$ .

Denying the Consequent (Modus Tollens)

If  $p$ , then  $q$ .

Not  $q$ .

Therefore, not  $p$ .

Example:

If Spot barks, a burglar is in the house.

Spot is barking.

Therefore, a burglar is in the house.

Example:

If it's raining, the park is closed.

The park is not closed.

Therefore, it's not raining.

### Invalid Forms

Affirming the Consequent

If  $p$ , then  $q$ .

$q$ .

Therefore,  $p$ .

Denying the Antecedent

If  $p$ , then  $q$ .

Not  $p$ .

Therefore, not  $q$ .

Example:

If the cat is on the mat, she is asleep.

She is asleep.

Therefore, she is on the mat.

Example:

If the cat is on the mat, she is asleep.

She is not on the mat.

Therefore, she is not asleep.

Recall Argument 2, a simple (and common) moral argument:

1. It's wrong to take the life of an innocent person.
2. Abortion takes the life of an innocent person.
3. Therefore, abortion is wrong.

Here, we can see all the standard features of a typical moral argument: (1) At least one premise (premise 1) is a moral statement asserting a general moral norm such as a moral principle; (2) at least one premise (premise 2) is a nonmoral statement describing an action or circumstance; and (3) the conclusion is a moral statement expressing a moral judgment about a specific action or circumstance.

Notice how natural this pattern seems. If we want to argue that a particular action (or kind of

action) is wrong, for example, we must provide a reason for this moral judgment. The natural (and logical) move is to reach for a general moral principle that supports the judgment. Why is performing surgery on Mrs. Johnson without her consent wrong? Because, we might say, treating people without their consent is a violation of their autonomy (a moral principle), and performing surgery on Mrs. Johnson without her consent would be an instance of such a violation (a nonmoral fact).

This natural way of proceeding reflects the logical realities of moral reasoning. In a moral argument, we *must* have at least one moral premise to draw a conclusion about the morality of a particular state of affairs. Without a moral premise, we cannot legitimately arrive at a moral conclusion. That is, from a nonmoral

## IN DEPTH

### FALLACIES IN MORAL REASONING

The world is full of bad arguments. Many of them occur again and again in different guises and contexts, being so common that they have been given names and are studied by those who wish to avoid such mistakes. These common, defective arguments are called *fallacies*. Here are a few that often crop up in moral reasoning.

#### STRAW MAN

The straw man fallacy is the misrepresentation of a person's views so they can be more easily attacked or dismissed. Suppose you argue that because an immunization program will save the lives of thousands of children and will likely cause the death of only 1 child out of every 500,000, we should fund the immunization program. But then your opponent replies that you think the life of a child isn't worth much. Thus, your point has been distorted, made to look extreme or unsavory—and is now an easier target. The straw man fallacy, of course, proves nothing, though many people fall for it every day.

#### APPEAL TO THE PERSON

Closely related to the straw man fallacy is appeal to the person (also known as the *ad hominem* fallacy). Appeal to the person is the rejecting of a statement on the grounds that it comes from a particular person, not because the statement, or claim, itself is false or dubious. For example:

*You can safely discard anything that Susan has to say about abortion. She's a Catholic.*

*Johnson argues that our current health care system is defective. But don't listen to him—he's a liberal.*

These arguments are defective because they ask us to reject a claim because of a person's character, background, or circumstances—things that are generally irrelevant to the truth of claims. A statement

must stand or fall on its own merits. The personal characteristics of the person espousing the view do not necessarily have a bearing on its truth. Only if we can show that someone's dubious traits somehow make the claim dubious are we justified in rejecting the claim because of a person's personal characteristics. Such a circumstance is rare.

#### APPEAL TO IGNORANCE

As its name implies, this fallacy tries to prove something by appealing to what we don't know. The appeal to ignorance is arguing either that (1) a claim is true because it has not been proven false or (2) a claim is false because it has not been proven true. For example:

*No one has proven that a fetus is not a person, so it is in fact a person.*

*It is obviously false that a fetus is a person because science has not proven that it is a person.*

The first argument tries to prove a claim by pointing out that it has not been proven false. The second argument tries to prove that a claim is false because it has not been proven true. Both kinds of arguments are bogus because they assume that a lack of evidence proves something. But a lack of evidence can prove nothing. Being ignorant of the facts does not enlighten us. Notice that if a lack of evidence could prove something, then you could prove just about anything you wanted. You could reason, for instance, that since no one can prove that horses cannot fly, horses must be able to fly.

#### BEGGING THE QUESTION

The fallacy of begging the question is trying to prove a conclusion by using that very same conclusion as support. It is arguing in a circle. This way of trying to prove something says, in effect, "X is true because X is true." Here is a classic example:

*The Bible says that God exists.*

*The Bible is true because God wrote it.*

*Therefore, God exists.*

The conclusion here (“God exists”) is supported by premises that assume that very conclusion.

Here’s another one:

*All citizens have the right to a fair trial because those whom the state is obliged to protect and give consideration are automatically due judicial criminal proceedings that are equitable by any reasonable standard.*

This passage may at first seem like a good argument, but it isn’t. It reduces to this unimpressive assertion: “All citizens have the right to a fair trial because all citizens have the right to a fair trial.” The conclusion is “All citizens have the right to a fair trial,” but that is more or less what the premise says. The premise—“those whom the state is obliged to protect and give consideration are automatically due judicial criminal proceedings that are equitable by any reasonable standard”—is equivalent to “All citizens have the right to a fair trial.”

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premise alone, a moral conclusion does not logically follow. For example, from the nonmoral fact that abortions are frequently performed, we cannot conclude that abortion is immoral. Nonmoral premises cannot support a conclusion expressing a moral judgment. Likewise, we cannot reason from a moral premise alone (one affirming a general moral principle) to a conclusion about the morality of a particular action. We need a nonmoral premise affirming that the particular action in question is an instance of the general class of actions referred to in the general moral premise. In Argument 2, the moral premise tells us it’s wrong to take the life of an innocent person, but we need the nonmoral premise to assert that abortion is an instance of taking the life of an innocent person. After all, that a fetus is a person—the kind of entity that is deserving of full moral rights—is not obviously true and not assented to by everyone. We must spell out in a

### SLIPPERY SLOPE

The metaphor behind this fallacy suggests the danger of stepping on a dicey incline, losing your footing, and sliding to disaster. The fallacy of slippery slope, then, is arguing erroneously that a particular action should not be taken because it will lead inevitably to other actions resulting in some dire outcome. The key word here is *erroneously*. A slippery slope scenario becomes fallacious when there is no reason to believe that the chain of events predicted will ever happen. For example:

*If dying patients are permitted to refuse treatment, then soon doctors will be refusing the treatment on their behalf. Then physician-assisted suicide will become rampant, and soon killing patients for almost any reason will become the norm.*

This argument is fallacious because there are no reasons for believing that the first step will ultimately result in the chain of events described. If good reasons could be given, the argument might be salvaged.

premise what we take to be the nonmoral fact of the matter.

This discussion underscores a previously mentioned fact about moral disagreements. When people disagree on a moral issue, they may or may not be disagreeing about moral principles. They may actually share the relevant moral principles but disagree about the nonmoral facts—or vice versa. So when people take contradictory stands on the conclusion of a moral argument, the source of the conflict could lie with the moral premises or the nonmoral premises or both.

Unfortunately, in everyday life moral arguments do not come with their premises clearly labeled, so we need to be able to identify the premises ourselves. This job is made more difficult by a simple fact of the moral life: Often premises (moral and nonmoral) are left unsaid and are merely implied. Sometimes premises are unstated because they are obvious assumptions

that need not be mentioned. But if we are to perform a thorough evaluation of an argument, we must drag the implicit premises into the open so they can be fully assessed. Such careful scrutiny is especially important in moral arguments because the implicit premises are often questionable assumptions—the secret, weak links in the chain of reasoning. For example:

**ARGUMENT 9**

1. In vitro fertilization is an entirely unnatural process, as far from natural reproduction as one could imagine.
2. Therefore, in vitro fertilization should not be used.

As it stands, this is a bad argument; the conclusion does not follow from the premise. But there is an implied (moral) premise lurking here, and if we make it explicit, the argument will be valid:

1. In vitro fertilization is an entirely unnatural process, as far from natural reproduction as one could imagine.
2. Any process that is unnatural should not be used.
3. Therefore, in vitro fertilization should not be used.

Now the argument is complete, and we can see both the nonmoral premise (premise 1) and the moral premise (premise 2), which is a moral principle. But now that we have brought the moral premise into the light of day, we can see that it is false or at least debatable. We use many processes and products that are unnatural (for example, modern pharmaceuticals, intravenous feeding, surgery, CAT scans, artificial limbs, and contact lenses), but we generally do not regard them as morally impermissible.

Very often we can tell that an argument has an unstated premise because there is a logical leap between the stated premises and the conclusion. The inference from stated premises to conclusion does not work unless the missing premise is supplied. A good candidate for the implicit premise will make the argument valid

or strong and will be plausible in the context of the argument. The most straightforward approach, however, is to treat the argument as deductive and look for a premise that will make the argument valid, as we did in Argument 9.

### Evaluating Premises

As we have seen, good arguments have true premises. But how do we know if the premises are true? Fortunately, there are ways to test, or evaluate, the truth of premises. The tests differ, however, depending on whether the premises are nonmoral or moral.

Checking the truth of nonmoral premises can involve the exploration of either empirical or conceptual matters. An empirical belief, or claim, is one that can be confirmed by sense experience—that is, by observation or scientific investigation. Most nonmoral premises are empirical claims that we can check by examining our own experience or that of others or by consulting the relevant scientific findings. By these methods we can test (and support) a wide variety of empirical assertions, such as many of the nonmoral premises examined earlier: “Incidents of serious crime have doubled”; “Eighty-five percent of the students at this university are Republicans”; “If the patient is getting better, then drugs are unnecessary.”

In bioethics, among the most controversial nonmoral premises are those affirming that a medical treatment or program will or will not have a particular effect on people. The issue is whether it will help or harm and to what degree. Sometimes reliable data are available to resolve the issue. Sometimes no clear evidence exists, leaving people to make educated guesses that are often in dispute.

In any case, critical reasoning in bioethics demands that we always seek the most reliable evidence available and try to assess its worth objectively. It requires that our empirical claims be supported by good empirical evidence and that we expect the same from others who make empirical assertions.

A conceptual matter has to do with the meaning of terms, something we need to pay attention to because disputes in bioethics sometimes hinge on the meaning of a concept. For example, in disagreements about the moral permissibility of abortion, the crux of the matter is often how the disputants define *person* (as in Argument 2), or *human life*, or *human being*. Similarly, whether someone supports or opposes euthanasia often hangs on how it is defined. Some, for example, define it in the narrow sense of taking direct action to kill someone for his sake (mercy killing), while others insist on a wider sense that encompasses both mercifully killing and allowing to die. Whether we are devising our own arguments or evaluating those of others, being clear on the meaning of terms is essential, and any proposed definition must be backed by good reasons.

Moral premises are like nonmoral ones in that they, too, should be supported by good reasons and be subjected to serious scrutiny. But just how are moral premises supported and scrutinized?

Support for a moral premise (a moral principle or standard) can come from at least three sources: other moral principles, moral theories, or our most reliable moral judgments. Probably the most common way to support a moral principle is to appeal to a higher-level principle (which often turns out to be one of the four major moral principles discussed earlier). Suppose the moral premise in question is “The patient’s wishes about whether surgery is performed on him should not be ignored.” Some would argue that this principle is derived from, or is based on, the higher principle that autonomous persons should be allowed to exercise their capacity for self-determination. Or let’s say the premise is “Individuals in a persistent vegetative state should never have their feeding tubes removed so they can ‘die with dignity.’” Many would base this assertion on the principle that human life is sacred and should be preserved at all costs. Frequently, the higher principle appealed to is plausible, seemingly universal, or

accepted by all parties so that further support for the principle is not necessary. At other times, the higher principle itself may be controversial and in need of support.

Moral premises can also be supported by a moral theory, a general explanation of what makes an action right or a person or motive good. (In Chapter 2 we discuss moral theories in depth.) For example, traditional utilitarianism is a moral theory affirming that right actions are those that produce the greatest happiness for all concerned. Appealing to utilitarianism, then, someone might insist that a baby born with severe brain damage who will die within a few days should not be allowed to suffer slowly away in pain but should be given a lethal injection. The justification for this policy is that it would produce the least amount of unhappiness (including pain and suffering) for all concerned, including baby, parents, and caregivers. Those who reject this policy would have to argue that there was something wrong with utilitarianism or that other considerations (including alternative theories) outweigh utilitarian concerns.

Another possible source of support for moral premises is what philosophers call our *considered moral judgments*. These are moral judgments we deem plausible or credible after careful reflection that is as unbiased as possible. They may apply to both particular cases and more general moral statements. For example, after deliberation we might conclude that “inflicting undeserved and unnecessary pain on someone is wrong,” or that “emergency care for accident victims should be provided regardless of their race or religion,” or that “amputating a patient’s leg for no good reason is never morally permissible.” Like moral principles and theories, such judgments can vary in how much weight they carry in moral arguments and can be given more or less credibility (or undermined completely) by relevant reasons. (We examine more closely the relationships among theories, principles, and considered judgments in Chapter 2.)

Moral premises can be called into question by showing that they somehow conflict with

credible principles, theories, or judgments. One way to do this is to cite *counterexamples*, instances in which the moral principle in question seems not to hold. Recall that a counterexample helps us see that the moral premise in Argument 9 is dubious. The premise says “Any process that is unnatural should not be used,” but we often use unnatural products or processes (CAT scans and contact lenses, for instance) and do not think these actions morally wrong. In the same way, we can use counterexamples to evaluate the moral premise in Argument 2:

1. It’s wrong to take the life of an innocent person.
2. Abortion takes the life of an innocent person.
3. Therefore, abortion is wrong.

Are there no exceptions to premise 1? Is it always wrong to kill an innocent person? We can imagine cases in which this premise seems either doubtful or at least not obviously true. What about situations in which many lives can be saved by taking the life of one person? What if all 50 people in a lifeboat at sea will drown unless one of them is cast overboard? What if the one unlucky person *agrees* to be cast overboard to save all the others? Or suppose a person is dying of cancer and is suffering unspeakable pain that cannot be relieved by any medical means—and she begs for a lethal injection of morphine. Some would argue that these scenarios raise serious questions about premise 1, suggesting that at least in its current form, it may not be true. In response to these counterexamples, some who wish to defend the premise might modify it to take the scenarios into account or even try to show that despite its implications premise 1 is justified.

### Assessing Whole Arguments

Moral argument, like any other kind of arguments, usually come to us embedded in larger tracts of speech or writing. Often the premises and conclusion are embellished or obscured by other elements—by explanations, asides, reiterations,

descriptions, examples, amplifications, or irrelevancies. So how do we evaluate such arguments in the rough?

Following this procedure will help:

**Step 1. Study the text until you thoroughly understand it.** You can’t locate the conclusion or premises until you know what you’re looking for—and that requires having a clear idea of what the author is driving at. Don’t attempt to find the conclusion or premises until you “get it.” This understanding entails having an overview of a great deal of text, a bird’s-eye view of the whole work.

**Step 2. Find the conclusion.** When you evaluate arguments surrounded by a lot of other prose, *your first task is to find the conclusion*. There may be a single conclusion, or several main conclusions, or one primary conclusion with several subconclusions. Or the conclusion may be nowhere explicitly stated but embodied in metaphorical language or implied by large expanses of prose. In any case, your job is to come up with a single conclusion statement for each conclusion—even if you have to paraphrase large sections of text to do it. When you identify the conclusion, the hunt for premises gets easier.

**Step 3. Identify the premises.** Like the search for a conclusion, unearthing the premises may involve condensing large sections of text into manageable form—namely, single premise statements. To do this, you need to disregard extraneous material and keep your eye on the “big picture.” Remember that in moral arguments you are looking for both moral and nonmoral premises.

Let’s see how this procedure works on the following passage:

[1] John and Nancy Jones had a 2-year-old son who suffered from a serious but very curable bowel obstruction. [2] For religious reasons, the Joneses decide to treat their son with prayer instead of modern medicine. [3] They refused medical treatment even though they were told by several doctors that the child would die unless medically treated. [4] As it turned out, the boy

did die. [5] The Joneses were arrested and charged with involuntary manslaughter. [6] Were the Joneses wrong to refuse treatment for their son?

[7] The answer is yes. [8] Regardless of what faith or religious dogma would have the Joneses do, they allowed their child to die. [9] According to just about any moral outlook, the care of a child by the parents is a fundamental obligation. [10] Above all other concerns, parents have a duty to ensure the health and safety of their children and to use whatever means are most likely to secure those benefits. [11] In other words, allowing a child to die when the death could easily have been prevented is morally reprehensible. [12] The Joneses were therefore guilty of a shockingly immoral act.

The first order of business is to find the conclusion, and in doing so we can see that the first paragraph is entirely background information. The conclusion is in sentence 12, and with this information, we can tell that sentence 7 is a short affirmation of the conclusion. We can also locate the premises. The nonmoral premise is in sentence 8: the nonmoral fact is that the Joneses permitted their child to die. The moral premise is stated most explicitly in sentence 11. Sentences 9 and 10 are equivalent to 11, although stated more generally.

The bare-bones argument then is:

[8] Regardless of what faith or religious dogma would have the Joneses do, they allowed their child to die.

[11] In other words, allowing a child to die when the death could easily have been prevented is morally reprehensible.

[12] The Joneses were therefore guilty of a shockingly immoral act.

This argument is deductively valid, so the crucial question is whether the premises are true. Presumably the nonmoral premise 8 is an uncontested assertion. We can imagine that everyone knows that the Joneses let their child die. Premise 11, the moral statement, seems to

be a plausible moral principle—some would say it's just common sense. Most people would find it difficult to think of a credible counterexample to it. But that is precisely what is at issue here: whether it's ever morally permissible to allow a child to die when the death can easily be prevented. To justify premise 11, those who accept it may appeal to a moral theory (utilitarianism or Kantian ethics, say) or to more general moral principles such as “always act to preserve life,” “treat persons with respect,” or “humans have a right to life.” However, it's hard to see how the rejection of premise 11 could be based on anything other than a religious moral principle.

## OBSTACLES TO CRITICAL REASONING

Possibly the most common psychological impediments to critical reasoning—and the hardest to overcome—are the following. They are hindrances that affect humans in every endeavor, from personal judgments to professional decision-making to high-stakes moral reasoning.

To define them, we need a correct understanding of the concept of **evidence**. In its most general sense, *evidence is something that makes a statement more likely to be true*. It does not mean “something that I feel or perceive is true.” Evidence that there's a tree in the quad is your unimpaired, clear perception of such a tree (and your confidence that there is no reason to doubt your perception). Evidence that most Republicans (or most Democrats) drink alcohol is a scientific opinion survey (done by a reputable, unbiased polling organization) showing the alcohol drinking habits of those groups. Evidence that a measles vaccine does not cause autism in young children is a growing body of scientific research showing no connection between autism and a measles vaccine (and the discrediting and nonreplication of a study that once tied those two together). The mere fact that you strongly believe a statement, or have a friend who strongly

believes it, or have read Twitter posts by people swearing that it's true, or hear from your favorite YouTube personality that it's so—*such things do not, by themselves, constitute evidence*. They do not, by themselves, make a statement more likely to be true. They may, however, give you good reason to start looking for evidence.

### **Denying Contrary Evidence**

An all-too-human tendency is to try to deny or resist evidence that flies in the face of our cherished beliefs. We may deny evidence, or ignore it, or reinterpret it so it fits better with our prejudices. Denying evidence may be psychologically comforting (for a while, anyway), but it thwarts any search for knowledge and stunts our understanding.

It's shockingly easy to find examples of the blatant denial of evidence. Scientific research and commonsense experience show that the practice permeates all walks of life. A political activist may refuse to consider evidence that conflicts with his party's principles. A scientist may be so committed to her theory that she refuses to take seriously any data that undermine it. An administrator of a grand program may insist that it is a huge success despite all evidence to the contrary.

Often our resistance to contrary evidence takes a subtle form. If we encounter evidence against our views, we frequently don't reject it outright. We simply apply more critical scrutiny to it than we would to evidence in favor of our views, or we seek out additional confirming information, or we find a way to interpret the data so it doesn't conflict with our expectations.

In one study, proponents and opponents of the death penalty were presented with evidence concerning whether capital punishment deterred crime. Both those opposed to and those in favor of capital punishment were given two types of evidence—(1) some that supported the practice and (2) some that discredited it. Psychologist Thomas Gilovich describes the outcome of the study:

The results of this experiment were striking. The participants considered the study that provided

evidence consistent with their prior beliefs—regardless of what type of study that was—to be a well-conducted piece of research that provided important evidence concerning the effectiveness of capital punishment. In contrast, they uncovered numerous flaws in the research that contradicted their initial beliefs. . . . Rather than ignoring outright the evidence at variance with their expectations, the participants cognitively transformed it into evidence that was considered relatively uninformative and could be assigned little weight.<sup>6</sup>

There is no cure for our tendency to resist opposing evidence. The only available remedy is to *make a conscious effort to look for opposing evidence*. Don't consider your evaluation of a statement or argument finished until you've carefully considered *all the relevant reasons*. Ask yourself, "What is the evidence or reasons against this statement?" This approach is at the heart of science. A basic principle of scientific work is not to accept a favored theory until competing (alternative) theories are thoroughly examined.

### **Looking for Confirming Evidence**

We often not only resist conflicting evidence but also seek out and use only confirming evidence—a phenomenon known as **confirmation bias**. When we go out of our way to find only confirming evidence, we can end up accepting a claim that's not true, seeing relationships that aren't there, and finding confirmation that isn't genuine.

In scientific research on confirmation bias, when subjects are asked to assess a claim, they often look for confirming evidence only, even though disconfirming evidence may be just as revealing. For example, in one study, a group of subjects was asked to assess whether practicing before a tennis match was linked to winning the match; another group, whether practicing before a match was linked to losing the match. All the subjects were asked to select the kind of evidence (regarding practice and winning or losing matches) that they thought would be the most helpful in answering the relevant question. Not surprisingly, the subjects deciding whether

pregame practicing was linked to winning focused on how many times players practiced and then won the match. And subjects assessing whether practicing was associated with losing focused on how many times players practiced and then lost the match.

Sometimes we look for confirming evidence even when disconfirming evidence is more telling. For example, take this claim: All swans are white. You can easily find confirming instances; white swans are plentiful and ubiquitous. But even your seeing thousands of white swans will not conclusively confirm that all swans are white because there may be swans in places where you haven't looked. But all you have to do is find one black swan to conclusively show that the claim is false. (People used to believe that the claim was absolutely true—until black swans were discovered in Australia.) In such cases, confirmation bias can lead us way off course.

The pull of confirmation bias is insidious and potent. It is an incredibly strong tendency to cherry-pick evidence while we think we're being perfectly fair and reasonable. It makes false statements seem not only true but irrefutable. It gives the deluded social media gadfly, who touts the reality of the nonexistent and the obvious evil of everyone in the opposing party, supreme confidence in the truth of the absurd and incredible.

Confirmation bias is one of the reasons that trying to carry on a coherent logical argument on social media can be so beat-your-head-against-the-wall frustrating. According to Tom Nichols, author of *The Death of Expertise*,

[C]onfirmation bias makes attempts at reasoned argument exhausting because it produces arguments and theories that are *nonfalsifiable*. It is the nature of confirmation bias itself to dismiss all contradictory evidence as irrelevant, and so *my* evidence is always the rule, *your* evidence is always a mistake or an exception.<sup>7</sup>

The moral to this story is that when we evaluate claims, we should look for disconfirming as well as confirming evidence. Doing so requires a

conscious effort to consider not only the information that supports what we want to believe but also the information that conflicts with it. We have to seek out disconfirming evidence just as we keep an eye out for confirming evidence—an approach that goes against our cognitive grain. We naturally gravitate to people and policies we agree with, to the books that support our views, to the magazines and newspapers that echo our political outlook. Acquiring a broader, smarter, more critical perspective takes effort—and guts.

### Motivated Reasoning

Suppose before beginning your investigation into a crime, before knowing anything about it, you decide what conclusion you will reach: Alex murdered Alice with an ax. So you glom onto evidence that Alex knew Alice, that they attended the same college, that they disliked each other, and that Alex owned an ax. And you disregard evidence that points in the opposite direction—evidence like phone records showing Alex and Alice two thousand miles apart at the time of the crime, and testimony of her friends that her boyfriend, not Alex, threatened to kill her. How likely is it that your investigation will uncover the truth?

Not very. Yet research shows that this is the kind of thinking we all engage in far more often than we would like to admit, especially when we want to protect or promote our cherished political or personal beliefs. It's called **motivated reasoning**—reasoning for the purpose of supporting a predetermined conclusion, not to uncover the truth. It's confirmation bias in overdrive. It's a way of piling up evidence that agrees with our preferred conclusion and of downplaying, ignoring, or devaluing evidence that supports the contrary view. We set out to prove our point, not to determine whether the point is justified.

Online, motivated reasoning has been the modus operandi of those who want to prove to themselves and others that the Apollo moon landing never happened, that climate change is

a hoax, that evolution is a fraud, that Barack Obama was not born in the United States, and that the Holocaust didn't happen. Through motivated reasoning, even very smart people can build, without realizing it, a very complex and impressive case for a claim that is complete rubbish. And the internet, with its vast stores of information easily accessible to anyone, is all the motivated reasoner needs to make the case overwhelming and irresistible—and dead wrong.

On social media, many people spend hours expounding on their one-sided arguments without once examining opposing views (except perhaps to try to trash them), or trying to understand the larger picture that could put issues and evidence in context, or examining contrary evidence impartially without indulging in knee-jerk rejection.

Defeating motivated reasoning is hard (and harder still to debate someone arguing in this way). But experts have offered some advice on how to avoid the trap:

- Be reasonably skeptical of *all* sources—but especially of those that support your beliefs.
- Be wary of your assessments of the credibility of sources that contradict your beliefs. Ask: Is this source *really* irrelevant, weak, or suspect—or is that my bias talking?
- Give opposing views a chance. Examine them carefully before deciding their worth. Do not dismiss them out of hand.
- Break out of the filter bubble. Seek out alternative views, read sources that you often disagree with, and don't surround yourself with people who always agree with you.

### Preferring Available Evidence

Another common mistake in evaluating evidence is the **availability error**. We commit this blunder when we rely on evidence not because it's trustworthy but because it's memorable or

striking—that is, psychologically available. In such cases, we put stock in evidence that's psychologically impressive or persuasive, not necessarily logically acceptable. You fall for the availability error if you vote to convict a murder suspect because he looks menacing, not because the evidence points to his guilt; or if you decide that a Honda Civic is an unsafe vehicle because you saw one get smashed in a highway accident; or if, just because you watched a TV news report about a mugging in your city, you believe that the risk of being mugged is extremely high.

Being taken in by the availability error can lead to some serious misjudgments about the risks involved in various situations. Some people (are you one of them?) believe that air travel is more dangerous than many other modes of transportation, so they shun travel by airplane in favor of the automobile. Their conclusion is based on nothing more than a few vivid media reports of tragic plane crashes. But research shows that per mile traveled, flying is far safer than automobile travel. Your chances of dying in a plane crash in 2001 were 1 in 310,560, but the odds of your dying in a car accident were only 1 in 19,075. The fact is, there are plenty of less vivid and less memorable (that is, psychologically unavailable) things that are much more dangerous than air travel: falling down stairs, drowning, choking, and accidental poisoning.

If we're in the habit of basing our judgments on evidence that's merely psychologically available, we will frequently commit the error known as *hasty generalization*. We're guilty of hasty generalization when we draw a conclusion about a whole group based on an inadequate sample of the group. We fall into this trap when we assert something like this: "Honda Civics are pieces of junk. I owned one for three months, and it gave me nothing but trouble." Our experience with a car is immediate and personal, so for many of us it can be a short step from this psychologically available evidence to a very hasty conclusion. If we give in to the availability error and stick to our guns about lousy Civics in

the face of good evidence to the contrary (say, automobile-reliability research done by the Consumer's Union or similar organizations), we should get an F in critical thinking.

### The Dunning-Kruger Effect

This scenario happens online every day: the least informed person in a discussion decides to educate everyone else on the topic, confidently lecturing on the fine points and presuming to correct people's "obvious" misconceptions, never doubting for a minute his own grasp of the facts and his own superior understanding, while gushing forth a lot of bad information, misjudgments, and non sequiturs. The problem here (other than the obnoxiousness of the gusher) is not just that he is ignorant, but that he doesn't know how ignorant he is. This is the **Dunning-Kruger effect**, the phenomenon of being ignorant of how ignorant we are. Tom Nichols puts it this way:

Dunning-Kruger Effect, in sum, means that the dumber you are, the more confident you are that you're not actually dumb. Dunning and Kruger [the researchers who originally studied the phenomenon] more gently label such people as "unskilled" or "incompetent." But that doesn't change their central finding: "Not only do they reach erroneous conclusions and make unfortunate choices, but their incompetence robs them of the ability to realize it."<sup>8</sup>

The Dunning-Kruger effect, unfortunately, is not just speculation. It's a fact about a common human failing. In an article titled "Confident Idiots," David Dunning says of the relevant research,

This isn't just an armchair theory. A whole battery of studies conducted by myself and others have confirmed that people who don't know much about a given set of cognitive, technical, or social skills tend to grossly overestimate their prowess and performance, whether it's grammar, emotional intelligence, logical reasoning, firearm care and safety,

debating, or financial knowledge. College students who hand in exams that will earn them Ds and Fs tend to think their efforts will be worthy of far higher grades; low-performing chess players, bridge players, and medical students, and elderly people applying for a renewed driver's license, similarly overestimate their competence by a long shot.<sup>9</sup>

The Dunning-Kruger effect is made worse by the tendency of many to believe that because they know a little something about a subject, they are experts, and because they have read a book or a few internet pages on a topic, they are as much an expert as any PhD. Nichols declares that "the pernicious idea that 'everyone can be an expert' is . . . dangerous."

It's true in a relative sense that almost anyone with particular skills can develop specialized knowledge to which others, in most circumstances, must defer. Trouble, however, rears its head when people start to believe that knowing a little bit about something means "expertise." It's a thin line between the hobbyist who knows a lot about warships from reading *Jane's Fighting Ships* and an actual expert on the capabilities of the world's naval vessels, but that line exists.

Knowing things is not the same as understanding them. Comprehension is not the same thing as analysis. Expertise is not a parlor game played with factoids.<sup>10</sup>

So how can we avoid the Dunning-Kruger trap? Guy Harrison, author of *Think Before You Like*, offers this advice:

Having the mere awareness and understanding that all people—yourself included—struggle to accurately assess competency levels can inspire the crucial and necessary pause, that moment of reflection before speaking, writing, clicking, liking, or swiping. Prior to declaring the "obvious answer" to gun violence, racism, sexism, or poverty—and then digging in to defend it—we must recall that confidence is not the same thing as knowledge. The Dunning-Kruger effect explains much of the loud, proud folly you find on social media.<sup>11</sup>

## KEY TERMS

applied ethics  
 availability error  
 bioethics  
 confirmation bias  
 cultural relativism  
 deductive argument  
 descriptive ethics  
 divine command theory  
 Dunning-Kruger effect  
 ethical relativism  
 ethics  
 evidence  
 inductive argument  
 metaethics  
 moral absolutism  
 moral argument  
 moral objectivism  
 morality  
 motivated reasoning  
 normative ethics  
 paternalism  
 subjective relativism

## SUMMARY

Morality refers to beliefs about right and wrong actions and morally good and bad persons or character. Ethics is the study of morality using the tools and methods of philosophy. The study of morality using the methodology of science is known as descriptive ethics. Ethics has three main branches: (1) normative ethics, the search for, and justification of, moral standards, or norms; (2) metaethics, the study of the meaning and justification of basic moral beliefs; and (3) applied ethics, the use of moral norms and concepts to resolve practical moral issues. Bioethics is applied ethics focused on health care, medical science, and medical technology.

Moral norms differ from other kinds of norms because they are characterized by (1) normative dominance, (2) universality, (3) impartiality, and (4) reasonableness. We apply moral norms to two distinct spheres of our moral experience—obligations and values. Moral obligations concern our duty, what we are

obligated to do or not do, and refer primarily to right and wrong actions. Moral values generally concern those things that we judge to be morally good, bad, praiseworthy, or blameworthy. A right action can be obligatory (one that would be wrong not to perform) or permissible (one that is not wrong to perform). A prohibited action would be one that would be wrong to perform. A supererogatory action is one that is “above and beyond” our duty.

In bioethics, five moral principles have been extremely influential and particularly relevant: (1) autonomy (autonomous persons should be allowed to exercise their capacity for self-determination); (2) nonmaleficence (we should not cause unnecessary harm to others); (3) beneficence (we should do good to others and prevent or remove harm); (4) utility (we should produce the most favorable balance of good over bad for all concerned); and (5) justice (we should treat equals equally).

According to ethical relativism, moral standards are not objective but are relative to what individuals or cultures believe. A familiar argument for cultural relativism is that if people’s moral judgments differ from culture to culture, then moral norms are relative to culture, and people’s moral judgments obviously do differ from culture to culture. But the first premise in the argument is false. In addition, cultural relativism seems implausible because it implies moral infallibility, immunity of all cultures from moral criticism from the outside, the automatic wrongness of the moral stance of social reformers, and the incoherence of the idea of moral progress. Moreover, cultural relativism does not necessarily lead to tolerance and does not logically entail it.

The divine command theory says that right actions are those commanded by God, and wrong actions are those forbidden by God. But many religious and nonreligious people have rejected the theory because it seems to imply that God’s commands are arbitrary.

Most critical reasoning is concerned in one way or another with the construction or

evaluation of arguments. All the skills required in dealing with arguments generally can be applied directly to handling moral arguments in particular. A moral argument is one whose conclusion is a moral statement, an assertion that an action is right or wrong or that a person or motive is good or bad.

Moral reasoning can be undone by common psychological hindrances—most notably by confirmation bias, denial of contrary evidence, motivated reasoning, the availability error, and the Dunning-Kruger effect.

## ARGUMENT EXERCISES

(All answers appear in the Appendix.)

### Exercise 1.1

In each of the following passages, add a moral premise to turn it into a valid moral argument.

1. Noah promised to drive Thelma to Los Angeles, so he should stop bellyaching and do it.
2. The refugees were shot at and lied to, and the authorities did nothing to stop any of this. The authorities should have intervened.
3. There was never any imminent threat from the Iraqi government, so the United States should not have invaded Iraq.
4. The Indian government posed an imminent threat to Pakistan and the world, so the Pakistanis were justified in attacking Indian troops.
5. Burton used a gun in the commission of a crime; therefore, he should get a long prison term.
6. Ellen knew that a murder was going to take place. It was her duty to try to stop it.
7. Ahmed should never have allowed his daughter to receive in vitro fertilization. Such a procedure is unnatural.
8. The doctors performed the experiment on 20 patients without their consent. Obviously, that was wrong.

9. What you did was immoral. You hacked into a database containing personal information on thousands of people and invaded their privacy.
10. Ling spent all day weeding Mrs. Black's garden for no pay. The least Mrs. Black should do is let Ling borrow some gardening tools.

### Exercise 1.2

For each of the following arguments, specify the conclusion and premises and indicate where possible whether it is cogent or sound.

1. Anyone who runs away from an automobile accident should be arrested. Janet ran away from an automobile accident. She should be arrested.
2. I write in response to the Nov. 4 *News* article, "Plans for group home, storage facility opposed." As the sister and guardian of a profoundly retarded woman who lives in a group home, I can assure the gentlemen quoted that their fears are very much unfounded. The home in which my sister resides is large, lovely, brand new, well staffed and well maintained. It does nothing but enhance the community, bring neighbors together and create a wonderfully diverse neighborhood.—Letter to the editor, *Buffalo News*
3. Scrawling "Rape all Asian bitches and dump them" on classroom walls is not a hate crime, and graffiti should be protected by the First Amendment, according to assistant professor of communication Laura Leets. This is outrageous. I hope Ms. Leets is simply arguing from a narrow legalistic interpretation and is merely insensitive to the tremendous hurt such graffiti can inflict, not to mention the additional damage caused when a professor on campus defends it. Words can be just as destructive as physical violence. Drawing a technical distinction between the two is

- at best insensitive, at worst evil.—Letter to the editor, *Stanford Magazine*
4. Yolanda took the money from petty cash even though she had plenty of money in her pocket. People shouldn't steal unless they are destitute. She shouldn't have taken that money.
  5. There is one principle we can never avoid: We should never do anything to disrespect human life. The artificial use of human cells—as scientists are now doing in stem-cell research—shows a complete disregard for human life. Stem-cell research is immoral.

### Exercise 1.3

Evaluate the following arguments:

1. Any form of expression or speech that offends people of faith should not be tolerated. *Penthouse* magazine definitely offends people of faith. Ban it!
2. Anyone who disagrees with the basic moral dictums of the prevailing culture should be censored. Dr. Tilden's graduation speech clearly was inconsistent with the prevailing moral opinions on campus. She should be reprimanded.

### Exercise 1.4

Identify the moral arguments in each of the following passages. Specify the premises and the conclusion, adding implicit premises where needed.

1. The movie *Lorenzo's Oil* is about a family's struggle to find a cure for their young son's fatal genetic disease, an illness that usually kills boys before they reach their eleventh birthday. The script is based on the true story of a family's attempt to save Lorenzo, their son, from this fatal genetic disease through the use of a medicinal oil. The movie is a tear-jerker, but it ends on a hopeful note that suggests that the oil will eventually cure Lorenzo and that the oil is an effective treatment for the genetic

disease. The problem is, there is no cure for the disease and no good scientific evidence showing that the oil works. But the movie touts the oil anyway—and gives false hope to every family whose son suffers from this terrible illness. Worse, the movie overplays the worth of the oil, seriously misleading people about the medical facts. The movie, therefore, is immoral. It violates the ageless moral dictum to, above all else, "do no harm." *Lorenzo's Oil* may be just a movie, but it has done harm nonetheless.

2. I, like many of my fellow Muslims, was appalled by the latest bombing in Saudi Arabia ("Among the Saudis, Attack Has Soured Qaeda Supporters," front page, Nov. 11). Yet I was disturbed to get the sense that Saudis were angered by this latest act of barbarity because the targets were mainly Arab and Muslim.

You quote one person as saying of the bombing in Riyadh in May, "At that time it was seen as justifiable because there was an invasion of a foreign country, there was frustration." Another says, "Jihad is not against your own people."

Regardless of whether the victims are Muslim or not, the vicious murder of innocent human beings is reprehensible and repugnant, an affront to everything Islam stands for. Any sympathy for Al Qaeda among the minority of Saudis should have evaporated after the May bombings in Riyadh, and it should have surprised no one in Saudi Arabia that Al Qaeda would attack a housing complex full of Arabs and Muslims.

That is what Al Qaeda is: a band of bloodthirsty murderers.—Letter to the editor, *New York Times*

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# Bioethics and Moral Theories

As we have seen, the moral life is dynamic, complex, and inescapable. In it we wrestle with momentous questions of moral value and moral rightness. We assert, challenge, accept, and reject moral statements. We make moral judgments about the rightness of actions, the goodness of persons or their character, and the moral quality and worth of our lives. Through general moral norms or principles, we direct our actions and inform our choices. We formulate and critique moral arguments, thereby testing what we know or think we know about moral realities. We do all this and one thing more: We naturally and unavoidably venture into the realm of moral theory, trying to see the larger moral meaning behind particular situations and precepts. In this chapter, we explore this realm and try to discern how it fits into the moral life in general and into bioethics in particular.

## THE NATURE OF MORAL THEORIES

In science, theories help us understand the empirical world by explaining the causes of events, why things are the way they are. The germ theory of disease explains how particular diseases arise and spread in a human population. The heliocentric (sun-centered) theory of planetary motion explains why the planets in our solar system behave the way they do. In ethics, moral theories have a similar explanatory role. A **moral theory** explains not why one event causes another but why an action is right or wrong or why a person or a person's character is good or bad. A moral theory tells us what it is about an action that *makes it right*, or what it is about a person that *makes him or her good*. The

divine command theory of morality, for example, says that right actions are those commanded or willed by God. Traditional utilitarianism says that right actions are those that produce the greatest happiness for all concerned. These and other moral theories are attempts to define rightness or goodness. In this way, they are both more general and more basic than moral principles or other general norms.

Moral theorizing—that is, making, using, or assessing moral theories or parts of theories—is normal and pervasive in the moral life, though it is often done without much recognition that theory is playing a part in the deliberations. Whenever we try to understand what a moral property such as rightness or goodness means, or justify a moral principle or other norm, or resolve a conflict between two credible principles, or explain why a particular action or practice is right or wrong, or evaluate the plausibility of specific moral intuitions or assumptions, we do moral theorizing. In fact, we *must* theorize if we are to make headway in such investigations. We must stand back from the situation at hand and try to grasp the larger pattern that only theory can reveal.

Moral theories that concentrate on right and wrong actions are known as theories of obligation (or duty) or simply as *theories of right action*. The divine command theory and utilitarianism are theories of right action. Philosophers often distinguish these from moral theories that focus on good and bad persons or character—so-called *virtue-based theories*. Virtue ethics (covered later in this chapter) is a prime example.

How do moral theories fit into our everyday moral reasoning? In answering that, let's focus on theories of right action, probably the most

influential type in bioethics. First, moral theories can figure directly in our moral arguments. As we saw earlier, moral arguments contain both moral and nonmoral premises. A moral premise can consist of a moral principle, a moral rule (a less general norm derived from or based on a principle), or a claim expressing a central tenet of a moral theory. Using such a tenet, someone might argue, for example, that stem-cell research should be fully funded rather than halted altogether because such a step would eventually lead to a greater benefit for more people, and right actions (according to utilitarianism) are those that result in the greatest overall benefit for the greatest number. Thus, the fundamental moral standard of utilitarianism becomes a premise in an argument for a specific action in a particular case.

Second, theories can have an indirect impact on moral arguments because principles appealed to are often supported in turn by a moral theory. The principles can be either derived from or supported by the theory's account of right and wrong action. Consider the prohibition against murder, the basic precept that it is wrong to take the life of an innocent person. This principle can be drawn from theories built around the fundamental notion of respect for persons. As one such theory would have it, murder is wrong because it treats people not as persons with inherent worth but as mere things to be used or dispensed with as one wishes.

Some people are tempted to deduce from all this that moral theories are the dominant force in moral reasoning as well as in the moral life. This view would be an oversimplification. By design, moral theories are certainly more general in scope than moral principles, rules, or judgments. But from this fact it does not follow that theories alone are the ultimate authority in moral deliberations. For one thing, to be truly useful, moral theories must be filled out with details about how to apply them in real life and the kinds of cases to which they are relevant. For another, there is more to morality than what can be captured in the general norms of a theory.

There is also the testimony of the particular, the evidence of individual moral judgments.

Our moral deliberations, then, involve both the general and the particular. Suppose we embrace a moral theory that seems to offer us a plausible explanation of what makes an action right or wrong. When we must decide which action is morally right in a particular situation, we look to our theory for general guidance. From our theory we may glean a set of moral principles that seem to apply to the case at hand. If the principles lead us to conflicting choices, we look again to the theory for insight in resolving the conflict. But we also must take into account our considered judgments about the case. (We may also formulate considered judgments about the relevant principles or rules.) If our considered judgments and the deliverances of our theory are consistent with one another, we have additional assurance that our decision in the case is correct. If our judgments clash with our theory or principles, we must decide which to revise or discard—for critical reasoning demands that our beliefs be coherent, that they do not harbor contradictions. If we believe our judgments to be more credible than the implications of our theory (or principles), we may modify the theory accordingly (or, rarely, regard the theory as irreparable and give it up). But if the theory seems more credible in this case, we may conclude that our judgment is untrustworthy and set it aside.

So a moral theory can show us what is important and reasonable in morality, guiding our judgments through overarching insights that may help us with specific cases and issues, sometimes correcting erring judgments along the way. Our considered judgments are fallible indicators of moral common sense and are checks against wayward theory or flawed principle. In bioethics, both of these moral resources are highly respected and widely used.

## **INFLUENTIAL MORAL THEORIES**

Several moral theories have played major roles in bioethics, and they continue to influence how people think about bioethical issues. Theories of

right action (in contrast to virtue-based theories) have dominated the field, each usually based on one of two broad views about the essential character of right actions. **Consequentialist** moral theories insist that the rightness of actions depends solely on their consequences or results. The key question is what or how much good the actions produce, however *good* is defined. **Deontological** (or *nonconsequentialist*) theories say that the rightness of actions is determined not solely by their consequences but partly or entirely by their intrinsic nature. For some or all actions, rightness depends on the kind of actions they are, not on how much good they produce. A consequentialist theory, then, may say that stealing is wrong because it causes more harm than good. But a deontological theory may contend that stealing is inherently wrong regardless of its consequences, good or bad.

### Utilitarianism

The leading consequentialist theory is **utilitarianism**, the view that right actions are those that result in the most beneficial balance of good over bad consequences for everyone involved. It says we should maximize the nonmoral good (the *utility*) of everyone affected, regardless of the contrary urgings of moral rules or unbending moral principles. Various forms of utilitarianism differ in how they define utility, with some equating it with happiness or pleasure (the hedonistic view), others with satisfaction of preferences or desires or some other intrinsically valuable things or states such as knowledge or perfection.

In applying the utilitarian moral standard (the greatest good, everyone considered), some moral philosophers concentrate on specific acts and some on rules covering kinds of acts. The former approach is called **act-utilitarianism**, the idea that the rightness of actions depends solely on the relative good produced by *individual actions*. An act is right if in a particular situation it produces a greater balance of good over bad than any alternative acts; determining rightness is a matter of weighing the effects of each possible act. The latter approach, known as

**rule-utilitarianism**, avoids judging rightness by specific acts and focuses instead on *rules governing categories of acts*. It says a right action is one that conforms to a rule that, if followed consistently, would create for everyone involved the most beneficial balance of good over bad. We are to adhere to the rules because they maximize the good for everyone considered—even though a given act may produce bad effects in a particular situation.

The classic version of utilitarianism was devised by English philosopher Jeremy Bentham (1748–1832) and given more detail and plausibility by another English philosopher, John Stuart Mill (1806–1873). Classic utilitarianism is hedonistic in that the utility to be maximized is pleasure, broadly termed happiness, the only intrinsic good. A right action produces more net happiness (amounts of happiness minus unhappiness) than any alternative action, everyone considered. As Mill put it,

[Actions] are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness. By “happiness” is intended pleasure, and the absence of pain; by “unhappiness,” pain and the privation of pleasure.<sup>1</sup>

Bentham and Mill, however, had different ideas about what happiness entailed, as do many philosophers today. Bentham thinks that happiness is one-dimensional: It is pleasure, pure and simple, something that varies only in the amount that an agent can experience. On this scheme, it seems that the moral ideal would be to experience maximum amounts of pleasure, as does the glutton or the debauchee. But Mill thinks that pleasures can vary in quality as well as quantity. For him, there are lower and higher pleasures—the lower and inferior ones indulged in by the glutton and his ilk and the higher and more satisfying ones found in such experiences as the search for knowledge and the appreciation of art and music. Mill famously sums up this contrast by saying, “It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied.”<sup>2</sup>

Like all forms of utilitarianism, the classic formulation demands a strong sense of impartiality. When promoting happiness, we must not only take into account the happiness of everyone affected but also give everyone's needs or interests equal weight. Mill explains:

[The] happiness which forms the utilitarian standard of what is right conduct, is not the agent's own happiness, but that of all concerned. As between his own happiness and that of others, utilitarianism requires him to be as strictly impartial as a disinterested and benevolent spectator.<sup>3</sup>

In classic utilitarianism, the emphasis is on maximizing the total quantity of net happiness, not ensuring that it is rationed in any particular amounts among the people involved. This means that an action resulting in 1,000 units of happiness for 10 people is better than an action yielding only 900 units of happiness for those same 10 people—regardless of how the units of happiness are distributed among them. Classic utilitarians do want to allocate the total amount of happiness among as many people as possible (thus their motto, “the greatest happiness for the greatest number”). But maximizing total happiness is the fundamental concern whether everyone gets an equal portion or one person gets the lion’s share.

How might utilitarianism apply to a bioethical issue? Consider this scenario: Johnny is a 10-year-old boy with cerebral palsy, emaciated and bedridden, hooked to feeding tubes and monitors, his body twisted in pain that is almost impossible to control, his days measured out by one agonizing surgical operation after another, locked in the mental life of an infant and acknowledged by all the experts to be without hope. His anguished parents, wanting desperately to end his suffering, beg the physician to give Johnny a lethal injection. What should the physician do?

Suppose in this case there are only two options: indefinitely maintaining Johnny in his present condition or carrying out the parents’ wishes. An act-utilitarian might reason like this. Allowing the current situation to continue

would cause enormous unhappiness—Johnny’s own physical agony, the unimaginable misery of the distraught parents, the anxiety of other family members and friends, and the distress and frustration of the physician and nurses who can do little more than stand by as Johnny withers away. However, administering the lethal injection would immediately end Johnny’s pain and prevent future suffering. The parents would grieve for Johnny but would at least find some relief—and perhaps peace—in knowing that his torture was over. The medical staff would probably also be relieved for the same reason. There would, of course, also be possible negative consequences to take into account. In administering the lethal injection, the physician would be risking both professional censure and criminal prosecution. If her actions were to become public, people might begin to mistrust physicians who treat severely impaired children, undermining the whole medical profession. Perhaps the physician’s action would lead to a general devaluing of the lives of disabled or elderly people everywhere. These dire consequences, however, would probably not be very likely if the physician acted discreetly. On balance, the act-utilitarian might say, greater net happiness (the least unhappiness) would result from the mercy killing, which would therefore be the morally permissible course.

A rule-utilitarian might judge the situation differently. The key question would be which rule if consistently followed would produce the greatest net happiness. Let us say that there are only two rules to consider. One is “Do not kill seriously impaired children, regardless of their suffering or the wishes of their parents.” The other one is “Killing seriously impaired children is permissible if they are suffering severely and improvement is hopeless.” The rule-utilitarian might reason that consistently following the second rule would have terrible consequences. It would cause widespread suspicion about the actions and motives of physicians who treat seriously impaired and disabled children. People would come to distrust physicians, which in

## IN DEPTH

### UTILITARIANISM AND THE GOLDEN RULE

Probably much to the dismay of his religious critics, John Stuart Mill defended his radical doctrine of utilitarianism by arguing that it was entirely consistent with a fundamental Christian teaching:

In the golden rule of Jesus of Nazareth, we read the complete spirit of the ethics of utility. To do as one would be done by, and to love one's neighbour as oneself, constitute the ideal perfection of utilitarian morality. As the means of making the nearest approach to this ideal, utility would enjoin, first, that laws and social arrangements should place the happiness, or (as

speaking practically it may be called) the interest, of every individual, as nearly as possible in harmony with the interest of the whole; and secondly, that education and opinion, which have so vast a power over human character, should so use that power as to establish in the mind of every individual an indissoluble association between his own happiness and the good of the whole; especially between his own happiness and the practice of such modes of conduct, negative and positive, as regard for the universal happiness prescribes: so that not only he may be unable to conceive the possibility of happiness to himself, consistently with conduct opposed to the general good, but also that a direct impulse to promote the general good may be in every individual one of the habitual motives of action, and the sentiments connected therewith may fill a large and prominent place in every human being's sentient existence.<sup>4</sup>

turn would damage the entire health care system. Society might begin to devalue the lives of disabled people generally as well as the elderly and other vulnerable populations. The rule would also appear to entail a blatant violation of the cardinal principle of medical practice—do no harm. Adhering to it might therefore cause an erosion of all ethical codes and professional standards in medicine. But following the first rule would have no such consequences. It would permit the suffering of some impaired children, but this consequence seems not to be as catastrophic as those produced by consistently conforming to the second rule. For the rule-utilitarian, then, the morally right action would be *not* to administer the lethal injection, despite the parents' pleas.

#### Kantian Ethics

From the great German philosopher Immanuel Kant (1724–1804) comes what is widely regarded as probably the most sophisticated and influential deontological theory ever devised. It is the

very antithesis of utilitarianism, holding that right actions do not depend in the least on consequences, the maximization of utility, the production of happiness, or the desires and needs of human beings. For Kant, the core of morality consists of following a rational and universally applicable moral rule and doing so solely out of a sense of duty. An action is right only if it conforms to such a rule, and we are morally praiseworthy only if we perform it for duty's sake alone.

In Kant's system, all our moral duties are expressed in the form of *categorical imperatives*. An imperative is a command to do something; it is categorical if it applies without exception and without regard for particular needs or purposes. A categorical imperative says, "Do this—regardless." In contrast, a *hypothetical imperative* is a command to do something if we want to achieve particular aims, as in "If you want good pay, work hard." The moral law, then, rests on absolute directives that do not depend on the contingencies of desire or utility.

Kant says that through reason and reflection we can derive our duties from a single moral principle, what he calls *the categorical imperative*. He formulates it in different ways, the first one being “Act only on that maxim through which you can at the same time will that it should become a universal law.”<sup>5</sup> For Kant, our actions have logical implications—they imply general rules, or maxims, of conduct. If you tell a lie for financial gain, you are in effect acting according to a maxim like “It’s okay to lie to someone when doing so benefits you financially.” The question is whether the maxim corresponding to an action is a legitimate moral law. To find out, we must ask if we could consistently will that the maxim become a universal law applicable to everyone—that is, if everyone could consistently act on the maxim and we would be willing to have them do so. If we could do this, then the action described by the maxim is morally permissible; if not, it is prohibited. Thus, moral laws embody two characteristics thought to be essential to morality itself: universality and impartiality.

To show us how to apply this formulation of the categorical imperative to a specific situation, Kant uses the example of a lying promise. Suppose you need to borrow money from a friend, but you know you could never pay her back. So to get the loan, you decide to lie, falsely promising to repay the money. To find out if such a lying promise is morally permissible, Kant would have you ask if you could consistently will the maxim of your action to become a universal law, to ask, in effect, “What would happen if everyone did this?” The maxim is “Whenever you need to borrow money you cannot pay back, make a lying promise to repay.” So what *would* happen if everyone in need of a loan acted in accordance with this maxim? People would make lying promises to obtain loans, but everyone would also know that such promises were worthless, and the custom of loaning money on promises would disappear. So willing the maxim to be a universal law involves a contradiction: If everyone made lying promises,

promise-making itself would be no more; you cannot consistently will the maxim to become a universal law. Therefore, your duty is clear: Making a lying promise to borrow money is morally wrong.

Kant’s first formulation of the categorical imperative yields several other duties, some of which are particularly relevant to bioethics. Notably he argues that there is an absolute moral prohibition against killing the innocent, lying, committing suicide, and failing to help others when feasible.

Perhaps the most renowned formulation of the categorical imperative is the principle of respect for persons (a formulation distinct from the first one, though Kant thought them equivalent). As he puts it, “Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.”<sup>6</sup> People must never be treated as if they were mere instruments for achieving some further end, for people are ends in themselves, possessors of ultimate inherent worth. People have ultimate value because they are the ultimate source of value for other things. They bestow value; they do not have it bestowed upon them. So we should treat both ourselves and other persons with the respect that all inherently valuable beings deserve.

According to Kant, the inherent worth of persons derives from their nature as free, rational beings capable of directing their own lives, determining their own ends, and decreeing their own rules by which to live. Thus, the inherent value of persons does not depend in any way on their social status, wealth, talent, race, or culture. Moreover, inherent value is something that all persons possess equally. Each person deserves the same measure of respect as any other.

Kant explains that we treat people merely as a means instead of an end-in-themselves if we disregard these characteristics of personhood—if we thwart people’s freely chosen actions by coercing them, undermine their rational decision-making by lying to them, or discount their

equality by discriminating against them. In bioethics, clear-cut cases of not respecting persons in Kant's sense would normally include experimenting on people without their knowledge and consent, lying to them about their medical condition and prognosis, and forcing patients to receive treatment against their will.

Notice that this formulation of the categorical imperative does not actually prohibit treating a person as a means but forbids treating a person *simply*, or *merely*, as a means—as nothing but a means. Kant recognizes that in daily life we often must use people to achieve our various ends. To buy milk, we use the cashier; to find books, we use the librarian; to get well, we use the doctor. But because their actions are freely chosen and we do not undermine their status as persons, we do not use them *solely* as instruments of our will. Medical researchers use their human subjects as a means to an end—but not merely as a means to an end if the subjects give their informed consent to participate in the research.

### **Principleism**

As we've seen, utilitarianism and Kantian ethics are each based on a single, absolute moral standard: utility and the categorical imperative. In the former, utility is the only moral measure of rightness, and it allows no exceptions; in the latter, every action must be judged against the categorical imperative, and it, too, permits no exceptions. Some theorists, however, think these relatively simple approaches to ethics are *too* simple, leaving too much out of account and failing to capture other important elements of the moral life—in particular, the other moral principles that are essential to moral deliberation. They argue that besides the moral principles of utility and autonomy embodied in utilitarianism and Kantian ethics, there are others that our moral experience reveals—for example, the principles of nonmaleficence, beneficence, and justice discussed in Chapter 1. They infer that there must be more than just one basic moral rule because we obviously have several distinct moral duties, and we cannot

derive them from one another or from an all-encompassing one-principle theory.

But a major problem arises if we assume that our moral principles are absolute. Since an absolute principle can allow no exceptions, conflicts between two or more such principles cannot be resolved. Honoring one rule will entail the violation of another. Say a moral theory consists of just two absolutist rules: "Do not lie" and "Do not harm patients." And suppose that telling a mentally unstable patient the truth about her terminal cancer will cause her immense psychological harm and probably hasten her death. If her doctor tells her the truth, she will be harmed; if her doctor lies and gives her only good news, she will not be harmed. The doctor cannot both tell her the truth and avoid harming her.

A theory with two or more main principles can get around this problem if the principles are *prima facie*—that is, if they apply in all cases unless there is a conflict between principles that requires deciding which principle is weightier. If the two duties in the dying-patient example are *prima facie*, then we would need to decide which duty was more important in the situation. The two principles would represent our *apparent* duties, but when we determine which duty is weightier, we would discover which is our *actual* duty. This way of thinking about conflicting principles fits well with our moral experience. We know that sometimes our duties do conflict, that some duties are more momentous than others, that occasionally doing the right thing means violating a principle, and that even after breaking or overriding the rules, they are still essential to the moral life.

Such a theory or approach is known as **principleism**. The philosopher W. D. Ross, who articulated the idea of *prima facie* principles in 1930, advocated a form of principleism that included several strong duties: tell the truth, keep promises, distribute benefits and burdens fairly, benefit others, refrain from harming others, make amends for causing injuries, and repay services done. A very influential principleism that is widely used in bioethics was developed by

Tom Beauchamp and James Childress in *Principles of Biomedical Ethics* (1979). They argue for four *prima facie* principles: respect autonomy, promote happiness (beneficence), refrain from harming others (nonmaleficence), and distribute benefits and burdens fairly (justice).

As you will see, the collision between important, competing duties is common in bioethics and is the source of some of the most heart-rending, exasperating, and thorny issues in society, medicine, and law. Care providers, for example, are duty-bound to respect the autonomy of patients (which includes being honest with them), but they are also required by the principle of beneficence to do good to patients, to advance patients' welfare. Suppose a physician discovers that his patient has a malignant breast tumor, but because she is terrified of cancer, he tells her that the tumor is benign but should be surgically removed anyway. Or a 10-year-old boy is seriously injured when he is hit by a speeding car, and the only way to save him is to give him a blood transfusion, a procedure that his Jehovah's Witness parents reject. But the physicians do the transfusion anyway and save the boy's life—and are promptly sued by the parents. Or a hopelessly ill patient in unrelieved agony requests help to be put out of his misery, and removing life-sustaining treatment will only prolong his agony. The physician—who has spent her whole career saving lives—is now forced to consider "mercy killing" as an option for her suffering patient.

Critics of principlism are quick to point out its most serious weakness: the lack of a stable formula or procedure for assigning weights to principles to see which is strongest. Principles don't have preassigned weights. Sometimes autonomy carries the greatest moral weight; sometimes utility does; sometimes it's unclear (at least initially) which principle is foremost. The challenge is to examine the facts of the case and make a considered moral judgment using the principles as general guides. Advocates of principlism insist that this weighting process is rational, generally reliable, and not excessively subjective.

### Natural Law Theory

From ancient times to the present day, many people have thought that the outlines of the moral law are plain to see because they are written large and true in nature itself. This basic notion has been developed over the centuries into what is known as **natural law theory**, the view that right actions are those that conform to moral standards discerned in nature through human reason. Undergirding this doctrine is the belief that all of nature (including humankind) is teleological, that it is somehow directed toward particular goals or ends, and that humans achieve their highest good when they follow their true, natural inclinations leading to these goals or ends. There is, in other words, a way things *are*—natural processes and functions that accord with the natural law—and how things are shows how things *should be*. The prime duty of humans, then, is to guide their lives toward these natural ends, acting in accordance with the requirements of natural law.

Implicit in all this is the element of rationality. According to natural law theory, humans are rational beings empowered by reason to perceive the workings of nature, determine the natural inclinations of humans, and recognize the implications therein for morally permissible actions. That is, reason enables human beings to ascertain the moral law implicit in nature and to apply that objective, universal standard to their lives.

Though natural law theory has both religious and nonreligious forms, the theistic formulation of theologian-philosopher Thomas Aquinas (1225–1274) has been the theory's dominant version. It is not only the official moral outlook of the Roman Catholic Church, but it has also been the intellectual starting point for many contemporary variations of the theory, secular and otherwise. For Aquinas, God is the author of the natural law who gave humans the gift of reason to discern the law for themselves and live accordingly. Aquinas argues that human beings naturally tend toward—and therefore have a duty of—preserving human life and health (and

so must not kill the innocent), producing and raising children, seeking knowledge (including knowledge of God), and cultivating cooperative social relationships. In all this, Aquinas says, the overarching aim is to do and promote good and avoid evil.

Natural law theory does not provide a relevant moral rule covering every situation, but it does offer guidance through general moral principles, some of which are thought to apply universally and absolutely (admitting no exceptions). Among these principles are absolutist prohibitions against directly killing the innocent, lying, and using contraceptives. In his list of acts considered wrong no matter what, Aquinas includes adultery, blasphemy, and sodomy.

Of course, moral principles or rules often conflict, demanding that we fulfill two or more incompatible duties. We may be forced, for example, to either tell a lie and save people's lives or tell the truth and cause their death—but we cannot do both. Some moral theories address these problems by saying that all duties are *prima facie*: When duties conflict, we must decide which ones override the others. Theories that posit absolute duties—natural law theory being a prime example—often do not have this option. How does the natural law tradition resolve such dilemmas? Among other resources, it uses the **doctrine of double effect**.

This principle, a cornerstone of Roman Catholic ethics, affirms that performing a bad action to bring about a good effect is never morally acceptable but that performing a good action may sometimes be acceptable even if it produces a bad effect. More precisely, the principle says it is always wrong to intentionally perform a bad action to produce a good effect, but doing a good action that results in a bad effect may be permissible if the bad effect is not intended although foreseen. In the former case, a bad thing is said to be directly intended; in the latter, a bad thing is not directly intended.

These requirements have been detailed in four “tests” that an action must pass to be judged

morally permissible. We can express a traditional version of these tests like this:

1. The action itself must be morally permissible.
2. Causing a bad effect must not be used to obtain a good effect (the end does not justify the means).
3. Whatever the outcome of an action, the intention must be to cause only a good effect (the bad effect can be foreseen but never intended).
4. The bad effect of an action must not be greater in importance than the good effect.

Consider the application of these tests to euthanasia. Suppose an 80-year-old hopelessly ill patient is in continuous, unbearable pain and begs to be put out of her misery. Is it morally permissible to grant her request (either by giving a lethal injection or ending all ordinary life-sustaining measures)? If we apply the doctrine of double effect as just outlined, we must conclude that the answer is *no*: Euthanasia—either active or passive—is not a morally permissible option here. (In the Roman Catholic view, all forms of euthanasia are wrong, although it is permissible not to treat a hopelessly ill person for whom ordinary life-sustaining treatments are useless.) Failing even one of the tests would render an action impermissible, but in this case let us run through all four as a natural law theorist might:

1. Taking steps to terminate someone's life is a clear violation of test 1. Whatever its effects, the action of taking a life is in itself immoral, a violation of the cardinal duty to preserve innocent life.
2. Ending the woman's life to save her from terrible suffering is an instance of causing a bad effect (the woman's death) as a means of achieving a good effect (cessation of pain)—a failure of test 2.
3. The death of the woman is intended; it is not merely a tragic side effect of the attempt solely to ease her pain. So the action fails test 3.

4. Causing the death of an innocent person is a great evil that cannot be counterbalanced by the good of pain relief. So the action does not pass test 4.

The verdict in such a case would be different, however, if the patient's death were not intentionally caused but unintentionally brought about. Suppose, for example, that the physician sees that the woman is in agony and so gives her a large injection of morphine to minimize her suffering—knowing full well that the dose will also probably speed her death. In this scenario, the act of easing the woman's pain is itself morally permissible (test 1). Her death is not a means to achieve some greater good; the goal is to ease her suffering (test 2). Her death is not intended; the intention is to alleviate her pain, though the unintended (but foreseen) side effect is her hastened death (test 3). Finally, the good effect of an easier death seems more or less equivalent in importance to the bad effect of a hastened death. Therefore, unintentionally but knowingly bringing about the woman's death in this way is morally permissible.

We get similar results if we apply the double-effect principle in the traditional way to abortion. We find that as the intentional destruction of an innocent human life (so-called direct), abortion is always immoral (test 1). Moreover, it is wrong even (or especially) if it is performed to bring about some good result, such as saving the mother's life or preventing serious harm to her (tests 2 and 3). However, actions leading unintentionally to the death of a fetus (so-called indirect abortion) may be permissible in rare cases. Say a pregnant woman has an infectious disease that will kill her unless she gets injections of a powerful drug. But the drug will abort the fetus. According to the doctrine of double effect, receiving the injections may be morally permissible if the action itself is morally permissible, which it is (test 1); if the death of the fetus is not used to rescue the woman (test 2); if the injections are given with the intention of curing the woman's disease, not of inducing an

abortion (test 3); and if the death of the fetus is balanced by the life of the woman (test 4).

### **Rawls's Contract Theory**

In its broadest sense, **contractarianism** refers to moral theories based on the idea of a social contract, or agreement, among individuals for mutual advantage. The most influential contemporary form of contractarianism is that of philosopher John Rawls (1921–2002), who uses the notion of a social contract to generate and defend moral principles governing how members of a society should treat one another. He asks, in effect, by what principles should a just society structure itself to ensure a fair distribution of rights, duties, and advantages of social cooperation?

His answer is that the required principles—essentially principles of justice—are those that people would agree to under hypothetical conditions that ensure fair and unbiased choices. He believes that if the starting point for the social contract is fair—if the initial conditions and bargaining process for producing the principles are fair—then the principles themselves will be just and will define the essential makeup of a just society. As Rawls says,

[The] guiding idea is that the principles of justice for the basic structure of society are the object of the original agreement. They are the principles that free and rational persons concerned to further their own interests would accept in an initial position of equality as defining the fundamental terms of their association. These principles are to regulate all further agreements; they specify the kinds of social cooperation that can be entered into and the forms of government that can be established.<sup>7</sup>

At the hypothetical starting point—what Rawls calls the “original position”—a group of normal, self-interested, rational individuals come together to choose the principles that will determine their basic rights and duties and their share of society's benefits and burdens. But to ensure that their decisions are as fair and impartial as possible, they must meet behind a

metaphorical “veil of ignorance.” Behind the veil, no one knows his own social or economic status, class, race, sex, abilities, talents, level of intelligence, or psychological makeup. Since the participants are rational and self-interested but ignorant of their situation in society, they will not agree to principles that will put any particular group at a disadvantage because they might very well be members of that group. They will choose principles that are unbiased and nondiscriminatory. The assumption is that since the negotiating conditions in the original position are fair, the agreements reached will also be fair—the principles will be just.

Rawls contends that given the original position, the participants would agree to arrange their social relationships according to these fundamental principles:

1. Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.
2. Social and economic inequalities are to be arranged so that they are both:
  - (a) to the greatest benefit of the least advantaged . . . and
  - (b) attached to offices and positions open to all under conditions of fair equality of opportunity.<sup>8</sup>

The first principle—the equal liberty principle—says that everyone is entitled to the most freedom possible in exercising basic rights and duties (for example, the right to vote and hold office and freedom of speech, assembly, and thought). Each person should get a maximum degree of basic liberties but no more than anyone else. This principle takes precedence over all other considerations (including the second principle) so that basic liberties cannot be reduced or canceled just to improve economic well-being.

The second principle concerns social and economic goods such as income, wealth, opportunities, and positions of authority. Part (b) says that everyone is entitled to an equal chance to try to acquire these basic goods. No one is

guaranteed an equal share of them, but opportunities to obtain these benefits must be open to all, regardless of social standing.

Rawls knows that social and economic inequalities will naturally arise in society. But as he asserts in part (a), they are not unjust if they work to everyone’s benefit, especially to the benefit of the least well off in society. “[There] is no injustice,” he says, “in the greater benefits earned by a few provided that the situation of persons not so fortunate is thereby improved.”<sup>9</sup> For Rawls, such a policy is far more just than one in which some people are made to suffer for the greater good of others: “[I]t is not just that some should have less in order that others may prosper.”

In Rawls’s scheme, the demands of the first principle must be satisfied before satisfying the second, and the requirements of part (b) must be met before those of part (a). In any just distribution of benefits and burdens, then, the first priority is to ensure equal basic liberties for all concerned, then equality of opportunity, then the arrangement of any inequalities to the benefit of the least advantaged.

As a theory of distributive justice, Rawls’s contractarianism seems to have significant implications for the allocation of society’s health care resources. For example, one prominent line of argument goes like this: As Rawls claims, everyone is entitled to fair equality of opportunity, and adequate (basic) health care enables fair equality of opportunity (by ensuring “normal species functioning”). Therefore, everyone is entitled to adequate health care, which includes all appropriate measures for eliminating or compensating for the disadvantages of disease and impairment.<sup>10</sup> In such a system, there would be universal access to a basic level of health care, while more elaborate or elective services would be available to anyone who could afford them.

Another implication: Suppose that to provide a basic level of health care to everyone (and meet the equality-of-opportunity requirement), society would have to spend 90 percent of its health care resources. But say that in the current system, 50 percent of the resources are being

spent on acute care for the elderly—that is, expensive measures to extend the lives of people who have already lived a long time. According to Rawlsian principles, is the current system of health care unjust?

### Virtue Ethics

Most moral theories—including all those just discussed—are theories of obligation. They emphasize the rightness of actions and the duties of moral agents. Their main concern is knowing and doing what's right, and their chief guide to these aims is moral principles or directives.

**Virtue ethics**, however, is a radically different kind of moral theory: It focuses on the development of virtuous character. According to virtue ethics, character is the key to the moral life, for it is from a virtuous character that moral conduct and values naturally arise. Virtues are ingrained dispositions to act by standards of excellence, so having the proper virtues leads as a matter of course to right actions properly motivated. The central task in morality, then, is not knowing and applying principles but being and becoming a good person, someone possessing the virtues that define moral excellence. In virtue ethics, someone determines right action not by consulting rules but by asking what a truly virtuous person would do or whether an action would accord with the relevant virtues.

Aristotle (384–322 BC) is the primary inspiration for contemporary versions of virtue ethics. For him, as for many modern virtue ethicists, the highest goal of humanity is the good life, or “human flourishing” (what Aristotle calls *eudaimonia*, or happiness), and developing virtues is the way to achieve such a rich and satisfying life. Thus, virtues are both the traits that make us good persons and the dispositions that enable us to live good lives. The good life is the virtuous life.

Unlike many theories of obligation, virtue ethics asks us to do more than just observe minimal moral rules—it insists that we *aspire to moral excellence*, that we cultivate the virtues that will make us better persons. In this sense, virtue ethics is goal-directed, not rule-guided.

The moral virtues—benevolence, honesty, loyalty, compassion, fairness, and the like—are ideals that we must ever strive to attain. (There are also nonmoral virtues such as patience, prudence, and reasonableness, which need not concern us here.) By the lights of both Aristotle and modern virtue ethicists, character is not static. We can become more virtuous by reflecting on our lives and those of others, practicing virtuous behavior, or imitating moral exemplars such as Gandhi, Buddha, Jesus, Muhammad, and Socrates. We can—and should—be better than we are.

To the virtue ethicist, possessing the right virtues means having the proper motivations that naturally accompany those virtues. To act morally, we must act from virtue, and acting from virtue means acting with the appropriate motives. It is not enough to do right; we must do right for the right motivating reasons. If we save a drowning friend, we should do so out of genuine feelings of compassion, kindness, or loyalty—not because of the prodding of moral rules or social expectations. In contrast, some moral theories (notably Kant's) maintain that acting morally is solely a matter of acting for duty's sake—performing an action simply because duty requires it. Virtuous motives are irrelevant; we act morally if we do our duty regardless of our motivations. But this notion seems to many to offer a barren picture of the moral life. Surely, they say, motivations for acting are often relevant to our evaluations of people's character and actions. The friend we saved from drowning would probably be appalled if we declared that we saved her out of duty even though we did not really care whether she lived or died. Many moral philosophers agree that motivations are indeed important considerations in moral judgments, and they have incorporated virtues into their theories of obligation.

Virtue ethics fits well with the emphasis on virtues that has always been part of the healing arts. Physicians and nurses are expected to possess particular virtues, including compassion, trustworthiness, justice, and honesty. They are expected to be more than just technically skilled

## IN DEPTH

### CAN VIRTUE BE TAUGHT?

Aristotle believes that moral virtues are not the sort of thing you can learn by merely studying them, as you would if you wanted to learn calculus. He insists that moral virtues can only be learned through practice, by *living* the virtues. As he says,

[M]oral virtue comes about as a result of habit. . . . From this it is also plain that none of the moral virtues arises in us by nature. . . . [B]ut the virtues we get by first exercising them, as also happens in the case of the arts as well. For the things we have to learn before we can do them, we learn by doing them, e.g., men become builders by building and lyreplayers by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts.<sup>12</sup>

and knowledgeable and to do more than merely follow the rules of conduct or procedure. They are obliged to do right by their patients, and this obligation is most likely met through the cultivation and possession of virtues.

The virtue ethics approach to bioethical issues is distinctive. On abortion, for example, the virtue ethicist might argue that a woman's decision to have an abortion should be judged by the virtues (or lack thereof) that she draws on in deciding what to do. If she decides to have an abortion just because she is afraid of the responsibilities of parenthood, she shows cowardice. If she wants to go through with an abortion merely because pregnancy would disrupt her vacation plans, she shows self-centeredness and callousness. In neither case is the virtue ethicist likely to call the woman's decision virtuous.<sup>11</sup>

### The Ethics of Care

The ethics of care is a distinctive moral perspective that arose out of feminist concerns and grew to challenge core elements of most other moral theories. Generally those theories emphasize abstract principles, general duties, individual rights, impartial judgments, and deliberative reasoning. But the ethics of care shifts the focus to the unique demands of specific situations and to the virtues and feelings that are central to close personal relationships—empathy, compassion, love, sympathy, and fidelity. The heart of the moral life is feeling for and caring for those with whom you have a special, intimate

connection—an approach that especially resonates with physicians and nurses.

Early on, the ethics of care drew inspiration from the notion that men and women have dramatically different styles of moral decision-making, with men seizing on principles, duties, and rights, and women homing in on personal relationships, caring, and empathy. This difference was highlighted in research done by psychologist Carol Gilligan and published in her 1982 book *In a Different Voice*.<sup>13</sup> Typically men recognize an ethic of justice and rights, she says, and women are guided by an ethic of compassion and care. In her view the latter is as legitimate as the former, and both have their place in ethics.

Other research has suggested that the differences between men and women in styles of moral thinking may not be as great as Gilligan suggests. But the credibility of the empirical claim does not affect the larger insight that the research seemed to some writers to suggest: Caring is an essential part of morality, and the most influential theories have not fully taken it into account.

These points get support along several lines. First, virtue ethics reminds us that virtues are part of the moral life. If caring is viewed as a virtue—in the form of compassion, empathy, or kindness—then caring, too, must be an element of morality. A moral theory then would be deficient if it made no room for care.

Moreover, many argue that unlike the ethics of care, most moral theories push the principle

of impartiality too far. Recall that impartiality in morality requires us to consider everyone as equal, counting everyone's interests the same. The principle applies widely, especially in matters of public justice, but less so in personal relationships of love, family, friendship, and the like. We seem to have special obligations (partiality) to close friends, family members, and others we care for, duties that we do not have to strangers or to universal humanity. As some philosophers explain it,

The care perspective is especially meaningful for roles such as parent, friend, physician, and nurse, in which contextual response, attentiveness to subtle clues, and deepening special relationships are likely to be more important morally than impartial treatment.<sup>14</sup>

May I devote my time and resources to caring for my own friends and family, even if this means ignoring the needs of other people whom I could also help? From an impartial point of view, our duty is to promote the interests of everyone alike. But few of us accept that view. The ethics of care confirms the priority that we naturally give to our family and friends, and so it seems a more plausible moral conception.<sup>15</sup>

Most moral theories emphasize duties and downplay the role of emotions, attitudes, and motivations. Kant, for example, would have us do our duty for duty's sake, whatever our feelings. For him, to be a morally good parent, we need only act from duty. But taking care of our children as a matter of moral obligation alone seems an empty exercise. Surely being a morally good parent also involves having feelings of love and attitudes of caring. The ethics of care eagerly takes these emotional elements into account.

Many philosophers, including several writing from a feminist perspective, have lodged such criticisms against the most influential moral theories while suggesting that a mature morality should accommodate both an ethic of obligation and an ethic of care. Annette Baier, for example, has taken this approach:

It is clear, I think, that the best moral theory has to be a cooperative product of women and men, has to harmonize justice and care. The morality it theorizes about is after all for all persons, for men and for women, and will need their combined insights. As Gilligan said, what we need now is a "marriage" of the old male and the newly articulated female insights.<sup>16</sup>

For many nurses, the ethics of care seems like a fitting, natural approach to morality in nursing practice. After all, caring has always been an essential part of what nurses do and how they think about their jobs. When the focus of concern is, say, a very sick patient and her family, traditional moral theories would have those involved attend to relevant moral principles, strive for an impartial stance, emphasize individual rights, and engage in impassive moral deliberations. But the ethics of care insists that medical care providers pay more attention to the specific needs of the patient and her family, be aware of the special relationships they have with each other, understand the attitudes and feelings at work among them, and act with compassion, sympathy, and respect.

### Feminist Ethics

Feminist ethics is an approach to morality aimed at rethinking or revamping traditional ethics to eliminate aspects that devalue or ignore the moral experience of women. Among its targets in traditional ethics are the assumptions that (1) women's moral concerns are not as important as men's, (2) women are morally inferior to men (less mature or less rational), (3) the moral issues that arise from domestic or private life (the area traditionally relegated exclusively to women) are inconsequential, and (4) the concepts or virtues traditionally associated with women in Western cultures (community, nature, interconnectedness, caring, feeling, sharing, among others) are not central to morality. Feminist ethics is defined by a distinctive focus on these issues, rather than by a set of doctrines or common ideology among feminists,

many of whom may disagree on the nature of feminist ethics or on particular moral issues. A variety of divergent perspectives have been identified as examples of feminist ethics, including the ethics of care.

Feminist ethics generally downplays the role of moral principles and traditional ethical concepts, insisting instead that moral reflection must take into account the social realities—the relevant social practices, relationships, institutions, and power arrangements. Many feminists think that the familiar principles of Western ethics—autonomy, utility, freedom, equality, and so forth—are too broad and abstract to help us make moral judgments about specific persons who are enmeshed in concrete social situations. It is not enough, for example, to respect a woman's decision to have an abortion if she is too poor to have one, or if her culture is so oppressive (or oppressed) as to make abortion impossible to obtain, or if social conditioning leads her to believe that she has no choice or that her views don't count. Theoretical autonomy does not mean much if it is so thoroughly undermined in reality.

Many theorists in feminist ethics also reject the traditional concept of the moral agent. Jan Crosthwaite says that the old notion is that of "abstract individuals as fundamentally autonomous agents, aware of their own preferences and values, and motivated by rational self-interest (though not necessarily selfish)."<sup>17</sup> But, she says, many feminists

present a richer conception of persons as historically and culturally located, socially related and essentially embodied. Individuals are located in and formed by specific relationships (chosen and unchosen) and ties of affection and responsibility. . . . Such a conception of socially embedded selves refocuses thinking about autonomy, shifting the emphasis from independent self-determination towards ideals of integrity within relatedness. . . . Respecting autonomy becomes less a matter of protecting individuals from "coercive" influences than one of positive empowerment, recognizing people's

interdependence and supporting individuals' development of their own understanding of their situation and options.<sup>18</sup>

Though all adherents of feminist ethics support liberation and equality for women, they disagree on how these values apply to specific moral issues. Most support unimpeded access to abortion, but some do not. As later chapters show, opinions among feminists also diverge on surrogacy and reproductive technologies such as in vitro fertilization.

### Casuistry

*Casuistry* is a method of moral reasoning that emphasizes cases and analogy rather than moral judgments are supposed to be deduced. Casuists say reasonable moral judgments are arrived at not by applying theories, rights, and rules, but by paying careful attention to specific cases and circumstances. In casuistry, judgments about new cases are made by analogy with similar or paradigm cases; as in law, casuistry operates by consulting precedent. Casuists point out that problems in moral reasoning are especially likely when theories or principles are strictly applied without regard to the relevant details of cases. They also note that we are often far more confident of specific moral judgments than we are of decisions based on general principles.

Moral philosophers, however, have voiced several concerns about the method. For one thing, it seems that casuistry is dependent on rules or principles just as moral theories are. Consider this criticism:

Casuists sometimes write as if paradigm cases speak for themselves or inform moral judgment by their facts alone, an implausible thesis. For the casuist to move constructively from case to case, a recognized and morally relevant norm must connect the cases. The norm is not part of the facts or narrative of the cases involved; it is a way of interpreting, evaluating, and linking cases. All analogical reasoning in casuistry requires a connecting norm to indicate that one sequence of events is morally like or unlike another sequence in relevant respects.<sup>19</sup>

Some critics also question the ability of casuistry to justify a moral decision or the selection of a paradigm case. Casuists hold that justification comes from a society's traditions, values, or conventions. But it seems that a solid set of principles or standards would be necessary to counteract the bias, arbitrariness, or vagueness of these influences.

Casuistry has made valuable contributions to our understanding and use of moral reasoning. But in its purest form it seems problematic. More recent scholarship, however, has demonstrated ways that casuistry can take into account some moral principles or norms.

### **CRITERIA FOR JUDGING MORAL THEORIES**

As you can see, as explanations of what makes actions right or character good, moral theories can differ dramatically in both content and quality. In their own fashion, they try to identify the true determinants of rightness or goodness, and they vary in how close they seem to get to the mark. Most moral philosophers would readily agree: Some moral theories are better than others, and a vital task in ethics is to try to tell which is which. Moral theories can be useful and valuable to us only if there are criteria for judging their worth—and fortunately there are such standards.

In several ways, moral theories are analogous to scientific theories. Scientists devise theories to explain the causes of events. The germ theory is offered to explain the cause and spread of infectious diseases. The Big Bang theory is used to explain the structure and expansion of the universe. The “greenhouse effect” is put forth to explain climate change. For each phenomenon to be explained, scientists usually have several possible theories to consider, and the challenge is to determine which one is best (and is therefore most likely to be correct). The superior theory is the one that fares best when judged by generally accepted yardsticks known as the *scientific criteria of adequacy*. One criterion often invoked is

*fruitfulness*—whether the theory makes successful predictions of previously unknown phenomena. All things being equal, a theory that makes successful predictions of novel phenomena is more likely to be true than one that does not. Another important criterion is *conservatism*—how well a theory fits with established facts, with what scientists already know. All things being equal, a theory that conflicts with what scientists already have good reasons to believe is less likely to be true than a theory that has no such conflicts. Of course, an unconservative theory can turn out to be correct, and a conservative theory wrong, but the odds are against this outcome. Analogously, moral theories are meant to explain what makes an action right or a person good, and to try to determine which moral theory is most likely correct, we apply conceptual yardsticks—the *moral criteria of adequacy*. Any plausible moral theory must measure up to these critical standards.

An important criterion of adequacy for moral theories is *Criterion I: consistency with our considered moral judgments*. Any plausible scientific theory must be consistent with the data that the theory is supposed to explain; there should be no conflicts between the theory and the relevant facts. A theory put forth to explain planetary motion, for example, must account for the relevant data—scientific observations of the movements of the planets and related objects. Likewise, a moral theory must also be consistent with the data it is supposed to explain: our considered moral judgments, what some call our moral common sense. We arrive at these judgments after careful deliberation that is as free of bias, self-interest, and other distorting influences as possible. Moral philosophers grant these judgments considerable respect and try to take them into account in their moral theorizing. As we have seen, these judgments are fallible, and they are often revised under pressure from trustworthy principles or theories. But we are entitled to trust them unless we have good reason to doubt them. Therefore, any moral theory that is seriously inconsistent with our considered judgments

## Review: Evaluating Moral Theories: Criteria of Adequacy

Criterion I: consistency with our considered moral judgments

Criterion II: consistency with the facts of the moral life

Criterion III: resourcefulness in moral problem-solving

must be regarded as badly flawed, perhaps fatally so, and in need of radical revision. Our considered judgments, for example, tell us that slavery, murder, rape, and genocide are wrong. A moral theory that implies otherwise fails this criterion and is a candidate for rejection.

In applying this standard, we must keep in mind that in both science and ethics, there is tension between theory and data. A good theory explains the data, which in turn influence the shape of the theory. Particularly strong data can compel scientists to alter a theory to account for the information, but a good theory can also give scientists reasons to question or reject particular data. In the same way, there is a kind of give and take between a moral theory and the relevant data. Our considered moral judgments may give us good reasons for altering or even rejecting our moral theory. But if our moral theory is coherent and well supported, it may oblige us to rethink or reject our considered judgments. In both science and ethics, the goal is to ensure that the fit between theory and data is as tight as possible. The fit is acceptably close when no further changes in the theory or the data are necessary—when there is a kind of balance between the two that moral philosophers call “reflective equilibrium.”

Another test of adequacy is *Criterion II: consistency with the facts of the moral life*. In science, good theories are consistent with scientific background knowledge, with what scientists already have good reasons to believe. They are, as mentioned earlier, conservative. This background knowledge includes other well-founded theories, highly reliable findings, and scientific (natural) laws. Moral theories should also be consistent with background knowledge—the *moral* background knowledge, the basic, inescapable

experiences of the moral life. These experiences include making moral judgments, disagreeing with others on moral issues, being mistaken in our moral beliefs, and giving reasons for accepting moral beliefs. That we do in fact experience these things from time to time is a matter of moral common sense—seemingly obvious facts of the moral life. Thus, any moral theory that is inconsistent with these aspects of the moral life is deeply problematic. It is possible that we are deluded about the moral life—that we, for example, merely think we are disagreeing with others on moral issues but are actually just venting our feelings. But our experience gives us good grounds for taking the commonsense view until we are given good reasons to believe otherwise.

Finally, we have *Criterion III: resourcefulness in moral problem-solving*. If a scientific theory helps scientists answer questions, solve problems, and control facets of the natural world, it demonstrates both its plausibility and usefulness. All things being equal, such a useful theory is better than one that has none of these advantages. Much the same is true for moral theories. A useful moral theory helps us solve moral problems. It can help us identify morally relevant aspects of conduct, judge the rightness of actions, resolve conflicts among moral principles and judgments, test and correct our moral intuitions, and understand the underlying point of morality itself. Any moral theory that lacks problem-solving resourcefulness is neither useful nor credible.

### APPLYING THE CRITERIA

In this section, we apply the three moral criteria of adequacy to two theories we discussed earlier

(one consequentialist, the other deontological). As we do, keep in mind that evaluating moral theories using these yardsticks is not a rote process. There is no standard procedure for applying the criteria to a theory and no set of instructions for assigning conceptual weight to each criterion as we judge a theory's worth. But the criteria do help us make broad judgments on rational grounds about a theory's strengths and weaknesses. We must use them as guides, relying on our best judgment in applying them, just as scientists must use their own educated judgment in wielding their kind of criteria of adequacy. In neither case is there a neat algorithm for theory assessment, but nonetheless in both arenas the process is objective, reasonable, and essential.

We should also remember that no moral theory is perfect, and none is likely to get the highest marks on every test. But there is much to learn even from flawed theories. If we look closely, we can see that each of the most influential theories of past centuries, even with its faults apparent, seems to have grasped at least a modest, gleaming piece of the truth about the moral life.

### **Utilitarianism**

For simplicity's sake, let us try to apply the criteria to classic act-utilitarianism, the view that right actions are those that result in the greatest overall happiness for everyone involved. First, note that the theory seems to pass the test suggested by Criterion II (consistency with the facts of the moral life). Utilitarianism assumes that we can indeed make moral judgments, have moral disagreements, be mistaken in our moral beliefs, and provide supporting reasons for our moral judgments.

The theory, however, has been accused of a lack of usefulness—failing Criterion III (resourcefulness in moral problem-solving). The usual charge is that utilitarianism is a poor guide to the moral life because the theory demands too much of us and blurs the distinction between obligatory and supererogatory actions.

Utilitarianism says that we should always try to maximize happiness for everyone considered, to do our utmost to increase overall utility. But some say this requirement would lead us to extreme beneficence—to, for example, give away most of our possessions, spend most of our time in charity work, and deem mandatory many acts that we would normally consider above and beyond the call of duty. Some defenders of the theory have suggested that it can be modified easily to ease the demands that it places on us. A few utilitarians have insisted that, contrary to the popular view, the commonsense distinction between obligatory and supererogatory acts is mistaken and that morality does demand the kind of sacrifice that utilitarianism implies.

The most serious accusation against classic utilitarianism is that it flies in the face of our considered moral judgments (Criterion I), especially concerning issues of justice and rights. Consider the case of a medical researcher trying to develop a cure for Alzheimer's disease. To devise this cure that would save countless lives, she needs only to conduct a single, secret experiment in which she gives a lethal drug to 10 early-stage Alzheimer's patients (without their knowledge) and does a postmortem examination on their brains. By increasing the unhappiness of 10 people (and depriving them of all possible happiness in the future), she can maximize happiness for thousands. Should she conduct the experiment? According to classic utilitarianism, if her actions would go undetected and have no additional unhappy effects, the answer is yes. The experiment would be justified by the enormous amount of net happiness it would generate. But the utilitarian verdict seems to conflict strongly with our considered judgments about justice. Taking the lives of a few people to benefit many others appears unjust, regardless of the good consequences that would flow from the deed. Critics claim that cases like this show that utilitarianism is a seriously inadequate theory.

Now consider the case of a competent patient with a serious illness who refuses medical treatment on religious grounds. He knows that he would suffer much less pain and have a longer and happier life if he were treated, but he still objects. But his physician wants to maximize the happiness and well-being of all her patients, so she surreptitiously treats the patient anyway without his consent. (Let us assume that no additional legal, professional, or psychological consequences ensue.) Does the physician do right? The utilitarian seems obliged to say yes. But our commonsense judgment would likely be that the physician violated her patient's autonomy—specifically, his right of self-determination.

Some utilitarians have replied to such Criterion I criticisms by saying that scenarios like those just presented are unrealistic and misleading. In the real world, they say, actions that seem to conflict with our moral intuitions almost always produce such bad consequences that the actions cannot be justified even on utilitarian grounds. Once *all* the possible consequences are taken into account, it becomes clear that the proposed actions do not maximize happiness and that commonsense morality and utilitarianism coincide. In real life, for example, the deeds of the researcher and the physician would almost certainly be exposed, resulting in a great deal of unhappiness for all concerned. Critics respond to the utilitarian by admitting that many times the judgments of commonsense morality and utilitarianism do in fact coincide when all the facts are known—but not always. Even the utilitarian must admit that there could be cases in which actions that maximize utility do clash with our considered moral judgments, and this possibility raises doubts about the utilitarian standard.

### Kant's Theory

Like utilitarianism, Kant's theory seems generally consistent with the basic facts of the moral life (Criterion II), but many philosophers argue

that it is not consistent with moral common sense (Criterion I). A major cause of the problem, they say, is Kant's insistence that we have absolute (or "perfect") duties—obligations that must be honored without exception. Thus, in Kantian ethics, we have an absolute duty not to lie or to break a promise or to kill the innocent, come what may. Imagine that a band of killers wants to murder an innocent man who has taken refuge in your house, and the killers come to your door and ask you point blank if he is in your house. To say no is to lie; to answer truthfully is to guarantee the man's death. What should you do? In a case like this, says Kant, you must *do your duty*—you must tell the truth though murder is the result and a lie would save a life. But in this case such devotion to moral absolutes seems completely askew, for saving an innocent life seems far more important morally than blindly obeying a rule. Our considered judgments suggest that sometimes the consequences of our actions do matter more than adherence to the letter of the law, even if the law is generally worthy of our respect and obedience.

Some have thought that Kant's theory can yield implausible results for another reason. Recall that the first formulation of the categorical imperative says that an action is permissible if persons could consistently act on the relevant maxim, and we would be willing to have them do so. This requirement seems to make sense if the maxim in question is something like "Do not kill the innocent" or "Treat equals equally." But what if the maxim is "Enslave all Christians" or "Kill all Ethiopians"? We could—without contradiction—will either one of these precepts to become a universal law. And if we were so inclined, we could be willing for everyone to act accordingly, even if we ourselves were Christians or Ethiopians. So by Kantian lights, these actions could very well be morally permissible, and their permissibility would depend on whether someone was willing to have them apply universally. Critics conclude that because the first

formulation of the categorical imperative seems to sanction such obviously immoral acts, the theory is deeply flawed. Defenders of Kant's theory, however, view the problems as repairable and have proposed revisions.

This apparent arbitrariness in the first formulation can significantly lessen the theory's usefulness (Criterion III). The categorical imperative is supposed to help us discern moral directives that are rational, universal, and objective. But if it is subjective in the way just described, its helpfulness as a guide for living morally is dubious. Defenders of Kant's theory, however, believe there are remedies for this difficulty. Some argue, for example, that the problem disappears if the second formulation is viewed as a supplement to the first, rather than as two independent principles.

### **KEY TERMS**

act-utilitarianism  
consequentialist theory  
contractarianism  
deontological (or nonconsequentialist) theory  
doctrine of double effect  
moral theory  
natural law theory  
rule-utilitarianism  
utilitarianism  
virtue ethics

### **SUMMARY**

A moral theory explains why an action is right or wrong or why a person or a person's character is good or bad. Making, using, or assessing moral theories is a normal, pervasive feature of the moral life.

Consequentialist moral theories assume that the rightness of actions depends on their consequences or results. Deontological theories say that the rightness of actions is determined partly or wholly by their intrinsic nature. The leading consequentialist theory is utilitarianism, the view that right actions are those that result in the most beneficial balance of good

over bad consequences for everyone involved. The theory comes in two main types. Act-utilitarianism is the idea that the rightness of actions depends on the relative good produced by individual actions. Rule-utilitarianism says a right action is one that conforms to a rule that, if followed consistently, would create for everyone involved the most beneficial balance of good over bad. Kantian ethics is opposed to consequentialist theories, holding that morality consists of following a rational and universally applicable moral rule and doing so solely out of a sense of duty. An action is right only if it conforms to such a rule, and we are morally praiseworthy only if we perform it for duty's sake alone. Principlism is the theory that right actions are not necessarily those sanctioned by single-rule theories such as utilitarianism, but rather by reference to multiple moral principles that must be weighed and balanced against one another. Natural law theory is a centuries-old view of ethics that maintains that right actions are those conforming to moral standards discerned in nature through human reason. Rawls's theory is a form of contractarianism, which means it is based on the idea of a social contract, or agreement, among individuals for mutual advantage. He argues for a set of moral principles that he believes would be arrived at through a fair, but hypothetical, bargaining process. Virtue ethics focuses on the development of virtuous character. The central task in morality is not knowing and applying principles but being and becoming a good person, someone possessing the virtues that define moral excellence. The ethics of care emphasizes the virtues and feelings that are central to close personal relationships.

The worth of moral theories can be assessed through the application of the moral criteria of adequacy. Criterion I is consistency with our considered moral judgments; Criterion II, consistency with the facts of the moral life; and Criterion III, resourcefulness in moral problem-solving.

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## READINGS

### Utilitarianism

JOHN STUART MILL

English philosopher John Stuart Mill argues for his view of ethics in *Utilitarianism* (1861), from which this excerpt is taken. He explains that utilitarians judge the morality of conduct by a single standard, the *principle of utility*: Right actions are those that result in greater overall well-being (or *utility*) for the people involved than any other possible actions. We are duty bound to maximize the utility of everyone affected, regardless of the contrary urgings of moral rules or unbending moral principles.

... The creed which accepts as the foundation of morals, Utility, or the Greatest Happiness Principle, holds that actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness. By happiness is intended pleasure, and the absence of pain; by unhappiness, pain, and the privation of pleasure. To give a clear view of the moral standard set up by the theory, much more requires to be said; in particular, what things it includes in the ideas of pain and pleasure; and to what extent this is left an open question. But these supplementary explanations do not affect the theory of life on which this theory of morality is grounded—namely, that pleasure, and freedom from pain, are the only things desirable as ends; and that all desirable things (which are as

numerous in the utilitarian as in any other scheme) are desirable either for the pleasure inherent in themselves, or as means to the promotion of pleasure and the prevention of pain.

Now, such a theory of life excites in many minds, and among them in some of the most estimable in feeling and purpose, inveterate dislike. To suppose that life has (as they express it) no higher end than pleasure—no better and nobler object of desire and pursuit—they designate as utterly mean and groveling; as a doctrine worthy only of swine, to whom the followers of Epicurus were, at a very early period, contemptuously likened; and modern holders of the doctrine are occasionally made the subject of equally polite comparisons by its German, French, and English assailants.

When thus attacked, the Epicureans have always answered, that it is not they, but their accusers, who represent human nature in a degrading light; since

From *Utilitarianism*, 7th ed. (London: Longmans, Green, and Co., 1879).

the accusation supposes human beings to be capable of no pleasures except those of which swine are capable. If this supposition were true, the charge could not be gainsaid, but would then be no longer an imputation; for if the sources of pleasure were precisely the same to human beings and to swine, the rule of life which is good enough for the one would be good enough for the other. The comparison of the Epicurean life to that of beasts is felt as degrading, precisely because a beast's pleasures do not satisfy a human being's conceptions of happiness. Human beings have faculties more elevated than the animal appetites, and when once made conscious of them, do not regard anything as happiness which does not include their gratification. I do not, indeed, consider the Epicureans to have been by any means faultless in drawing out their scheme of consequences from the utilitarian principle. To do this in any sufficient manner, many Stoic, as well as Christian elements require to be included. But there is no known Epicurean theory of life which does not assign to the pleasures of the intellect; of the feelings and imagination, and of the moral sentiments, a much higher value as pleasures than to those of mere sensation. It must be admitted, however, that utilitarian writers in general have placed the superiority of mental over bodily pleasures chiefly in the greater permanency, safety, uncostliness, &c., of the former—that is, in their circumstantial advantages rather than in their intrinsic nature. And on all these points utilitarians have fully proved their case; but they might have taken the other, and, as it may be called, higher ground, with entire consistency. It is quite compatible with the principle of utility to recognise the fact, that some *kinds* of pleasure are more desirable and more valuable than others. It would be absurd that while, in estimating all other things, quality is considered as well as quantity, the estimation of pleasures should be supposed to depend on quantity alone.

If I am asked, what I mean by difference of quality in pleasures, or what makes one pleasure more valuable than another, merely as a pleasure, except its being greater in amount, there is but one possible answer. Of two pleasures, if there be one to which all or almost all who have experience of both give a

decided preference, irrespective of any feeling of moral obligation to prefer it, that is the more desirable pleasure. If one of the two is, by those who are competently acquainted with both, placed so far above the other that they prefer it, even though knowing it to be attended with a greater amount of discontent, and would not resign it for any quantity of the other pleasure which their nature is capable of, we are justified in ascribing to the preferred enjoyment a superiority in quality, so far outweighing quantity as to render it, in comparison, of small account.

Now it is an unquestionable fact that those who are equally acquainted with, and equally capable of appreciating and enjoying, both, do give a most marked preference to the manner of existence which employs their higher faculties. Few human creatures would consent to be changed into any of the lower animals, for a promise of the fullest allowance of a beast's pleasures; no intelligent human being would consent to be a fool, no instructed person would be an ignoramus, no person of feeling and conscience would be selfish and base, even though they should be persuaded that the fool, the dunce, or the rascal is better satisfied with his lot than they are with theirs. They would not resign what they possess more than he, for the most complete satisfaction of all the desires which they have in common with him. If they ever fancy they would, it is only in cases of unhappiness so extreme, that to escape from it they would exchange their lot for almost any other, however undesirable in their own eyes. A being of higher faculties requires more to make him happy, is capable probably of more acute suffering, and is certainly accessible to it at more points, than one of an inferior type; but in spite of these liabilities, he can never really wish to sink into what he feels to be a lower grade of existence. We may give what explanation we please of this unwillingness; we may attribute it to pride, a name which is given indiscriminately to some of the most and to some of the least estimable feelings of which mankind are capable; we may refer it to the love of liberty and personal independence, an appeal to which was with the Stoics one of the most effective means for the inculcation of it; to the love of power, or to the love of excitement, both of which do really enter

into and contribute to it: but its most appropriate appellation is a sense of dignity, which all human beings possess in one form or other, and in some, though by no means in exact proportion to their higher faculties, and which is so essential a part of the happiness of those in whom it is strong, that nothing which conflicts with it could be, otherwise than momentarily, an object of desire to them. Whoever supposes that this preference takes place at a sacrifice of happiness—that the superior being, in anything like equal circumstances, is not happier than the inferior—confounds the two very different ideas, of happiness, and content. It is indisputable that the being whose capacities of enjoyment are low, has the greatest chance of having them fully satisfied; and a highly-endowed being will always feel that any happiness which he can look for, as the world is constituted, is imperfect. But he can learn to bear its imperfections, if they are at all bearable; and they will not make him envy the being who is indeed unconscious of the imperfections, but only because he feels not at all the good which those imperfections qualify. It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied. And if the fool, or the pig, is of a different opinion, it is because they only know their own side of the question. The other party to the comparison knows both sides.

It may be objected, that many who are capable of the higher pleasures, occasionally, under the influence of temptation, postpone them to the lower. But this is quite compatible with a full appreciation of the intrinsic superiority of the higher. Men often, from infirmity of character, make their election for the nearer good, though they know it to be the less valuable; and this no less when the choice is between two bodily pleasures, than when it is between bodily and mental. They pursue sensual indulgences to the injury of health, though perfectly aware that health is the greater good. It may be further objected, that many who begin with youthful enthusiasm for everything noble, as they advance in years sink into indolence and selfishness. But I do not believe that those who undergo this very common change voluntarily choose the lower description of pleasures in preference to the higher. I believe that before they devote themselves exclusively to the one, they have

already become incapable of the other. Capacity for the nobler feelings is in most natures a very tender plant, easily killed, not only by hostile influences, but by mere want of sustenance; and in the majority of young persons it speedily dies away if the occupations to which their position in life has devoted them, and the society into which it has thrown them, are not favourable to keeping that higher capacity in exercise. Men lose their high aspirations as they lose their intellectual tastes, because they have not time or opportunity indulging them; and they addict themselves to inferior pleasures, not because they deliberately prefer them, but because they are either the only ones to which they have access, or the only ones which they are any longer capable of enjoying. It may be questioned whether any one who has remained equally susceptible to both classes of pleasures, ever knowingly and calmly preferred the lower; though many, in all ages, have broken down in an ineffectual attempt to combine both.

From this verdict of the only competent judges, I apprehend there can be no appeal. On a question which is the best worth having of two pleasures, or which of two modes of existence is the most grateful to the feelings, apart from its moral attributes and from its consequences, the judgment of those who are qualified by knowledge of both, or, if they differ, that of the majority among them, must be admitted as final. And there needs be the less hesitation to accept this judgment respecting the quality of pleasures, since there is no other tribunal to be referred to even on the question of quantity. What means are there of determining which is the acutest of two pains, or the intensest of two pleasurable sensations, except the general suffrage of those who are familiar with both? Neither pains nor pleasures are homogeneous, and pain is always heterogeneous with pleasure. What is there to decide whether a particular pleasure is worth purchasing at the cost of a particular pain, except the feelings and judgment of the experienced? When, therefore, those feelings and judgment declare the pleasures derived from the higher faculties to be preferable in *kind*, apart from the question of intensity, to those of which the animal nature, disjoined from the higher faculties, is susceptible, they are entitled on this subject to the same regard....

## The Moral Law

IMMANUEL KANT

Kant argues that his moral theory is the very antithesis of utilitarianism, holding that right actions do not depend in the least on consequences, the production of happiness, or the desires and needs of human beings. For Kant, the core of morality consists of following a rational and universally applicable moral rule—the Categorical Imperative—and doing so solely out of a sense of duty. An action is right only if it conforms to such a rule, and we are morally praiseworthy only if we perform it for duty's sake alone.

### Preface

As my concern here is with moral philosophy, I limit the question suggested to this: Whether it is not of the utmost necessity to construct a pure moral philosophy, perfectly cleared of everything which is only empirical, and which belongs to anthropology? for that such a philosophy must be possible is evident from the common idea of duty and of the moral laws. Everyone must admit that if a law is to have moral force, i.e., to be the basis of an obligation, it must carry with it absolute necessity; that, for example, the precept, "Thou shall not lie," is not valid for men alone, as if other rational beings had no need to observe it; and so with all the other moral laws properly so called; that, therefore, the basis of obligation must not be sought in the nature of man, or in the circumstances in the world in which he is placed, but a priori simply in the conception of pure reason; and although any other precept which is founded on principles of mere experience may be in certain respects universal, yet in as far as it rests even in the least degree on an empirical basis, perhaps only as to motive, such a precept, while it may be a practical rule, can never be called a moral law. . . .

### The Good Will

Nothing can possibly be conceived in the world, or even out of it, which can be called good, without qualification, except a Good Will. Intelligence, wit,

judgment, and the other *talents* of the mind, however they may be named, or courage, resolution, perseverance, as qualities of temperament, are undoubtedly good and desirable in many respects; but these gifts of nature may also become extremely bad and mischievous if the will which is to make use of them, and which, therefore, constitutes what is called *character*, is not good. It is the same with the *gifts of fortune*. Power, riches, honour, even health, and the general well-being and contentment with one's conditions which is called *happiness*, inspire pride, and often presumption, if there is not a good will to correct the influence of these on the mind, and with this also to rectify the whole principle of acting, and adapt it to its end. The sight of a being who is not adorned with a single feature of a pure and good will, enjoying unbroken prosperity, can never give pleasure to an impartial rational spectator. Thus a good will appears to constitute the indispensable condition even of being worthy of happiness.

There are even some qualities which are of service to this good will itself, and may facilitate its action, yet which have no intrinsic unconditional value, but always presuppose a good will, and this qualifies the esteem that we justly have for them, and does not permit us to regard them as absolutely good. Moderation in the affections and passions, self-control, and calm deliberation are not only good in many respects, but even seem to constitute part of the intrinsic worth of the person but they are far from deserving to be called good without qualification, although they have been so unconditionally

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praised by the ancients. For without the principles of a good will, they may become extremely bad; and the coolness of a villain not only makes him far more dangerous, but also directly makes him more abominable in our eyes than he would have been without it.

A good will is good not because of what it performs or effects, not by its aptness for the attainment of some proposed end, but simply by virtue of the volition, that is, it is good in itself, and considered by itself to be esteemed much higher than all that can be brought about by it in favor of any inclination, nay, even of the sum-total of all inclinations. Even if it should happen that, owing to special disfavor of fortune, or the niggardly provision of a step-motherly nature, this will should wholly lack power to accomplish its purpose, if with its greatest efforts it should yet achieve nothing, and there should remain only the good will (not, to be sure, a mere wish, but the summoning of all means in our power), then, like a jewel, it would still shine by its own light, as a thing which has its whole value in itself. Its usefulness or fruitlessness can neither add to nor take away anything from this value. It would be, as it were, only the setting to enable us to handle it the more conveniently in common commerce, or to attract to it the attention of those who are not yet connoisseurs, but not to recommend it to true connoisseurs, or to determine its value. . . .

### **The Supreme Principle of Morality: The Categorical Imperative**

As I have deprived the will of every impulse which could arise to it from obedience to any law, there remains nothing but the universal conformity of its actions to law in general, which alone is to serve the will as principle, i.e., I am never to act otherwise than so that *I could also will that my maxim should become a universal law*. Here, now, it is the simple conformity to law in general, without assuming any particular law applicable to certain actions, that serves the will as its principle, and must so serve it, if duty is not to be a vain delusion and a chimerical notion. The common reason of men in its practical judgments perfectly coincides with this, and always has in view the principle here suggested. Let the question be, for example: May I when in distress

make a promise with the intention not to keep it? I readily distinguish here between the two significations which the question may have: Whether it is prudent, or whether it is right, to make a false promise? The former may undoubtedly often be the case. I see clearly indeed that it is not enough to extricate myself from a present difficulty by means of this subterfuge, but it must be well considered whether there may not hereafter spring from this lie much greater inconvenience than that from which I now free myself, and as, with all my supposed *cunning*, the consequences cannot be so easily foreseen but the credit once lost may be much more injurious to me than any mischief which I seek to avoid at present, it should be considered whether it would not be more *prudent* to act herein according to a universal maxim, and to make it a habit to promise nothing except with the intention of keeping it. But it is soon clear to me that such a maxim will still only be based on the fear of consequences. Now it is a wholly different thing to be truthful from duty, and to be so from apprehension of injurious consequences. In the first case, the very notion of the action already implies a law for me; in the second case, I must first look about elsewhere to see what results may be combined with it which would affect myself. For to deviate from the principle of duty is beyond all doubt wicked; but to be unfaithful to my maxim of prudence may often be very advantageous to me, although to abide by it is certainly safer. The shortest way, however, and an unerring one, to discover the answer to this question whether a lying promise is consistent with duty, is to ask myself, Should I be content that my maxim (to extricate myself from difficulty by a false promise) should hold good as a universal law, for myself as well as for others? And should I be able to say to myself, "Every one may make a deceitful promise when he finds himself in a difficulty from which he cannot otherwise extricate himself"? Then I presently become aware that while I can will the lie, I can by no means will that lying should be a universal law. For with such a law there would be no promises at all, since it would be in vain to allege my intention in regard to my future actions to those who would not believe this allegation, or if they over-hastily did so, would pay me back in my own

coin. Hence my maxim, as soon as it should be made a universal law, would necessarily destroy itself.

I do not, therefore, need any far-reaching penetration to discern what I have to do in order that my will may be morally good. Inexperienced in the course of the world, incapable of being prepared for all its contingencies, I only ask myself: canst thou also will that thy maxim should be a universal law? If not, then it must be rejected, and that not because of a disadvantage accruing from myself or even to others, but because it cannot enter as a principle into a possible universal legislation, and reason extorts from me immediate respect for such legislation. I do not indeed as yet *discern* on what this respect is based (this the philosopher may inquire), but at least I understand this, that it is an estimation of the worth which far outweighs all worth of what is recommended by inclination, and that the necessity of acting from *pure* respect for the practical law is what constitutes duty, to which every other motive must give place, because it is the condition of a will being good in *itself*, and the worth of such a will is above everything.

Thus, then, without quitting the moral knowledge of common human reason, we have arrived at its principle. And although, no doubt, common men do not conceive it in such an abstract and universal form, yet they always have it really before their eyes, and use it as the standard of their decision....

Nor could anything be more fatal to morality than that we should wish to derive it from examples. For every example of it that is set before me must be first itself tested by principles of morality, whether it is worthy to serve as an original example, i.e., as a pattern, but by no means can it authoritatively furnish the conception of morality. Even the Holy one of the Gospels must first be compared with our ideal of moral perfection before we can recognize Him as such; and so He says of Himself, "Why call ye Me [whom you see] good; none is good [the model of good] but God only [whom ye do not see]." But whence have we the conception of God as the supreme good? Simply from the *idea* of moral perfection, which reason frames a priori, and connects inseparably with the notion of a free will.

Imitation finds no place at all in morality, and examples serve only for encouragement, i.e., they put beyond doubt the feasibility of what the law commands, they make visible that which the practical rule expresses more generally, but they can never authorize us to set aside the true original which lies in reason, and to guide ourselves by examples.

From what has been said, it is clear that all moral conceptions have their seat and origin completely *a priori* in the reason, and that, moreover, in the commonest reason just as truly as in that which is in the highest degree speculative; that they cannot be obtained by abstraction from any empirical, and therefore merely contingent knowledge; that it is just this purity of their origin that makes them worthy to serve as our supreme practical principle, and that just in proportion as we add anything empirical, we detract from their genuine influence, and from the absolute value of actions; that it is not only of the greatest necessity, in a purely speculative point of view, but is also of the greatest practical importance, to derive these notions and laws from pure reason, to present them pure and unmixed, and even to determine the compass of this practical or pure rational knowledge, i.e. to determine the whole faculty of pure practical reason; and, in doing so, we must not make its principles dependent on the particular nature of human reason, though in speculative philosophy this may be permitted, or may even at times be necessary; but since moral laws ought to hold good for every rational creature, we must derive them from the general concept of a rational being. In this way, although for its *application* to man morality has need of anthropology, yet, in the first instance, we must treat it independently as pure philosophy, i.e., as metaphysic, complete in itself (a thing which in such distinct branches of science is easily done); knowing well that unless we are in possession of this, it would not only be vain to determine the moral element of duty in right actions for purposes of speculative criticism, but it would be impossible to base morals on their genuine principles, even for common practical purposes, especially of moral instruction, so as to produce pure moral dispositions, and to engrave them on men's minds to the promotion of the greatest possible good in the world....

### **First Formulation of the Categorical Imperative: Universal Law**

In this problem we will first inquire whether the mere conception of a categorical imperative may not perhaps supply us also with the formula of it, containing the proposition which alone can be a categorical imperative; for even if we know the tenor of such an absolute command, yet how it is possible will require further special and laborious study, which we postpone to the last section.

When I conceive a hypothetical imperative, in general I do not know beforehand what it will contain until I am given the condition. But when I conceive a categorical imperative, I know at once what it contains. For as the imperative contains besides the law only the necessity that the maxims shall conform to this law, while the law contains no conditions restricting it, there remains nothing but the general statement that the maxim of the action should conform to a universal law, and it is this conformity alone that the imperative properly represents as necessary.

There is therefore but one categorical imperative, namely, this: *Act only in that maxim whereby thou canst at the same time will that it should become a universal law.*

Now if all imperatives of duty can be deduced from this one imperative as from their principle, then, although it should remain undecided whether what is called duty is not merely a vain notion, yet at least we shall be able to show what we understand by it and what this notion means.

Since the universality of the law according to which effects are produced constitutes what is properly called *nature* in the most general sense (as to form), that is the existence of things so far as it is determined by general laws, the imperative of duty may be expressed thus: *Act as if the maxim of thy action were to become by thy will a universal law of nature.*

### **Four Illustrations**

We will now enumerate a few duties, adopting the usual division of them into duties to ourselves and to others and into perfect and imperfect duties.

1. A man reduced to despair by a series of misfortunes feels wearied of life, but is still so far in

possession of his reason that he can ask himself whether it would not be contrary to his duty to himself to take his own life. Now he inquires whether the maxim of his action could become a universal law of nature. His maxim is: From self-love I adopt it as a principle to shorten my life when its longer duration is likely to bring more evil than satisfaction. It is asked then simply whether this principle founded on self-love can become a universal law of nature. Now we see at once that a system of nature of which it should be a law to destroy life by means of the very feeling whose special nature it is to impel to the improvement of life would contradict itself, and therefore could not exist as a system of nature, and consequently would be wholly inconsistent with the supreme principle of all duty.

2. Another finds himself forced by necessity to borrow money. He knows that he will not be able to repay it, but sees also that nothing will be lent to him, unless he promises stoutly to repay it in a definite time. He desires to make this promise, but he has still so much conscience as to ask himself: Is it not unlawful and inconsistent with duty to get out of a difficulty in this way? Suppose, however, that he resolves to do so, then the maxim of his action would be expressed thus: When I think myself in want of money, I will borrow money and promise to repay it, although I know that I never can do so. Now this principle of self-love or of one's own advantage may perhaps be consistent with my whole future welfare; but the question is, Is it right? I change then the suggestion of self-love into a universal law, and state the question thus: How would it be if my maxim were a universal law? Then I see at once that it could never hold as a universal law of nature, but would necessarily contradict itself. For supposing it to be a universal law that everyone when he thinks himself in a difficulty should be able to promise whatever he pleases, with the purpose of not keeping his promise, the promise itself would become impossible, as well as the end that one might have in view in it, since no one would consider that anything was promised to him, but would consider that anything was promised to him, but would ridicule all such statements as vain pretenses.

3. A third finds in himself a talent which with the help of some culture might make him a useful man

in many respects. But he finds himself in comfortable circumstances, and prefers to indulge in pleasure rather than to take pains in enlarging and improving his happy natural capacities. He asks, however, whether his maxim of neglect of his natural gifts, besides agreeing with his inclination to indulgence, agrees also with what is called duty. He sees then that a system of nature could indeed subsist with such a universal law although men (like the South Sea islanders) should let their talents rest, and resolve to devote their lives merely to idleness, amusement, and propagation of their species—in a word, to enjoyment; but he cannot possibly *will* that this should be a universal law of nature, or be implanted in us as such by a natural instinct. For, as a rational being, he necessarily wills that his faculties be developed, since they serve him, and have been given him, for all sorts of possible purposes.

4. A fourth, who is in prosperity, while he sees that others have to contend with great wretchedness and that he could help them, thinks: What concern is it of mine? Let everyone be as happy as Heaven pleases, or as he can make himself; I will take nothing from him nor even envy him, only I do not wish to contribute anything to his welfare or to his assistance in distress! Now no doubt if such a mode of thinking were a universal law, the human race might very well subsist, and doubtless even better than in a state in which everyone talks of sympathy and good-will, or even takes care occasionally to put it into practice, but, on the other side, also cheats when he can, betrays the right of men, or otherwise violates them. But although it is possible that a universal law of nature might exist in accordance with that maxim, it is impossible to *will* that such a principle should have the universal validity of a law of nature. For a will which resolved this would contradict itself, inasmuch as many cases might occur in which one would have need of the love and sympathy of others, and in which, by such a law of nature, sprung from his own will, he would deprive himself of all hope of the aid he desires.

These are a few of the many actual duties, or at least what we regard as such, which obviously fall into two classes on the one principle that we have laid down. We must be *able to will* that a maxim of our action should be a universal law. This is the canon of

the moral appreciation of the action generally. Some actions are of such a character that their maxim cannot without contradiction be even *conceived* as a universal law of nature, far from it being possible that we should *will* that it *should* be so. In others this intrinsic impossibility is not found, but still it is impossible to *will* that their maxim should be raised to the universality of a law of nature, since such a will would contradict itself. It is easily seen that the former violate strict or rigorous (inflexible) duty; the latter only laxer (meritorious) duty. Thus it has been completely shown by these examples how all duties depend as regards the nature of the obligation (not the object of the action) on the same principle.

### **Second Formulation of the Categorical Imperative: Humanity as an End in Itself**

... Now I say: man and generally any rational being exists as an end in himself, *not merely as a means* to be arbitrarily used by this or that will, but in all his actions, whether they concern himself or other rational beings, must be always regarded at the same time as an end. All objects of the inclinations have only a conditional worth; for if the inclinations and the wants founded on them did not exist, then their object would be without value. But the inclinations themselves being sources of want are so far from having an absolute worth for which they should be desired, that on the contrary, it must be the universal wish of every rational being to be wholly free from them. Thus the worth of any object which is *to be acquired* by our action is always conditional. Beings whose existence depends not on our will but on nature's, have nevertheless, if they are nonrational beings, only a relative value as means, and are therefore called *things*; rational beings, on the contrary, are called *persons*, because their very nature points them out as ends in themselves, that is as something which must not be used merely as means, and so far therefore restricts freedom of action (and is an object of respect). These, therefore, are not merely subjective ends whose existence has a worth *for us* as an effect of our action, but *objective ends*, that is things whose existence is an end in itself: an end moreover for which no other can be substituted, which they should subserve *merely* as means, for otherwise nothing whatever would possess *absolute worth*; but if all worth were conditioned

and therefore contingent, then there would be no supreme practical principle of reason whatever.

If then there is a supreme practical principle or, in respect of the human will, categorical imperative, it must be one which, being drawn from the conception of that which is necessarily an end for everyone because it is *an end in itself*, constitutes an *objective* principle of will, and can therefore serve as a universal practical law. The foundation of this principle is: *rational nature exists as an end in itself*. Man necessarily conceives his own existence as being so; so far then this is a *subjective* principle of human actions. But every other rational being regards its existence similarly, just on the same rational principle that holds for me: so that it is at the same time an objective principle, from which as a supreme practical law all laws of the will must be capable of being deduced. Accordingly the practical imperative will be as follows. *So act as to treat humanity, whether in thine own person or in that of any other, in every case as an end withal, never as means only...*

... Looking back now on all previous attempts to discover the principle of morality, we need not

wonder why they all failed. It was seen that man was bound to laws by duty, but it was not observed that the laws to which he is subject are *only those of his own giving*, though at the same time they are *universal*, and that he is only bound to act in conformity with his own will; a will, however, which is designed by nature to give universal laws. For when one has conceived man only as subject to a law (no matter what), then this law required some interest, either by way of attraction or constraint, since it did not originate as a law from *his own will*, but his will was according to a law obliged by *something else* to act in a certain manner. Now by this necessary consequence all the labour spent in finding a supreme principle of duty was irrevocably lost. For men never elicited *duty*, but only a necessity of acting from a certain interest. Whether this interest was private or otherwise, in any case the imperative must be conditional, and could not by any means be capable of being a moral command. I will therefore call this the principle of *Autonomy* of the will, in contrast with every other which I accordingly reckon as *Heteronomy*.

## Nicomachean Ethics

ARISTOTLE

Aristotle (384–322 BC) was born in Stagira in Macedon, the son of a physician. He was a student of Plato at the Academy in Athens and tutor of Alexander the Great. Aristotle saw ethics as the branch of political philosophy concerned with a good life. It is thus a practical rather than a purely theoretical science. In this selection from *Nicomachean Ethics*, Aristotle considers the nature of ethics in relation to human nature. From this same perspective he discusses the nature of virtue, which he defines as traits that enable us to live well in communities. To achieve a state of well-being or happiness, proper social institutions are necessary. Thus, the moral person cannot exist in isolation from a flourishing political community that enables the person to develop the necessary virtues for the good life.

Aristotle goes on to show the difference between moral and intellectual virtues. While the intellectual virtues may be taught directly, the moral ones must be lived in order to be learned. By living well, we acquire the best guarantee to the happy life. But again, happiness requires that one be lucky enough to live in a flourishing state.

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1. Every art and every inquiry, and similarly every action and choice, is thought to aim at some good; and for this reason the good has rightly been declared to be that at which all things aim. But a certain difference is found among ends; some are activities, others are products apart from the activities that produce them. Where there are ends apart from the actions, it is the nature of the products to be better than the activities. Now, as there are many actions, arts, and sciences, their ends also are many; the end of the medical art is health, that of ship-building a vessel, that of strategy victory, that of economics wealth. But where such arts fall under a single capacity—as bridle-making and the other arts concerned with the equipment of horses fall under the art of riding, and this and every military action under strategy, in the same way other arts fall under yet others—in all of these the ends of the master arts are to be preferred to all the subordinate ends; for it is for the sake of the former that the latter are pursued. It makes no difference whether the activities themselves are the ends of the actions, or something else apart from the activities, as in the case of the sciences just mentioned.

2. If, then, there is some end of the things we do, which we desire for its own sake (everything else being desired for the sake of this), and if we do not choose everything for the sake of something else (for at that rate the process would go on to infinity, so that our desire would be empty and vain), clearly this must be the good and the chief good. Will not the knowledge of it, then, have a great influence on life? Shall we not, like archers who have a mark to aim at, be more likely to hit upon what we should? If so, we must try, in outline at least, to determine what it is, and of which of the sciences or capacities it is the object. It would seem to belong to the most authoritative art and that which is most truly the master art. And politics appears to be of this nature; for it is this that ordains which of the sciences should be studied in a state, and which each class of citizens should learn and up to what point they should learn them; and we see even the most highly esteemed of capacities to fall under this, e.g. strategy, economics, rhetoric; now, since politics uses the rest of the sciences, and since, again, it legislates

as to what we are to do and what we are to abstain from, the end of this science must include those of the others, so that this end must be the good for man. For even if the end is the same for a single man and for a state, that of the state seems at all events something greater and more complete both to attain and to preserve; for though it is worth while to attain the end merely for one man, it is finer and more godlike to attain it for a nation or for city-states. These, then, are the ends at which our inquiry, being concerned with politics, aims.

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3. Our discussion will be adequate if it has as much clearness as the subject-matter admits of; for precision is not to be sought for alike in all discussions, any more than in all the products of the crafts. Now fine and just actions, which political science investigates, exhibit much variety and fluctuation, so that they may be thought to exist only by convention, and not by nature. And goods also exhibit a similar fluctuation because they bring harm to many people; for before now men have been undone by reason of their wealth, and others by reason of their courage. We must be content, then, in speaking of such subjects and with such premisses to indicate the truth roughly and in outline, and in speaking about things which are only for the most part true and with premisses of the same kind to reach conclusions that are no better. In the same spirit, therefore, should each of our statements be *received*; for it is the mark of an educated man to look for precision in each class of things just so far as the nature of the subject admits: it is evidently equally foolish to accept probable reasoning from a mathematician and to demand from a rhetorician demonstrative proofs.

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Now each man judges well the things he knows, and of these he is a good judge. And so the man who has been educated in a subject is a good judge of that subject, and the man who has received an all-round education is a good judge in general. Hence a young man is not a proper hearer of lectures on political science; for he is inexperienced in the actions that occur in life, but its discussions start from these and are about these; and, further, since he tends to follow his passions, his study will be vain and unprofitable, because the end aimed at is not knowledge but action. And it makes no difference

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whether he is young in years or youthful in character; the defect does not depend on time, but on his living and pursuing each successive object as passion directs. For to such persons, as to the incontinent, knowledge brings no profit; but to those who desire and act in accordance with a rational principle knowledge about such matters will be of great benefit.

These remarks about the student, the way in which our statements should be received, and the purpose of the inquiry, may be taken as our preface.

4. Let us resume our inquiry and state, in view of the fact that all knowledge and choice aims at some good, what it is that we say political science aims at and what is the highest of all goods achievable by action. Verbally there is very general agreement; for both the general run of men and people of superior refinement say that it is happiness, and identify living well and faring well with being happy; but with regard to what happiness is they differ, and the many do not give the same account as the wise. For the former think it is some plain and obvious thing, like pleasure, wealth, or honour; they differ, however, from one another—and often even the same man identifies it with different things, with health when he is ill, with wealth when he is poor; but, conscious of their ignorance, they admire those who proclaim some great thing that is above their comprehension. Now some thought that apart from these many goods there is another which is good in itself and causes the goodness of all these as well. To examine all the opinions that have been held would no doubt be somewhat fruitless: it is enough to examine those that are most prevalent or that seem to have some reason in their favour.

Let us not fail to notice, however, that there is a difference between arguments from and those to the first principles. For Plato, too, was right in raising this question and asking, as he used to do, “are we on the way from or to the first principles?” There is a difference, as there is in a race-course between the course from the judges to the turning-point and the way back. For, while we must begin with what is familiar, things are so in two ways—some to us, some without qualification. Presumably, then, *we* must begin with things familiar to *us*. Hence any

one who is to listen intelligently to lectures about what is noble and just and, generally, about the subjects of political science must have been brought up in good habits. For the facts are the starting-point, and if they are sufficiently plain to him, he will not need the reason as well; and the man who has been well brought up has or can easily get starting-points. And as for him who neither has nor can get them, let him hear the words of Hesiod:<sup>1</sup>

*Far best is he who knows all things himself; Good, he that hearkens when men counsel right; But he who neither knows, nor lays to heart Another's wisdom, is a useless wight.*

5. Let us, however, resume our discussion from the point at which we digressed. To judge from the lives that men lead, most men, and men of the most vulgar type, seem (not without some reason) to identify the good, or happiness, with pleasure; which is the reason why they love the life of enjoyment. For there are, we may say, three prominent types of life—that just mentioned, the political, and thirdly the contemplative life. Now the mass of mankind are evidently quite slavish in their tastes, preferring a life suitable to beasts, but they get some reason for their view from the fact that many of those in high places share the tastes of Sardanapalus. But people of superior refinement and of active disposition identify happiness with honour; for this is, roughly speaking, the end of the political life. But it seems too superficial to be what we are looking for, since it is thought to depend on those who bestow honour rather than on him who receives it, but the good we divine to be something of one's own and not easily taken from one. Further, men seem to pursue honour in order that they may be assured of their merit; at least it is by men of practical wisdom that they seek to be honoured, and among those who know them, and on the ground of their excellence; clearly, then, according to them, at any rate, excellence is better. And perhaps one might even suppose this to be, rather than honour, the end of the political life. But even this appears somewhat incomplete; for possession of excellence seems actually compatible with being asleep, or with lifelong inactivity, and, further, with the greatest sufferings and misfortunes; but a man who was

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living so no one would call happy, unless he were maintaining a thesis at all costs. But enough of this; for the subject has been sufficiently treated even in ordinary discussions. Third comes the contemplative life, which we shall consider later.

The life of money-making is one undertaken under compulsion, and wealth is evidently not the good we are seeking; for it is merely useful and for the sake of something else. And so one might rather take the aforementioned objects to be ends; for they are loved for themselves. But it is evident that not even these are ends—although many arguments have been thrown away in support of them. Let us then dismiss them.

6. We had perhaps better consider the universal good and discuss thoroughly what is meant by it, although such an inquiry is made an uphill one by the fact that the Forms have been introduced by friends of our own. Yet it would perhaps be thought to be better, indeed to be our duty, for the sake of maintaining the truth even to destroy what touches us closely, especially as we are philosophers; for, while both are dear, piety requires us to honour truth above our friends.

The men who introduced this doctrine did not posit Ideas of classes within which they recognized priority and posteriority (which is the reason why they did not maintain the existence of an Idea embracing all numbers); but things are called good both in the category of substance and in that of quality and in that of relation, and that which is *per se*, i.e. substance, is prior in nature to the relative (for the latter is like an offshoot and accident of what is); so that there could not be a common Idea set over all these goods. Further, since things are said to be good in as many ways as they are said to be (for things are called good both in the category of substance, as God and reason, and in quality, e.g. the virtues, and in quantity, e.g. that which is moderate, and in relation, e.g. the useful, and in time, e.g. the right opportunity, and in place, e.g. the right locality and the like), clearly the good cannot be something universally present in all cases and single; for then it would not have been predicated in all the categories but in one only. Further, since of the things answering to one Idea there is one science, there would have been one science of all the

goods; but as it is there are many sciences even of the things that fall under one category, e.g. of opportunity (for opportunity in war is studied by strategy and in disease by medicine), and the moderate in food is studied by medicine and in exercise by the science of gymnastics. And one might ask the question, what in the world they *mean* by “a thing itself,” if in man himself and in a particular man the account of man is one and the same. For in so far as they are men, they will in no respect differ; and if this is so, neither will there be a difference in so far as they are good. But again it will not be good any the more for being eternal, since that which lasts long is no whiter than that which perishes in a day. The Pythagoreans seem to give a more plausible account of the good, when they place the one in the column of goods; and it is they that Speusippus seems to have followed.

But let us discuss these matters elsewhere; an objection to what we have said, however, may be discerned in the fact that the Platonists have not been speaking about *all* goods, and that the goods that are pursued and loved for themselves are called good by reference to a single Form, while those which tend to produce or to preserve these somehow or to prevent their contraries are called so by reference to these, and in a different sense. Clearly, then, goods must be spoken of in two ways, and some must be good in themselves, the others by reason of these. Let us separate, then, things good in themselves from things useful, and consider whether the former are called good by reference to a single Idea. What sort of goods would one call good in themselves? Is it those that are pursued even when isolated from others, such as intelligence, sight, and certain pleasures and honours? Certainly, if we pursue these also for the sake of something else, yet one would place them among things good in themselves. Or is nothing other than the Idea good in itself? In that case the Form will be empty. But if the things we have named are also things good in themselves, the account of the good will have to appear as something identical in them all, as that of whiteness is identical in snow and in white lead. But of honour, wisdom, and pleasure, just in respect of their goodness, the accounts are distinct and diverse. The good, therefore, is not something common answering to one Idea.

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But then in what way are things called good? They do not seem to be like the things that only chance to have the same name. Are goods one, then, by being derived from one good or by all contributing to one good, or are they rather one by analogy? Certainly as sight is in the body, so is reason in the soul, and so on in other cases. But perhaps these subjects had better be dismissed for the present; for perfect precision about them would be more appropriate to another branch of philosophy. And similarly with regard to the Idea; even if there is some one good which is universally predictable of goods or is capable of separate and independent existence, clearly it could not be achieved or attained by man; but we are now seeking something attainable. Perhaps, however, some one might think it worth while to have knowledge of it with a view to the goods that *are* attainable and achievable; for having this as a sort of pattern we shall know better the goods that are good for us, and if we know them shall attain them. This argument has some plausibility, but seems to clash with the procedure of the sciences; for all of these, though they aim at some good and seek to supply the deficiency of it, leave on one side the knowledge of *the* good. Yet that all the exponents of the arts should be ignorant of, and should not even seek, so great an aid is not probable. It is hard, too, to see how a weaver or a carpenter will be benefited in regard to his own craft by knowing this "good itself," or how the man who has viewed the Idea itself will be a better doctor or general thereby. For a doctor seems not even to study health in this way, but the health of man, or perhaps rather the health of a particular man; for it is individuals that he is healing. But enough of these topics....

## Book II

1. Excellence, then, being of two kinds, intellectual and moral, intellectual excellence in the main owes both its birth and its growth to teaching (for which reason it requires experience and time), while moral excellence comes about as a result of habit, whence also its name is one that is formed by a slight variation from the word for "habit."<sup>2</sup> From this it is also plain that none of the moral excellences arises in us by nature; for nothing that exists by nature can

form a habit contrary to its nature. For instance the stone which by nature moves downwards cannot be habituated to move upwards, not even if one tries to train it by throwing it up ten thousand times; nor can fire be habituated to move downwards, nor can anything else that by nature behaves in one way be trained to behave in another. Neither by nature, then, nor contrary to nature do excellences arise in us; rather we are adapted by nature to receive them, and are made perfect by habit.

Again, of all the things that come to us by nature we first acquire the potentiality and later exhibit the activity (this is plain in the case of the senses; for it was not by often seeing or often hearing that we got these senses, but on the contrary we had them before we used them, and did not come to have them by using them); but excellences we get by first exercising them, as also happens in the case of the arts as well. For the things we have to learn before we can do, we learn by doing, e.g. men become builders by building and lyre-players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts.

This is confirmed by what happens in states; for legislators make the citizens good by forming habits in them, and this is the wish of every legislator; and those who do not effect it miss their mark, and it is in this that a good constitution differs from a bad one.

Again, it is from the same causes and by the same means that every excellence is both produced and destroyed, and similarly every art; for it is from playing the lyre that both good and bad lyre-players are produced. And the corresponding statement is true of builders and of all the rest; men will be good or bad builders as a result of building well or badly. For if this were not so, there would have been no need of a teacher, but all men would have been born good or bad at their craft. This, then, is the case with the excellences also; by doing the acts that we do in our transactions with other men we become just or unjust, and by doing the acts that we do in the presence of danger, and being habituated to feel fear or confidence, we become brave or cowardly. The same is true of appetites and feelings of anger; some men become temperate and good-tempered,

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others self-indulgent and irascible, by behaving in one way or the other in the appropriate circumstances. Thus, in one word, states arise out of like activities. This is why the activities we exhibit must be of a certain kind; it is because the states correspond to the differences between these. It makes no small difference, then, whether we form habits of one kind or of another from our very youth; it makes a very great difference, or rather *all* the difference.

2. Since, then, the present inquiry does not aim at theoretical knowledge like the others (for we are inquiring not in order to know what excellence is, but in order to become good, since otherwise our inquiry would have been of no use), we must examine the nature of actions, namely how we ought to do them; for these determine also the nature of the states that are produced, as we have said. Now, that we must<sup>3</sup> act according to right reason is a common principle and must be assumed—it will be discussed later, i.e. both what it is, and how it is related to the other excellences. But this must be agreed upon beforehand, that the whole account of matters of conduct must be given in outline and not precisely, as we said at the very beginning that the accounts we demand must be in accordance with the subject-matter; matters concerned with conduct and questions of what is good for us have no fixity, any more than matters of health. The general account being of this nature, the account of particular cases is yet more lacking in exactness; for they do not fall under any art or set of precepts, but the agents themselves must in each case consider what is appropriate to the occasion, as happens also in the art of medicine or of navigation.

But though our present account is of this nature we must give what help we can. First, then, let us consider this, that it is the nature of such things to be destroyed by defect and excess, as we see in the case of strength and of health (for to gain light on things imperceptible we must use the evidence of sensible things); both excessive and defective exercise destroys the strength, and similarly drink or food which is above or below a certain amount destroys the health, while that which is proportionate both produces and increases and preserves it. So

too is it, then, in the case of temperance and courage and the other excellences. For the man who flies from and fears everything and does not stand his ground against anything becomes a coward, and the man who fears nothing at all but goes to meet every danger becomes rash; and similarly the man who indulges in every pleasure and abstains from none becomes self-indulgent, while the man who shuns every pleasure, as boors do, becomes in a way insensible; temperance and courage, then, are destroyed by excess and defect, and preserved by the mean.

But not only are the sources and causes of their origination and growth the same as those of their destruction, but also the sphere of their activity will be the same; for this is also true of the things which are more evident to sense, e.g. of strength; it is produced by taking much food and undergoing much exertion, and it is the strong man that will be most able to do these things. So too is it with the excellences; by abstaining from pleasures we become temperate, and it is when we have become so that we are most able to abstain from them; and similarly too in the case of courage; for by being habituated to despise things that are terrible and to stand our ground against them we become brave, and it is when we have become so that we shall be most able to stand our ground against them.

3. We must take as a sign of states the pleasure or pain that supervenes on acts; for the man who abstains from bodily pleasures and delights in this very fact is temperate, while the man who is annoyed at it is self-indulgent, and he who stands his ground against things that are terrible and delights in this or at least is not pained is brave, while the man who is pained is a coward. For moral excellence is concerned with pleasures and pains; it is on account of pleasure that we do bad things, and on account of pain that we abstain from noble ones. Hence we ought to have been brought up in a particular way from our very youth, as Plato says, so as both to delight in and to be pained by the things that we ought; for this is the right education.

Again, if the excellences are concerned with actions and passions, and every passion and every action is accompanied by pleasure and pain, for this reason also excellence will be concerned with

pleasures and pains. This is indicated also by the fact that punishment is inflicted by these means; for it is a kind of cure, and it is the nature of cures to be effected by contraries.

Again, as we said but lately, every state of soul has a nature relative to and concerned with the kind of things by which it tends to be made worse or better; but it is by reason of pleasures and pains that men become bad, by pursuing and avoiding these—either the pleasures and pains they ought not or when they ought not or as they ought not, or by going wrong in one of the other similar ways that reason can distinguish. Hence men even define the excellences as certain states of impassivity and rest; not well, however, because they speak absolutely, and do not say “as one ought” and “as one ought not” and “when one ought or ought not,” and the other things that may be added. We assume, then, that this kind of excellence tends to do what is best with regard to pleasures and pains, and badness does the contrary.

The following facts also may show us that they are concerned with these same things. There being three objects of choice and three of avoidance, the noble, the advantageous, the pleasant, and their contraries, the base, the injurious, the painful, about all of these the good man tends to go right and the bad man to go wrong, and especially about pleasure; for this is common to the animals, and also it accompanies all objects of choice; for even the noble and the advantageous appear pleasant.

Again, it has grown up with us all from our infancy; this is why it is difficult to rub off this passion, engrained as it is in our life. And we measure even our actions, some of us more and others less, by pleasure and pain. For this reason, then, our whole inquiry must be about these; for to feel delight and pain rightly or wrongly has no small effect on our actions.

Again, it is harder to fight with pleasure than with anger, to use Heraclitus's phrase, but both art and excellence are always concerned with what is harder; for even the good is better when it is harder. Therefore for this reason also the whole concern both of excellence and of political science is with pleasures and pains; for the man who uses these well will be good, he who uses them badly bad.

That excellence, then, is concerned with pleasures and pains, and that by the acts from which it arises it is both increased and, if they are done differently, destroyed, and that the acts from which it arose are those in which it actualizes itself—let this be taken as said.

4. The question might be asked, what we mean by saying that we must become just by doing just acts, and temperate by doing temperate acts; for if men do just and temperate acts, they are already just and temperate, exactly as, if they do what is grammatical or musical they are proficient in grammar and music.

Or is this not true even of the arts? It is possible to do something grammatical either by chance or under the guidance of another. A man will be proficient in grammar, then, only when he has both done something grammatical and done it grammatically; and this means doing it in accordance with the grammatical knowledge in himself.

Again, the case of the arts and that of the excellences are not similar; for the products of the arts have their goodness in themselves, so that it is enough that they should have a certain character, but if the acts that are in accordance with the excellences have themselves a certain character it does not follow that they are done justly or temperately. The agent also must be in a certain condition when he does them; in the first place he must have knowledge, secondly he must choose the acts, and choose them for their own sakes, and thirdly his action must proceed from a firm and unchangeable character. These are not reckoned in as conditions of the possession of the arts, except the bare knowledge; but as a condition of the possession of the excellences, knowledge has little or no weight, while the other conditions count not for a little but for everything, i.e. the very conditions which result from often doing just and temperate acts.

Actions, then, are called just and temperate when they are such as the just or the temperate man would do; but it is not the man who does these that is just and temperate, but the man who also does them as just and temperate men do them. It is well said, then, that it is by doing just acts that the just man is produced, and by doing temperate acts the temperate man; without doing these no one would have even a prospect of becoming good.

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But most people do not do these, but take refuge in theory and think they are being philosophers and will become good in this way, behaving somewhat like patients who listen attentively to their doctors, but do none of the things they are ordered to do. As the latter will not be made well in body by such a course of treatment, the former will not be made well in soul by such a course of philosophy.

Next we must consider what excellence is. Since things that are found in the soul are of three kinds—passions, faculties, states—excellence must be one of these. By passions I mean appetite, anger, fear, confidence, envy, joy, love, hatred, longing, emulation, pity, and in general the feelings that are accompanied by pleasure or pain; by faculties the things in virtue of which we are said to be capable of feeling these, e.g. of becoming angry or being pained or feeling pity; by states the things in virtue of which we stand well or badly with reference to the passions, e.g. with reference to anger we stand badly if we feel it violently or too weakly, and well if we feel it moderately; and similarly with reference to the other passions.

Now neither the excellences nor the vices are *passions*, because we are not called good or bad on the ground of our passions, but are so called on the ground of our excellences and our vices, and because we are neither praised nor blamed for our passions (for the man who feels fear or anger is not praised, nor is the man who simply feels anger blamed, but the man who feels it in a certain way), but for our excellences and our vices we are praised or blamed.

Again, we feel anger and fear without choice, but the excellences are choices or involve choice. Further, in respect of the passions we are said to be moved, but in respect of the excellences and the vices we are said not to be moved but to be disposed in a particular way.

For these reasons also they are not *faculties*; for we are neither called good nor bad, nor praised nor blamed, for the simple capacity of feeling the passions; again, we have the faculties by nature, but we are not made good or bad by nature; we have spoken of this before.

If, then, the excellences are neither passions nor faculties, all that remains is that they should be *states*.

Thus we have stated what excellence is in respect of its genus.

We must, however, not only describe it as a state, but also say what sort of state it is. We may remark, then, that every excellence both brings into good condition the thing of which it is the excellence and makes the work of that thing be done well; e.g. the excellence of the eye makes both the eye and its work good; for it is by the excellence of the eye that we see well. Similarly the excellence of the horse makes a horse both good in itself and good at running and at carrying its rider and at awaiting the attack of the enemy. Therefore, if this is true in every case, the excellence of man also will be the state which makes a man good and which makes him do his own work well.

How this is to happen we have stated already, but it will be made plain also by the following consideration of the nature of excellence. In everything that is continuous and divisible it is possible to take more, less, or an equal amount, and that either in terms of the thing itself or relatively to us; and the equal is an intermediate between excess and defect. By the intermediate in the object I mean that which is equidistant from each of the extremes, which is one and the same for all men; by the intermediate relatively to us that which is neither too much nor too little—and this is not one, nor the same for all. For instance, if ten is many and two is few, six is intermediate, taken in terms of the object; for it exceeds and is exceeded by an equal amount; this is intermediate according to arithmetical proportion.

But the intermediate relatively to us is not to be taken so; if ten pounds are too much for a particular person to eat and two too little, it does not follow that the trainer will order six pounds; for this also is perhaps too much for the person who is to take it, or too little—too little for Milo, too much for the beginner in athletic exercises. The same is true of running and wrestling. Thus a master of any art avoids excess and defect, but seeks the intermediate and chooses this—the intermediate not in the object but relatively to us.

If it is thus, then, that every art does its work well—by looking to the intermediate and judging its works by this standard (so that we often say of good works of the art that it is not possible either to

take away or to add anything, implying that excess and defect destroy the goodness of works of art, while the mean preserves it; and good artists, as we say, look to this in their work), and if, further, excellence is more exact and better than any art, as nature also is, then it must have the quality of aiming at the intermediate. I mean moral excellence; for it is this that is concerned with passions and actions, and in these there is excess, defect, and the intermediate. For instance, both fear and confidence and appetite and anger and pity and in general pleasure and pain may be felt both too much and too little, and in both cases not well; but to feel them at the right times, with reference to the right objects, towards the right people, with the right aim, and in the right way, is what is both intermediate and best, and this is characteristic of excellence. Similarly with regard to actions also there is excess, defect, and the intermediate. Now excellence is concerned with passions and actions, in which excess is a form of failure, and so is defect, while the intermediate is praised and is a form of success; and both these things are characteristics of excellence. Therefore excellence is a kind of mean, since it aims at what is intermediate.

Again, it is possible to fail in many ways (for evil belongs to the class of the unlimited, as the Pythagoreans conjectured, and good to that of the limited), while to succeed is possible only in one way (for which reason one is easy and the other difficult—to miss the mark easy, to hit it difficult); for these reasons also, then, excess and defect are characteristic of vice, and the mean of excellence;

For men are good in but one way, but bad in many.

Excellence, then, is a state concerned with choice, lying in a mean relative to us, this being determined by reason and in the way in<sup>4</sup> which the man of practical wisdom would determine it. Now it is a mean between two vices, that which depends on excess and that which depends on defect; and again it is a mean because the vices respectively fall short of or exceed what is right in both passions and actions, while excellence both finds and chooses that which is intermediate. Hence in respect of its substance and the account which states its essence is a mean, with regard to what is best and right it is an extreme.

But not every action nor every passion admits of a mean; for some have names that already imply badness, e.g. spite, shamelessness, envy, and in the case of actions adultery, theft, murder; for all of these and suchlike things imply by their names that they are themselves bad, and not the excesses or deficiencies of them. It is not possible, then, ever to be right with regard to them; one must always be wrong. Nor does goodness or badness with regard to such things depend on committing adultery with the right woman, at the right time, and in the right way, but simply to do any of them is to go wrong. It would be equally absurd, then, to expect that in unjust, cowardly, and self-indulgent action there should be a mean, an excess, and a deficiency; for at that rate there would be a mean of excess and of deficiency, an excess of excess, and a deficiency of deficiency. But as there is no excess and deficiency of temperance and courage because what is intermediate is in a sense an extreme, so too of the actions we have mentioned there is no mean nor any excess and deficiency, but however they are done they are wrong; for in general there is neither a mean of excess and deficiency, nor excess and deficiency of a mean.

7. We must, however, not only make this general statement, but also apply it to the individual facts. For among statements about conduct those which are general apply more widely, but those which are particular are more true, since conduct has to do with individual cases, and our statements must harmonize with the facts in these cases. We may take these cases from the diagram. With regard to feelings of fear and confidence courage is the mean; of the people who exceed, he who exceeds in fearlessness has no name (many of the states have no name), while the man who exceeds in confidence is rash, and he who exceeds in fear and falls short in confidence is a coward. With regard to pleasures and pains—not all of them, and not so much with regard to the pains—the mean is temperance, the excess self-indulgence. Persons deficient with regard to the pleasures are not often found; hence such persons also have received no name. But let us call them “insensible.”

With regard to giving and taking of money the mean is liberality, the excess and the defect

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prodigality and meanness. They exceed and fall short in contrary ways to one another:<sup>5</sup> The prodigal exceeds in spending and falls short in taking, while the mean man exceeds in taking and falls short in spending. (At present we are giving a mere outline or summary, and are satisfied with this; later these states will be more exactly determined.) With regard to money there are also other dispositions—a mean, magnificence (for the magnificent man differs from the liberal man; the former deals with large sums, the latter with small ones), an excess, tastelessness and vulgarity, and a deficiency, niggardliness; these differ from the states opposed to liberality, and the mode of their difference will be stated later.

With regard to honour and dishonour the mean is proper pride, the excess is known as a sort of empty vanity, and the deficiency is undue humility; and as we said liberality was related to magnificence, differing from it by dealing with small sums, so there is a state similarly related to proper pride, being concerned with small honours while that is concerned with great. For it is possible to desire small honours<sup>6</sup> as one ought, and more than one ought, and less, and the man who exceeds in his desires is called ambitious, the man who falls short unambitious, while the intermediate person has no name. The dispositions also are nameless, except that that of the ambitious man is called ambition. Hence the people who are at the extremes lay claim to the middle place; and we ourselves sometimes call the intermediate person ambitious and sometimes unambitious, and sometimes praise the ambitious man and sometimes the unambitious. The reason of our doing this will be stated in what follows; but now let us speak of the remaining states according to the method which has been indicated.

With regard to anger also there is an excess, a deficiency, and a mean. Although they can scarcely be said to have names, yet since we call the intermediate person good-tempered let us call the mean good temper; of the persons at the extremes let the one who exceeds be called irascible, and his vice irascibility, and the man who falls short an inirascible sort of person, and the deficiency inirascibility.

There are also three other means, which have a certain likeness to one another, but differ from one

another: for they are all concerned with intercourse in words and actions, but differ in that one is concerned with truth in this sphere, the other two with pleasantness; and of this one kind is exhibited in giving amusement, the other in all the circumstances of life. We must therefore speak of these too, that we may the better see that in all things the mean is praiseworthy, and the extremes neither praiseworthy nor right, but worthy of blame. Now most of these states also have no names, but we must try, as in the other cases, to invent names ourselves so that we may be clear and easy to follow. With regard to truth, then, the intermediate is a truthful sort of person and the mean may be called truthfulness, while the pretence which exaggerates is boastfulness and the person characterized by it a boaster, and that which understates is mock modesty and the person characterized by it mock-modest. With regard to pleasantness in the giving of amusement the intermediate person is ready-witted and the disposition ready wit, the excess is buffoonery and the person characterized by it a buffoon, while the man who falls short is a sort of boor and his state is boorishness. With regard to the remaining kind of pleasantness, that which is exhibited in life in general, the man who is pleasant in the right way is friendly and the mean is friendliness, while the man who exceeds is an obsequious person if he has no end in view, a flatterer if he is aiming at his own advantage, and the man who falls short and is unpleasant in all circumstances is a quarrelsome and surly sort of person.

There are also means in the passions and concerned with the passions; since shame is not an excellence, and yet praise is extended to the modest man. For even in these matters one man is said to be intermediate, and another to exceed, as for instance the bashful man who is ashamed of everything; while he who falls short or is not ashamed of anything at all is shameless, and the intermediate person is modest. Righteous indignation is a mean between envy and spite, and these states are concerned with the pain and pleasure that are felt at the fortunes of our neighbours; the man who is characterized by righteous indignation is pained at undeserved good fortune, the envious man, going beyond him, is pained at all good fortune, and the

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s spiteful man falls so far short of being pained that he even rejoices. But these states there will be an opportunity of describing elsewhere; with regard to justice, since it has not one simple meaning, we shall, after describing the other states, distinguish  
 10 its two kinds and say how each of them is a mean; and similarly we shall treat also of the rational excellences.

8. There are three kinds of disposition, then, two of them vices, involving excess and deficiency and one an excellence, viz. the mean, and all are in  
 15 a sense opposed to all; for the extreme states are contrary both to the intermediate state and to each other, and the intermediate to the extremes; as the equal is greater relatively to the less, less relatively to the greater, so the middle states are excessive relatively to the deficiencies, deficient relatively to  
 20 the excesses, both in passions and in actions. For the brave man appears rash relatively to the coward, and cowardly relatively to the rash man; and similarly the temperate man appears self-indulgent relatively to the insensible man, insensible relatively to the self-indulgent, and the liberal man prodigal relatively to the mean man, mean relatively to the prodigal. Hence also the people at the extremes push the intermediate man each over to the other, and the brave man is called rash by the coward,  
 25 cowardly by the rash man, and correspondingly in the other cases.

These states being thus opposed to one another, the greatest contrariety is that of the extremes to each other, rather than to the intermediate; for these are further from each other than from the intermediate, as the great is further from the small and the small from the great than both are from the equal. Again, to the intermediate some extremes show a certain likeness, as that of rashness to courage and that of prodigality to liberality; but the extremes show the greatest unlikeness to each other; now contraries are defined as the things that are furthest from each other, so that things that are further apart are more contrary.  
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To the mean in some cases the deficiency, in some the excess is more opposed; e.g. it is not rashness, which is an excess, BUT cowardice, which is a deficiency, that is more opposed to courage, and not insensibility, which is a deficiency, but self-indulgence,  
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which is an excess, that is more opposed to temperance. This happens from two reasons, one being drawn from the thing itself; for because one extreme is nearer and liker to the intermediate, we oppose not this but rather its contrary to the intermediate. E.g., since rashness is thought liker and nearer to courage, and cowardice more unlike, we oppose rather the latter to courage; for things that are further from the intermediate are thought more contrary to it. This, then, is one cause, drawn from the thing itself; another is drawn from ourselves; for the things to which we ourselves more naturally tend seem more contrary to the intermediate. For instance, we ourselves tend more naturally to pleasures, and hence are more easily carried away towards self-indulgence than towards propriety. We describe as contrary to the mean, then, the states into which we are more inclined to lapse; and therefore self-indulgence, which is an excess, is the more contrary to temperance.

9. That moral excellence is a mean, then, and in what sense it is so, and that it is a mean between two vices, the one involving excess, the other deficiency, and that it is such because its character is to aim at what is intermediate in passions and in actions, has been sufficiently stated. Hence also it is no easy task to be good. For in everything it is no easy task to find the middle, e.g. to find the middle of a circle is not for every one but for him who knows; so, too, any one can get angry—that is easy—or give or spend money; but to do this to the right person, to the right extent, at the right time, with the right aim, and in the right way, *that* is not for every one, nor is it easy; that is why goodness is both rare and laudable and noble.

Hence he who aims at the intermediate must first depart from what is the more contrary to it, as Calypso advises—

*Hold the ship out beyond that surf and spray.<sup>7</sup>*

For of the extremes one is more erroneous, one less so; therefore, since to hit the mean is hard in the extreme, we must as a second best, as people say, take the least of the evils; and this be done best in the way we describe.

But we must consider the things towards which we ourselves also are easily carried away; for some  
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of us tend to one thing, some to another; and this will be recognizable from the pleasure and the pain we feel. We must drag ourselves away to the contrary extreme; for we shall get into the intermediate state by drawing well away from error, as people do in straightening sticks that are bent.

Now in everything the pleasant or pleasure is most to be guarded against; for we do not judge it impartially. We ought, then, to feel towards pleasure as the elders of the people felt towards Helen, and in all circumstances repeat their saying; for if we dismiss pleasure thus we are less likely to go astray. It is by doing this, then, (to sum the matter up) that we shall best be able to hit the mean.

But this is no doubt difficult, and especially in individual cases; for it is not easy to determine both how and with whom and on what provocation and how long one should be angry; for we too sometimes praise those who fall short and call them good-tempered, but sometimes we praise those who get angry and call them manly. The man, however who deviates little from goodness is not

blamed, whether he do so in the direction of the more or of the less, but only the man who deviates more widely; for he does not fail to be noticed. But up to what point and to what extent a man must deviate before he becomes blameworthy it is not easy to determine by reasoning, any more than anything else that is perceived by the senses; such things depend on particular facts, and the decision rests with perception. So much, then, makes it plain that the intermediate state is in all things to be praised, but that we must incline sometimes towards the excess, sometimes towards the deficiency; for so shall we most easily hit the mean and what is right. . . .  
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#### NOTES

1. *Works and Days* 293–7.
2. ηθική from έθις.
3. Reading πράττειν δεῖν.
4. Reading ὡς ἀν.
5. Reading ἐναντίως δὲ αὐτοῖς.
6. Reading μικρὰς τιμῆς.
7. *Odyssey* XII 219.

## The Need for More Than Justice

ANNETTE C. BAIER

Baier makes a case for moral theories that can accommodate both an ethic of justice (thought by some to be the traditional male view) and an ethic of care (the alleged female view). “I think,” she says, “that the best moral theory has to be a cooperative product of women and men, has to harmonize justice and care.”

In recent decades in North American social and moral philosophy, alongside the development and discussion of widely influential theories of justice, taken as Rawls takes it as the “first virtue of social institutions,” there has been a counter-movement

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gathering strength, one coming from some interesting sources. For some of the most outspoken of the diverse group who have in a variety of ways been challenging the assumed supremacy of justice among the moral and social virtues are members of those sections of society whom one might have expected to be especially aware of the supreme importance of justice, namely blacks and women. Those who have only recently won recognition of their equal rights, who have only recently seen the correction or partial correction of longstanding racist

and sexist injustices to their race and sex, are among the philosophers now suggesting that justice is only one virtue among many, and one that may need the presence of the others in order to deliver its own undenied value. Among these philosophers of the philosophical counterculture, as it were—but an increasingly large counterculture—I include Alasdair MacIntyre,<sup>2</sup> Michael Stocker,<sup>3</sup> Lawrence Blum,<sup>4</sup> Michael Slote,<sup>5</sup> Laurence Thomas,<sup>6</sup> Claudia Card,<sup>7</sup> Alison Jaggar,<sup>8</sup> Susan Wolf<sup>9</sup> and a whole group of men and women, myself included, who have been influenced by the writings of Harvard educational psychologist Carol Gilligan, whose book *In a Different Voice* (Harvard 1982; hereafter D.V.) caused a considerable stir both in the popular press and, more slowly, in the philosophical journals.<sup>10</sup>

Let me say quite clearly at this early point that there is little disagreement that justice is a social value of very great importance, and injustice an evil. Nor would those who have worked on theories of justice want to deny that other things matter besides justice. Rawls, for example, incorporates the value of freedom into his account of justice, so that denial of basic freedoms counts as injustice. Rawls also leaves room for a wider theory of the right, of which the theory of justice is just a part. Still, he does claim that justice is the “first” virtue of social institutions, and it is only that claim about priority that I think has been challenged. It is easy to exaggerate the differences of view that exist, and I want to avoid that. The differences are as much in emphasis as in substance, or we can say that they are differences in tone of voice. But these differences do tend to make a difference in approaches to a wide range of topics not just in moral theory but in areas like medical ethics, where the discussion used to be conducted in terms of patients’ rights, of informed consent, and so on, but now tends to get conducted in an enlarged moral vocabulary, which draws on what Gilligan calls the ethics of *care* as well as that of *justice*.

For “care” is the new buzz-word. It is not, as Shakespeare’s Portia demanded, mercy that is to season justice, but a less authoritarian humanitarian supplement, a felt concern for the good of others and for community with them. The “cold jealous virtue of justice” (Hume) is found to be too cold,

and it is “warmer” more communitarian virtues and social ideals that are being called in to supplement it. One might say that liberty and equality are being found inadequate without fraternity, except that “fraternity” will be quite the wrong word, if as Gilligan initially suggested, it is *women* who perceive this value most easily. (“Sorority” will do no better, since it is too exclusive, and English has no gender-neuter word for the mutual concern of siblings.) She has since modified this claim, allowing that there are two perspectives on moral and social issues that we all tend to alternate between, and which are not always easy to combine, one of them what she called the justice perspective, the other the care perspective. It is increasingly obvious that there are many male philosophical spokespersons for the care perspective (Laurence Thomas, Lawrence Blum, Michael Stocker) so that it cannot be the prerogative of women. Nevertheless Gilligan still wants to claim that women are most unlikely to take *only* the justice perspective, as some men are claimed to, at least until some mid-life crisis jolts them into “bifocal” moral vision (see D.V., ch. 6).

Gilligan in her book did not offer any explanatory theory of why there should be any difference between female and male moral outlook, but she did tend to link the naturalness to women of the care perspective with their role as primary caretakers of young children, that is with their parental and specifically maternal role. She avoided the question of whether it is their biological or their social role that is relevant, and some of those who dislike her book are worried precisely by this uncertainty. Some find it retrograde to hail as a special sort of moral wisdom an outlook that may be the product of the socially enforced restriction of women to domestic roles (and the reservation of such roles for them alone). For that might seem to play into the hands of those who still favor such restriction. (Marxists, presumably, will not find it so surprising that moral truths might depend for their initial clear voicing on the social oppression, and memory of it, of those who voice the truths.) Gilligan did in the first chapter of D.V. cite the theory of Nancy Chodorow (as presented in *The Reproduction of Mothering* [Berkeley 1978]) which traces what appears as gender differences in personality to early

social development, in particular to the effects of the child's primary caretaker being or not being of the same gender as the child. Later, both in "The Conquistador and the Dark Continent: Reflections on the Nature of Love" (*Daedalus* [Summer 1984]), and "The Origins of Morality in Early Childhood" (in press), she develops this explanation. She postulates two evils that any infant may become aware of, the evil of detachment or isolation from others whose love one needs, and the evil of relative powerlessness and weakness. Two dimensions of moral development are thereby set—one aimed at achieving satisfying community with others, the other aiming at autonomy or equality of power. The relative predominance of one over the other development will depend both upon the relative salience of the two evils in early childhood, and on early and later reinforcement or discouragement in attempts made to guard against these two evils. This provides the germs of a theory about *why*, given current customs of childrearing, it should be mainly women who are not content with only the moral outlook that she calls the justice perspective, necessary though that was and is seen by them to have been to their hard won liberation from sexist oppression. They, like the blacks, used the language of rights and justice to change their own social position, but nevertheless see limitations in that language, according to Gilligan's findings as a moral psychologist. She reports their discontent with the individualist more or less Kantian moral framework that dominates Western moral theory and which influenced moral psychologists such as Lawrence Kohlberg, to whose conception of moral maturity she seeks an alternative. Since the target of Gilligan's criticism is the dominant Kantian tradition, and since that has been the target also of moral philosophers as diverse in their own views as Bernard Williams, Alasdair MacIntyre, Philippa Foot, Susan Wolf, [and] Claudia Card, her book is of interest as much for its attempt to articulate an alternative to the Kantian justice perspective as for its implicit raising of the question of male bias in Western moral theory, especially liberal-democratic theory. For whether the supposed blind spots of that outlook are due to male bias, or to non-parental bias, or to early traumas of powerlessness or to early

resignation to "detachment" from others, we need first to be persuaded that they *are* blind spots before we will have any interest in their cause and cure. Is justice blind to important social values, or at least only one-eyed? What is it that comes into view from the "care perspective" that is not seen from the "justice perspective"?

Gilligan's position here is mostly easily described by contrasting it with that of Kohlberg, against which she developed it. Kohlberg, influenced by Piaget and the Kantian philosophical tradition as developed by John Rawls, developed a theory about typical moral development which saw it to progress from a pre-conventional level, where what is seen to matter is pleasing or not offending parental authority-figures, through a conventional level in which the child tries to fit in with a group, such as a school community, and conform to its standards and rules, to a post-conventional critical level, in which such conventional rules are subjected to tests, and where those tests are of a Utilitarian, or, eventually, a Kantian sort—namely ones that require respect for each person's individual rational will, or autonomy, and conformity to any implicit social contract such wills are deemed to have made, or to any hypothetical ones they would make if thinking clearly. What was found when Kohlberg's questionnaires (mostly by verbal response to verbally sketched moral dilemmas) were applied to female as well as male subjects, Gilligan reports, is that the girls and women not only scored generally lower than the boys and men, but tended to *revert* to the lower stage of the conventional level even after briefly (usually in adolescence) attaining the post conventional level; Piaget's finding that girls were deficient in "the legal sense" was confirmed.

These results led Gilligan to wonder if there might not be a quite different pattern of development to be discerned, at least in female subjects. She therefore conducted interviews designed to elicit not just how far advanced the subjects were towards an appreciation of the nature and importance of Kantian autonomy, but also to find out what the subjects themselves saw as progress or lack of it, what conceptions of moral maturity they came to possess by the time they were adults. She found that although the Kohlberg version of moral maturity as

respect for fellow persons, and for their rights as equals (rights including that of free association), did seem shared by many young men, the women tended to speak in a different voice about morality itself and about moral maturity. To quote Gilligan, "Since the reality of interconnexions is experienced by women as given rather than freely contracted, they arrive at an understanding of life that reflects the limits of autonomy and control. As a result, women's development delineates the path not only to a less violent life but also to a maturity realized by interdependence and taking care" (D.V., 172). She writes that there is evidence that "women perceive and construe social reality differently from men, and that these differences center around experiences of attachment and separation . . . because women's sense of integrity appears to be intertwined with an ethics of care, so that to see themselves as women is to see themselves in a relationship of connexion, the major changes in women's lives would seem to involve changes in the understanding and activities of care" (D.V., 171). She contrasts this progressive understanding of care, from merely pleasing others to helping and nurturing, with the sort of progression that is involved in Kohlberg's stages, a progression in the understanding, not of mutual care, but of mutual *respect*, where this has its Kantian overtones of distance, even of some fear for the respected, and where personal autonomy and independence, rather than more satisfactory interdependence, are the paramount values.

This contrast, one cannot but feel, is one which Gilligan might have used the Marxist language of alienation to make. For the main complaint about the Kantian version of a society with its first virtue justice, construed as respect for equal rights to formal goods such as having contracts kept, due process, equal opportunity including opportunity to participate in political activities leading to policy and law-making, to basic liberties of speech, free association and assembly, religious worship, is that none of these goods do much to ensure that the people who have and mutually respect such rights will have any other relationships to one another than the minimal relationship needed to keep such a "civil society" going. They may well be lonely, driven to suicide, apathetic about their work and

about participation in political processes, find their lives meaningless and have no wish to leave offspring to face the same meaningless existence. Their rights, and respect for rights, are quite compatible with very great misery, and misery whose causes are not just individual misfortunes and psychic sickness, but social and moral impoverishment.

What Gilligan's older male subjects complain of is precisely this sort of alienation from some dimly glimpsed better possibility for human beings, some richer sort of network of relationships. As one of Gilligan's male subjects put it, "People have real emotional needs to be attached to something, and equality does not give you attachment. Equality fractures society and places on every person the burden of standing on his own two feet" (D.V., 167). It is not just the difficulty of self reliance which is complained of, but its socially "fracturing" effect. Whereas the younger men, in their college years, had seen morality as a matter of reciprocal non-interference, this older man begins to see it as reciprocal attachment. "Morality is . . . essential . . . for creating the kind of environment, interaction between people, that is a prerequisite to the fulfillment of individual goals. If you want other people not to interfere with your pursuit of whatever you are into, you have to play the game," says the spokesman for traditional liberalism (D.V., 98). But if what one is "into" is interconnexion, interdependence rather than an individual autonomy that may involve "detachment," such a version of morality will come to seem inadequate. And Gilligan stresses that the interconnexion that her mature women subjects, and some men, wanted to sustain was not merely freely chosen interconnexion; nor interconnexion between equals, but also the sort of interconnexion that can obtain between a child and her unchosen mother and father, or between a child and her unchosen older and younger siblings, or indeed between most workers and their unchosen fellow workers, or most citizens and their unchosen fellow citizens.

A model of a decent community different from the liberal one is involved in the version of moral maturity that Gilligan voices. It has in many ways more in common with the older religion-linked versions of morality and a good society than with

the modern Western liberal ideal. That perhaps is why some find it so dangerous and retrograde. Yet it seems clear that it also has much in common with what we can call Hegelian versions of moral maturity and of social health and malaise, both with Marxist versions and with so-called right-Hegelian views.

Let me try to summarize the main differences, as I see them, between on the one hand Gilligan's version of moral maturity and the sort of social structures that would encourage, express and protect it, and on the other the orthodoxy she sees herself to be challenging. I shall from now on be giving my own interpretation of the significance of her challenges, not merely reporting them.<sup>11</sup> The most obvious point is the challenge to the individualism of the Western tradition, to the fairly entrenched belief in the possibility and desirability of each person pursuing his own good in his own way, constrained only by a minimal formal common good, namely a working legal apparatus that enforces contracts and protects individuals from undue interference by others. Gilligan reminds us that non-interference can, especially for the relatively powerless, such as the very young, amount to neglect, and even between equals can be isolating and alienating. On her less individualist version of individuality, it becomes defined by responses to dependency and to patterns of interconnection, both chosen and unchosen. It is not something a person *has*, and which she then chooses relationships to suit, but something that develops out of a series of dependencies and inter-dependencies, and responses to them. This conception of individuality is not flatly at odds with, say, Rawls's Kantian one, but there is at least a difference of tone of voice between speaking as Rawls does of each of us having our own rational life plan, which a just society's moral traffic rules will allow us to follow, and which may or may not include close association with other persons, and speaking as Gilligan does of a satisfactory life as involving "progress of affiliative relationship" (D.V., 170) where "the concept of identity expands to include the experience of interconnection" (D.V., 173). Rawls can allow that progress to Gilligan-style moral maturity may be a rational life plan, but not a moral constraint on every life-pattern. The trouble

is that it will not do just to say "let this version of morality be an optional extra. Let us agree on the essential minimum, that is on justice and rights, and let whoever wants to go further, and cultivate this more demanding ideal of responsibility and care." For, first, it cannot be satisfactorily cultivated without closer cooperation from others than respect for rights and justice will ensure, and, second, the encouragement of some to cultivate it while others do not could easily lead to exploitation of those who do. It obviously *has* suited some in most societies well enough that others take on the responsibilities of care (for the sick, the helpless, the young) leaving them free to pursue their own less altruistic goods. Volunteer forces of those who accept an ethic of care, operating within a society where the power is exercised and the institutions designed, redesigned, or maintained by those who accept a less communal ethic of minimally constrained self-advancement, will not be the solution. The liberal individualists may be able to "tolerate" the more communally minded, if they keep the liberals' rules, but it is not so clear that the more communally minded can be content with just those rules, nor be content to be tolerated and possibly exploited.

For the moral tradition which developed the concept of rights, autonomy and justice is the same tradition that provided "justifications" of the oppression of those whom the primary right-holders depended on to do the sort of work they themselves preferred not to do. The domestic work was left to women and slaves, and the liberal morality for right-holders was surreptitiously supplemented by a different set of demands made on domestic workers. As long as women could be got to assume responsibility for the care of home and children, and to train their children to continue the sexist system, the liberal morality could continue to be the official morality, by turning its eyes away from the contribution made by those it excluded. The long unnoticed moral proletariat were the domestic workers, mostly female. Rights have usually been for the privileged. Talking about laws, and the rights those laws recognize and protect, does not in itself ensure that the group of legislators and rights-holders will not be restricted to some elite. Bills of rights have

usually been proclamations of the rights of some in-group, barons, landowners, males, whites, non-foreigners. The “justice perspective,” and the legal sense that goes with it, are shadowed by their patriarchal past. What did Kant, the great prophet of autonomy, say in his moral theory about women? He said they were incapable of legislation, not fit to vote, that they needed the guidance of more “rational” males.<sup>12</sup> Autonomy was not for them, only for first class, really rational, persons. It is ironic that Gilligan’s original findings in a way confirm Kant’s views—it seems that autonomy really may not be for women. Many of them reject that ideal (D.V., 48), and have been found not as good at making rules as are men. But where Kant concludes—“so much the worse for women,” we can conclude—“so much the worse for the male fixation on the special skill of drafting legislation, for the bureaucratic mentality of rule worship, and for the male exaggeration of the importance of independence over mutual interdependence.”

It is however also true that the moral theories that made the concept of a person’s rights central were not just the instruments for excluding some persons, but also the instruments used by those who demanded that more and more persons be included in the favored group. Abolitionists, reformers, women, used the language of rights to assert their claims to inclusion in the group of full members of a community. The tradition of liberal moral theory has in fact developed so as to include the women it had for so long excluded, to include the poor as well as rich, blacks and whites, and so on. Women like Mary Wollstonecraft used the male moral theories to good purpose. So we should not be wholly ungrateful for those male moral theories, for all their objectionable earlier content. They were undoubtedly patriarchal, but they also contained the seeds of the challenge, or antidote, to this patriarchal poison.

But when we transcend the values of the Kantians, we should not forget the facts of history—that those values were the values of the oppressors of women. The Christian church, whose version of the moral law Aquinas codified, in his very legalistic moral theory, still insists on the maleness of the God it worships, and jealously reserves for males all

the most powerful positions in its hierarchy. Its patriarchal prejudice is open and avowed. In the secular moral theories of men, the sexist patriarchal prejudice is today often less open, not as blatant as it is in Aquinas, in the later natural law tradition, and in Kant and Hegel, but is often still there. No moral theorist today would say that women are unfit to vote, to make laws, or to rule a nation without powerful male advisors (as most queens had), but the old doctrines die hard. In one of the best male theories we have, John Rawls’s theory, a key role is played by the idea of the “head of a household.” It is heads of households who are to deliberate behind a “veil of ignorance” of historical details, and of details of their own special situation, to arrive at the “just” constitution for a society. Now of course Rawls does not think or say that “heads” are fathers rather than mothers. But if we have really given up the age-old myth of women needing, as Grotius put it, to be under the “eye” of a more “rational” male protector and master, then how do families come to have any one “head,” except by the death or desertion of one parent? They will either be two-headed, or headless. Traces of the old patriarchal poison still remain in even the best contemporary moral theorizing. Few may actually say that women’s place is in the home, but there is much muttering, when unemployment figures rise, about how the relatively recent flood of women into the workforce complicates the problem, as if it would be a good thing if women just went back home whenever unemployment rises, to leave the available jobs for the men. We still do not really have a wide acceptance of the equal right of women to employment outside the home. Nor do we have wide acceptance of the equal duty of men to perform those domestic tasks which in no way depend on special female anatomy, namely cooking, cleaning, and the care of weaned children. All sorts of stories (maybe true stories), about children’s need for one “primary” parent, who must be the mother if the mother breast feeds the child, shore up the unequal division of domestic responsibility between mothers and fathers, wives and husbands. If we are really to transvalue the values of our patriarchal past, we need to rethink all of those assumptions, really test those psychological theories. And how will men ever develop an understanding of the

"ethics of care" if they continue to be shielded or kept from that experience of caring for a dependent child, which complements the experience we all have had of being cared for as dependent children? These experiences form the natural background for the development of moral maturity as Gilligan's women saw it.

Exploitation aside, why would women, once liberated, not be content to have their version of morality merely tolerated? Why should they not see themselves as voluntarily, for their own reasons, taking on *more* than the liberal rules demand, while having no quarrel with the content of those rules themselves, nor with their remaining the only ones that are expected to be generally obeyed? To see why, we need to move on to three more differences between the Kantian liberals (usually contractarians) and their critics. These concern the relative weight put on relationships between equals, and the relative weight put on freedom of choice, and on the authority of intellect over emotions. It is a typical feature of the dominant moral theories and traditions, since Kant, or perhaps since Hobbes, that relationships between equals or those who are deemed equal in some important sense, have been the relations that morality is concerned primarily to regulate. Relationships between those who are clearly unequal in power, such as parents and children, earlier and later generations in relation to one another, states and citizens, doctors and patients, the well and the ill, large states and small states, have had to be shunted to the bottom of the agenda, and then dealt with by some sort of "promotion" of the weaker so that an appearance of virtual equality is achieved. Citizens collectively become equal to states, children are treated as adults-to-be, the ill and dying are treated as continuers of their earlier more potent selves, so that their "rights" could be seen as the rights of equals. This pretence of an equality that is in fact absent may often lead to desirable protection of the weaker, or more dependent. But it somewhat masks the question of what our moral relationships *are* to those who are our superiors or our inferiors in power. A more realistic acceptance of the fact that we begin as helpless children, that at almost every point of our lives we deal with both the more and the less helpless, that equality of power and interdependency, between two persons or groups, is rare

and hard to recognize when it does occur, might lead us to a more direct approach to questions concerning the design of institutions structuring these relationships between unequals (families, schools, hospitals, armies) and of the morality of our dealings with the more and the less powerful. One reason why those who agree with the Gilligan version of what morality is about will not want to agree that the liberals' rules are a good minimal set, the only ones we need pressure *everyone* to obey, is that these rules do little to protect the young or the dying or the starving or any of the relatively powerless against neglect, or to ensure an education that will form persons to be *capable* of conforming to an ethics of care and responsibility. Put baldly, and in a way Gilligan certainly has not put it, the liberal morality, if un-supplemented, may *unfit* people to be anything other than what its justifying theories suppose them to be, ones who have no interest in each other's interests. Yet some must take an interest in the next generation's interests. Women's traditional work, of caring for the less powerful, especially for the young, is obviously socially vital. One cannot regard any version of morality that does not ensure that it gets well done as an adequate "minimal morality," any more than we could so regard one that left any concern for more distant future generations an optional extra. A moral theory, it can plausibly be claimed, cannot regard concern for new and future persons as an optional charity left for those with a taste for it. If the morality the theory endorses is to sustain itself, it must provide for its own continuers, not just take out a loan on a carefully encouraged maternal instinct or on the enthusiasm of a self-selected group of environmentalists, who make it their business or hobby to be concerned with what we are doing to mother earth.

The recognition of the importance for all parties of relations between those who are and cannot but be unequal, both of these relations in themselves and for their effect on personality formation and so on other relationships, goes along with a recognition of the plain fact that not all morally important relationships can or should be freely chosen. So far I have discussed three reasons women have not to be content to pursue their own values within the framework of the liberal morality. The first was its dubious record. The second was its inattention to

relations of inequality or its pretence of equality. The third reason is its exaggeration of the scope of choice, or its inattention to unchosen relations. Showing up the partial myth of equality among actual members of a community, and of the undesirability of trying to pretend that we are treating all of them as equals, tends to go along with an exposure of the companion myth that moral obligations arise from freely *chosen* associations between such equals. Vulnerable future generations do not choose their dependence on earlier generations. The unequal infant does not choose its place in a family or nation, nor is it treated as free to do as it likes until some association is freely entered into. Nor do its parents always choose their parental role, or freely assume their parental responsibilities any more than we choose our power to affect the conditions in which later generations will live. Gilligan's attention to the version of morality and moral maturity found in women, many of whom had faced a choice of whether or not to have an abortion, and who had at some point become mothers, is attention to the perceived inadequacy of the language of rights to help in such choices or to guide them in their parental role. It would not be much of an exaggeration to call the Gilligan "different voice" the voice of the potential parents. The emphasis on care goes with a recognition of the often unchosen nature of the responsibilities of those who give care, both of children who care for their aged or infirm parents, and of parents who care for the children they in fact have. Contract soon ceases to seem the paradigm source of moral obligation once we attend to parental responsibility, and justice as a virtue of social institutions will come to seem at best only first equal with the virtue, whatever its name, that ensures that each new generation is made appropriately welcome and prepared for their adult lives.

This all constitutes a belated reminder to Western moral theorists of a fact they have always known, that as Adam Ferguson, and David Hume before him emphasized, we are born into families, and the first society we belong to, one that fits or misfits us for later ones, is the small society of parents (or some sort of child-attendants) and children, exhibiting as it may both relationships of near equality and of inequality in power. This simple reminder, with the fairly considerable implications it

can have for the plausibility of contractarian moral theory, is at the same time a reminder of the role of human emotions as much as human reason and will in moral development as it actually comes about. The fourth feature of the Gilligan challenge to liberal orthodoxy is a challenge to its typical *rationalism*, or intellectualism, to its assumption that we need not worry what passions persons have, as long as their rational wills can control them. This Kantian picture of a controlling reason dictating to possibly unruly passions also tends to seem less useful when we are led to consider what sort of person we need to fill the role of parent, or indeed want in any close relationship. It might be important for father figures to have rational control over their violent urges to beat to death the children whose screams enrage them, but more than control of such nasty passions seems needed in the mother or primary parent, or parent-substitute, by most psychological theories. They need to love their children, not just to control their irritation. So the emphasis in Kantian theories on rational control of emotions, rather than on cultivating desirable forms of emotion, is challenged by Gilligan, along with the challenge to the assumption of the centrality of autonomy, or relations between equals, and of freely chosen relations.

The same set of challenges to "orthodox" liberal moral theory has come not just from Gilligan and other women, who are reminding other moral theorists of the role of the family as a social institution and as an influence on the other relationships people want to or are capable of sustaining, but also, as I noted at the start, from an otherwise fairly diverse group of men, ranging from those influenced by both Hegelian and Christian traditions (MacIntyre) to all varieties of other backgrounds. From this group I want to draw attention to the work of one philosopher in particular, namely Laurence Thomas, the author of a fairly remarkable article<sup>13</sup> in which he finds sexism to be a more intractable social evil than racism. In a series of articles and a book,<sup>14</sup> Thomas makes a strong case for the importance of supplementing a concern for justice and respect for rights with an emphasis on equally needed virtues, and on virtues seen as appropriate *emotional* as well as rational capacities. Like Gilligan (and unlike MacIntyre) Thomas gives a lot of attention to the

childhood beginnings of moral and social capacities, to the role of parental love in making that possible, and to the emotional as well as the cognitive development we have reason to think both possible and desirable in human persons.

It is clear, I think, that the best moral theory has to be a cooperative product of women and men, has to harmonize justice and care. The morality it theorizes about is after all for all persons, for men and for women, and will need their combined insights. As Gilligan said (D.V., 174), what we need now is a “marriage” of the old male and the newly articulated female insights. If she is right about the special moral aptitudes of women, it will most likely be the women who propose the marriage, since they are the ones with more natural empathy, with the better diplomatic skills, the ones more likely to shoulder responsibility and take moral initiative, and the ones who find it easiest to empathize and care about how the other party feels. Then, once there is this union of male and female moral wisdom, we maybe can teach each other the moral skills each gender currently lacks, so that the gender difference in moral outlook that Gilligan found will slowly become less marked.

#### NOTES

1. John Rawls, *A Theory of Justice* (Cambridge: Harvard University Press).
2. Alasdair MacIntyre, *After Virtue* (Notre Dame: Notre Dame University Press).
3. Michael Stocker, “The Schizophrenia of Modern Ethical Theories,” *Journal of Philosophy* 73, 14, 453–66, and “Agent

and Other: Against Ethical Universalism,” *Australasian Journal of Philosophy* 54, 206–20.

4. Lawrence Blum, *Friendship, Altruism and Morality* (London: Routledge & Kegan Paul 1980).

5. Michael Slote, *Goods and Virtues* (Oxford: Oxford University Press 1983).

6. Laurence Thomas, “Love and Morality,” in *Epistemology and Sociobiology*, James Fetzer, ed. (1985); and “Justice, Happiness and Self Knowledge,” *Canadian Journal of Philosophy* (March, 1986). Also “Beliefs and the Motivation to be Just,” *American Philosophical Quarterly* 22 (4), 347–52.

7. Claudia Card, “Mercy,” *Philosophical Review* 81, 1, and “Gender and Moral Luck,” in *Identity, Character, and Morality*, ed. Owen Flanagan and Amélie O. Rorty (Cambridge: MIT Press 1990).

8. Alison Jaggar, *Feminist Politics and Human Nature* (London: Rowman and Allenheld 1983).

9. Susan Wolf, “Moral Saints,” *Journal of Philosophy* 79 (August, 1982), 419–39.

10. For a helpful survey article see Owen Flanagan and Kathryn Jackson, “Justice, Care & Gender: The Kohlberg-Gilligan Debate Revisited,” *Ethics*.

11. I have previously written about the significance of her findings for moral philosophy in “What Do Women Want in a Moral Theory?” *Nous* 19 (March 1985), “Trust and Antitrust,” *Ethics* 96 (1986), and in “Hume the Women’s Moral Theorist” in *Women and Moral Theory*, E. Kittay and D. Meyers, eds. (Totowa, NJ: Rowman and Littlefield 1987).

12. Immanuel Kant, *Metaphysics of Morals*, sec. 46.

13. Laurence Thomas, “Sexism and Racism: Some Conceptual Differences,” *Ethics* 90 (1980), 239–50; republished in *Philosophy, Sex and Language*, Vetterling-Braggin, ed. (Totowa, NJ: Littlefield Adams 1980).

14. See articles listed in note 6, above. Laurence Thomas, *Living Morally: A Psychology of Moral Character* (Philadelphia: Temple University Press 1989).

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## MORAL SAINTS

### SUSAN WOLF

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Susan Wolf is a professor of philosophy at the University of North Carolina, Chapel Hill, working mostly in ethics and the related areas of philosophy of mind, philosophy of action, political philosophy, and aesthetics. In this selection, she examines the idea of moral saints, exploring the implications of moral sainthood for utilitarianism, Kantian ethics, and moral philosophy generally.

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From Susan Wolf, “Moral Saints,” *Journal of Philosophy* LXXIX, no. 8 (1982).

I don't know whether there are any moral saints. But if there are, I am glad that neither I nor those about whom I care most are among them. By *moral saint* I mean a person whose every action is as morally good as possible, a person, that is, who is as morally worthy as can be. Though I shall in a moment acknowledge the variety of types of person that might be thought to satisfy this description, it seems to me that none of these types serve as unequivocally compelling personal ideals. In other words, I believe that moral perfection, in the sense of moral saintliness, does not constitute a model of personal well-being toward which it would be particularly rational or good or desirable for a human being to strive.

Outside the context of moral discussion, this will strike many as an obvious point. But, within that context, the point, if it be granted, will be granted with some discomfort. For within that context it is generally assumed that one ought to be as morally good as possible and that what limits there are to morality's hold on us are set by features of human nature of which we ought not to be proud. If, as I believe, the ideals that are derivable from common sense and philosophically popular moral theories do not support these assumptions, then something has to change. Either we must change our moral theories in ways that will make them yield more palatable ideals, or, as I shall argue, we must change our conception of what is involved in affirming a moral theory.

In this paper, I wish to examine the notion of a moral saint, first, to understand what a moral saint would be like and why such a being would be unattractive, and, second, to raise some questions about the significance of this paradoxical figure for moral philosophy. I shall look first at the model(s) of moral sainthood that might be extrapolated from the morality or moralities of common sense. Then I shall consider what relations these have to conclusions that can be drawn from utilitarian and Kantian moral theories. Finally, I shall speculate on the implications of these considerations for moral philosophy.

### **Moral Saints and Common Sense**

Consider first what, pretheoretically, would count for us—contemporary members of Western

culture—as a moral saint. A necessary condition of moral sainthood would be that one's life be dominated by a commitment to improving the welfare of others or of society as a whole. As to what role this commitment must play in the individual's motivational system, two contrasting accounts suggest themselves to me which might equally be thought to qualify a person for moral sainthood.

First, a moral saint might be someone whose concern for others plays the role that is played in most of our lives by more selfish, or, at any rate, less morally worthy concerns. For the moral saint, the promotion of the welfare of others might play the role that is played for most of us by the enjoyment of material comforts, the opportunity to engage in the intellectual and physical activities of our choice, and the love, respect, and companionship of people whom we love, respect, and enjoy. The happiness of the moral saint, then, would truly lie in the happiness of others, and so he would devote himself to others gladly, and with a whole and open heart.

On the other hand, a moral saint might be someone for whom the basic ingredients of happiness are not unlike those of most of the rest of us. What makes him a moral saint is rather that he pays little or no attention to his own happiness in light of the overriding importance he gives to the wider concerns of morality. In other words, this person sacrifices his own interests to the interests of others, and feels the sacrifice as such.

Roughly, these two models may be distinguished according to whether one thinks of the moral saint as being a saint out of love or one thinks of the moral saint as being a saint out of duty (or some other intellectual appreciation and recognition of moral principles). We may refer to the first model as the model of the Loving Saint; to the second, as the model of the Rational Saint.

The two models differ considerably with respect to the qualities of the motives of the individuals who conform to them. But this difference would have limited effect on the saints' respective public personalities. The shared content of what these individuals are motivated to be—namely, as morally good as possible—would play the dominant role in the determination of their characters. Of course, just as a variety of large-scale projects, from

tending the sick to political campaigning, may be equally and maximally morally worthy, so a variety of characters are compatible with the ideal of moral sainthood. One moral saint may be more or less jovial, more or less garrulous, more or less athletic than another. But, above all, a moral saint must have and cultivate those qualities which are apt to allow him to treat others as justly and kindly as possible. He will have the standard moral virtues to a nonstandard degree. He will be patient, considerate, even-tempered, hospitable, charitable in thought as well as in deed. He will be very reluctant to make negative judgments of other people. He will be careful not to favor some people over others on the basis of properties they could not help but have.

Perhaps what I have already said is enough to make some people begin to regard the absence of moral saints in their lives as a blessing. For there comes a point in the listing of virtues that a moral saint is likely to have where one might naturally begin to wonder whether the moral saint isn't, after all, too good—if not too good for his own good, at least too good for his own well-being. For the moral virtues, given that they are, by hypothesis, *all* present in the same individual, and to an extreme degree, are apt to crowd out the nonmoral virtues, as well as many of the interests and personal characteristics that we generally think contribute to a healthy, well-rounded, richly developed character.

In other words, if the moral saint is devoting all his time to feeding the hungry or healing the sick or raising money for Oxfam, then necessarily he is not reading Victorian novels, playing the oboe, or improving his backhand. Although no one of the interests or tastes in the category containing these latter activities could be claimed to be a necessary element in a life well lived, a life in which *none* of these possible aspects of character are developed may seem to be a life strangely barren.

The reasons why a moral saint cannot, in general, encourage the discovery and development of significant nonmoral interests and skills are not logical but practical reasons. There are, in addition, a class of nonmoral characteristics that a moral saint cannot encourage in himself for reasons that are not just practical. There is a more substantial

tension between having any of these qualities unashamedly and being a moral saint. These qualities might be described as going against the moral grain. For example, a cynical or sarcastic wit, or a sense of humor that appreciates this kind of wit in others, requires that one take an attitude of resignation and pessimism toward the flaws and vices to be found in the world. A moral saint, on the other hand, has reason to take an attitude in opposition to this—he should try to look for the best in people, give them the benefit of the doubt as long as possible, try to improve regrettable situations as long as there is any hope of success. This suggests that, although a moral saint might well enjoy a good episode of *Father Knows Best*, he may not in good conscience be able to laugh at a Marx Brothers movie or enjoy a play by George Bernard Shaw.

An interest in something like gourmet cooking will be, for different reasons, difficult for a moral saint to rest easy with. For it seems to me that no plausible argument can justify the use of human resources involved in producing a *paté de canard en croute* against possible alternative beneficent ends to which these resources might be put. If there is a justification for the institution of haute cuisine, it is one which rests on the decision *not* to justify every activity against morally beneficial alternatives, and this is a decision a moral saint will never make. Presumably, an interest in high fashion or interior design will fare much the same, as will, very possibly, a cultivation of the finer arts as well.

A moral saint will have to be very, very nice. It is important that he not be offensive. The worry is that, as a result, he will have to be dull-witted or humorless or bland.

This worry is confirmed when we consider what sorts of characters, taken and refined both from life and from fiction, typically form our ideals. One would hope they would be figures who are morally good—and by this I mean more than just not morally bad—but one would hope, too, that they are not *just* morally good, but talented or accomplished or attractive in nonmoral ways as well. We may make ideals out of athletes, scholars, artists—more frivolously, out of cowboys, private eyes, and rock stars. We may strive for Katharine Hepburn's grace, Paul Newman's "cool"; we are attracted to the

high-spirited passionate nature of Natasha Rostov; we admire the keen perceptiveness of Lambert Strether. Though there is certainly nothing immoral about the ideal characters or traits I have in mind, they cannot be superimposed upon the ideal of a moral saint. For although it is a part of many of these ideals that the characters set high, and not merely acceptable, moral standards for themselves, it is also essential to their power and attractiveness that the moral strengths go, so to speak, alongside of specific, independently admirable, nonmoral ground projects and dominant personal traits.

When one does finally turn one's eyes toward lives that are dominated by explicitly moral commitments, moreover, one finds oneself relieved at the discovery of idiosyncrasies or eccentricities not quite in line with the picture of moral perfection. One prefers the blunt, tactless, and opinionated Betsy Trotwood to the unfailingly kind and patient Agnes Copperfield; one prefers the mischievousness and the sense of irony in Chesterton's Father Brown to the innocence and undiscriminating love of St. Francis.

It seems that, as we look in our ideals for people who achieve nonmoral varieties of personal excellence in conjunction with or colored by some version of high moral tone, we look in our paragons of moral excellence for people whose moral achievements occur in conjunction with or colored by some interests or traits that have low moral tone. In other words, there seems to be a limit to how much morality we can stand. . . .

Moreover, there is something odd about the idea of morality itself, or moral goodness, serving as the object of a dominant passion in the way that a more concrete and specific vision of a goal (even a concrete *moral* goal) might be imagined to serve. Morality itself does not seem to be a suitable object of passion. Thus, when one reflects, for example, on the Loving Saint easily and gladly giving up his fishing trip or his stereo or his hot fudge sundae at the drop of the moral hat, one is apt to wonder not at how much he loves morality, but at how little he loves these other things. One thinks that, if he can give these up so easily, he does not know what it is to truly love them. There seems, in other words, to be a kind of joy which the Loving Saint, either by

nature or by practice, is incapable of experiencing. The Rational Saint, on the other hand, might retain strong nonmoral and concrete desires—he simply denies himself the opportunity to act on them. But this is no less troubling. The Loving Saint one might suspect of missing a piece of perceptual machinery, of being blind to some of what the world has to offer. The Rational Saint, who sees it but foregoes it, one suspects of having a different problem—a pathological fear of damnation, perhaps, or an extreme form of self-hatred that interferes with his ability to enjoy the enjoyable in life.

In other words, the ideal of a life of moral sainthood disturbs not simply because it is an ideal of a life in which morality unduly dominates. The normal person's direct and specific desires for objects, activities, and events that conflict with the attainment of moral perfection are not simply sacrificed but removed, suppressed, or subsumed. The way in which morality, unlike other possible goals, is apt to dominate is particularly disturbing, for it seems to require either the lack or the denial of the existence of an identifiable, personal self. . . .

It must be remembered that from the fact that there is a tension between having any of these qualities and being a moral saint it does not follow that having any of these qualities is immoral. For it is not part of common-sense morality that one ought to be a moral saint. Still, if someone just happened to want to be a moral saint, he or she would not have or encourage these qualities, and, on the basis of our common-sense values, this counts as a reason *not* to want to be a moral saint. . . .

### Moral Saints and Moral Theories

I have tried so far to paint a picture—or, rather, two pictures—of what a moral saint might be like, drawing on what I take to be the attitudes and beliefs about morality prevalent in contemporary, common-sense thought. To my suggestion that common-sense morality generates conceptions of moral saints that are unattractive or otherwise unacceptable, it is open to someone to reply, “so much the worse for common-sense morality.” After all, it is often claimed that the goal of moral philosophy is to correct and improve upon common-sense morality, and I have as yet given no attention to the

question of what conceptions of moral sainthood, if any, are generated from the leading moral theories of our time.

A quick, breezy reading of utilitarian and Kantian writings will suggest the images, respectively, of the Loving Saint and the Rational Saint. A utilitarian, with his emphasis on happiness, will certainly prefer the Loving Saint to the Rational one, since the Loving Saint will himself be a happier person than the Rational Saint. A Kantian, with his emphasis on reason, on the other hand, will find at least as much to praise in the latter as in the former. Still, both models, drawn as they are from common sense, appeal to an impure mixture of utilitarian and Kantian intuitions. A more careful examination of these moral theories raises questions about whether either model of moral sainthood would really be advocated by a believer in the explicit doctrines associated with either of these views.

Certainly, the utilitarian in no way denies the value of self-realization. He in no way disparages the development of interests, talents, and other personally attractive traits that I have claimed the moral saint would be without. Indeed, since just these features enhance the happiness both of the individuals who possess them and of those with whom they associate, the ability to promote these features both in oneself and in others will have considerable positive weight in utilitarian calculations.

This implies that the utilitarian would not support moral sainthood as a universal ideal. A world in which everyone, or even a large number of people, achieved moral sainthood—even a world in which they *strove* to achieve it—would probably contain less happiness than a world in which people realized a diversity of ideals involving a variety of personal and perfectionist values. More pragmatic considerations also suggest that, if the utilitarian wants to influence more people to achieve more good, then he would do better to encourage them to pursue happiness-producing goals that are more attractive and more within a normal person's reach.

These considerations still leave open, however, the question of what kind of an ideal the committed utilitarian should privately aspire to himself. Utilitarianism requires him to want to achieve the

greatest general happiness, and this would seem to commit him to the ideal of the moral saint.

One might try to use the claims I made earlier as a basis for an argument that a utilitarian should choose to give up utilitarianism. If, as I have said, a moral saint would be a less happy person both to be and to be around than many other possible ideals, perhaps one could create more total happiness by not trying too hard to promote the total happiness. But this argument is simply unconvincing in light of the empirical circumstances of our world. The gain in happiness that would accrue to oneself and one's neighbors by a more well-rounded, richer life than that of the moral saint would be pathetically small in comparison to the amount by which one could increase the general happiness if one devoted oneself explicitly to the care of the sick, the down-trodden, the starving, and the homeless. Of course, there may be psychological limits to the extent to which a person can devote himself to such things without going crazy. But the utilitarian's individual limitations would not thereby become a positive feature of his personal ideals.

The unattractiveness of the moral saint, then, ought not rationally convince the utilitarian to abandon his utilitarianism. It may, however, convince him to take efforts not to wear his saintly moral aspirations on his sleeve. If it is not too difficult, the utilitarian will try not to make those around him uncomfortable. He will not want to appear “holier than thou”; he will not want to inhibit others' ability to enjoy themselves. In practice, this might make the perfect utilitarian a less nauseating companion than the moral saint I earlier portrayed. But insofar as this kind of reasoning produces a more bearable public personality, it is at the cost of giving him a personality that must be evaluated as hypocritical and condescending when his private thoughts and attitudes are taken into account.

Still, the criticisms I have raised against the saint of common-sense morality should make some difference to the utilitarian's conception of an ideal which neither requires him to abandon his utilitarian principles nor forces him to fake an interest he does not have or a judgment he does not make. For

it may be that a limited and carefully monitored allotment of time and energy to be devoted to the pursuit of some nonmoral interests or to the development of some nonmoral talents would make a person a better contributor to the general welfare than he would be if he allowed himself no indulgences of this sort. The enjoyment of such activities in no way compromises a commitment to utilitarian principles as long as the involvement with these activities is conditioned by a willingness to give them up whenever it is recognized that they cease to be in the general interest.

This will go some way in mitigating the picture of the loving saint that an understanding of utilitarianism will on first impression suggest. But I think it will not go very far. For the limitations on time and energy will have to be rather severe, and the need to monitor will restrict not only the extent but also the quality of one's attachment to these interests and traits. They are only weak and somewhat peculiar sorts of passions to which one can consciously remain so conditionally committed. Moreover, the way in which the utilitarian can enjoy these "extracurricular" aspects of his life is simply not the way in which these aspects are to be enjoyed insofar as they figure into our less saintly ideals.

The problem is not exactly that the utilitarian values these aspects of his life only as a means to an end, for the enjoyment he and others get from these aspects are not a means to, but a part of, the general happiness. Nonetheless, he values these things only because of and insofar as they *are* a part of the general happiness. He values them, as it were, under the description "a contribution to the general happiness." This is to be contrasted with the various ways in which these aspects of life may be valued by nonutilitarians. A person might love literature because of the insights into human nature literature affords. Another might love the cultivation of roses because roses are things of great beauty and delicacy. It may be true that these features of the respective activities also explain why these activities are happiness-producing. But, to the nonutilitarian, this may not be to the point. For if one values these activities in these more direct ways, one may not be willing to exchange them for others that produce an

equal, or even a greater amount of happiness. From that point of view, it is not because they produce happiness that these activities are valuable; it is because these activities are valuable in more direct and specific ways that they produce happiness. . . .

The Kantian believes that being morally worthy consists in always acting from maxims that one could will to be universal law, and doing this not out of any pathological desire but out of reverence for the moral law as such. Or, to take a different formulation of the categorical imperative, the Kantian believes that moral action consists in treating other persons always as ends and never as means only. Presumably, and according to Kant himself, the Kantian thereby commits himself to some degree of benevolence as well as to the rules of fair play. But we surely would not will that *every* person become a moral saint, and treating others as ends hardly requires bending over backwards to protect and promote their interests. On one interpretation of Kantian doctrine, then, moral perfection would be achieved simply by unerring obedience to a limited set of side-constraints. On this interpretation, Kantian theory simply does not yield an ideal conception of a person of any fullness comparable to that of the moral saints I have so far been portraying.

On the other hand, Kant does say explicitly that we have a duty of benevolence, a duty not only to allow others to pursue their ends, but to take up their ends as our own. In addition, we have positive duties to ourselves, duties to increase our natural as well as our moral perfection. These duties are unlimited in the degree to which they *may* dominate a life. If action in accordance with and motivated by the thought of these duties is considered virtuous, it is natural to assume that the more one performs such actions, the more virtuous one is. Moreover, of virtue in general Kant says, "it is an ideal which is unattainable while yet our duty is constantly to approximate to it."<sup>10</sup> On this interpretation, then, the Kantian moral saint, like the other moral saints I have been considering, is dominated by the motivation to be moral.

Which of these interpretations of Kant one prefers will depend on the interpretation and the importance one gives to the role of the imperfect

duties in Kant's over-all system. Rather than choose between them here, I shall consider each briefly in turn.

On the second interpretation of Kant, the Kantian moral saint is, not surprisingly, subject to many of the same objections I have been raising against other versions of moral sainthood. Though the Kantian saint may differ from the utilitarian saint as to *which* actions he is bound to perform and which he is bound to refrain from performing, I suspect that the range of activities acceptable to the Kantian saint will remain objectionably restrictive. Moreover, the manner in which the Kantian saint must think about and justify the activities he pursues and the character traits he develops will strike us, as it did with the utilitarian saint, as containing "one thought too many." As the utilitarian could value his activities and character traits only insofar as they fell under the description of "contributions to the general happiness," the Kantian would have to value his activities and character traits insofar as they were manifestations of respect for the moral law. If the development of our powers to achieve physical, intellectual, or artistic excellence, or the activities directed toward making others happy are to have any moral worth, they must arise from a reverence for the dignity that members of our species have as a result of being endowed with pure practical reason. This is a good and noble motivation, to be sure. But it is hardly what one expects to be dominantly behind a person's aspirations to dance as well as Fred Astaire, to paint as well as Picasso, or to solve some outstanding problem in abstract algebra, and it is hardly what one hopes to find lying dominantly behind a father's action on behalf of his son or a lover's on behalf of her beloved. . . .

### Moral Saints and Moral Philosophy

In pointing out the regrettable features and the necessary absence of some desirable features in a moral saint, I have not meant to condemn the moral saint or the person who aspires to become one. Rather, I have meant to insist that the ideal of moral sainthood should not be held as a standard against which any other ideal must be judged or justified, and that

the posture we take in response to the recognition that our lives are not as morally good as they might be need not be defensive.<sup>2</sup> It is misleading to insist that one is *permitted* to live a life in which the goals, relationships, activities, and interests that one pursues are not maximally morally good. For our lives are not so comprehensively subject to the requirement that we apply for permission, and our non-moral reasons for the goals we set ourselves are not excuses, but may rather be positive, good reasons which do not exist *despite* any reasons that might threaten to outweigh them. In other words, a person may be *perfectly wonderful* without being *perfectly moral*.

Recognizing this requires a perspective which contemporary moral philosophy has generally ignored. This perspective yields judgments of a type that is neither moral nor egoistic. Like moral judgments, judgments about what it would be good for a person to be are made from a point of view outside the limits set by the values, interests, and desires that the person might actually have. And, like moral judgments, these judgments claim for themselves a kind of objectivity or a grounding in a perspective which any rational and perceptive being can take up. Unlike moral judgments, however, the good with which these judgments are concerned is not the good of anyone or any group other than the individual himself.

Nonetheless, it would be equally misleading to say that these judgments are made for the sake of the individual himself. For these judgments are not concerned with what kind of life it is in a person's interest to lead, but with what kind of interests it would be good for a person to have, and it need not be in a person's interest that he acquire or maintain objectively good interests. Indeed, the model of the Loving Saint, whose interests are identified with the interests of morality, is a model of a person for whom the dictates of rational self-interest and the dictates of morality coincide. Yet, I have urged that we have reason not to aspire to this ideal and that some of us would have reason to be sorry if our children aspired to and achieved it.

The moral point of view, we might say, is the point of view one takes up insofar as one takes the

recognition of the fact that one is just one person among others equally real and deserving of the good things in life as a fact with practical consequences, a fact the recognition of which demands expression in one's actions and in the form of one's practical deliberations. Competing moral theories offer alternative answers to the question of what the most correct or the best way to express this fact is. In doing so, they offer alternative ways to evaluate and to compare the variety of actions, states of affairs, and so on that appear good and bad to agents from other, nonmoral points of view. But it seems that alternative interpretations of the moral point of view do not exhaust the ways in which our actions, characters, and their consequences can be comprehensively and objectively evaluated. Let us call the point of view from which we consider what kinds of lives are good lives, and what kinds of persons it would be good for ourselves and others to be, the *point of view of individual perfection*.

Since either point of view provides a way of comprehensively evaluating a person's life, each point of view takes account of, and, in a sense, subsumes the other. From the moral point of view, the perfection of an individual life will have some, but limited, value—for each individual remains, after all, just one person among others. From the perfectionist point of view, the moral worth of an individual's relation to his world will likewise have some, but limited, value—for, as I have argued, the (perfectionist) goodness of an individual's life does not vary proportionally with the degree to which it exemplifies moral goodness.

It may not be the case that the perfectionist point of view is like the moral point of view in being a point of view we are ever *obliged* to take up and express in our actions. Nonetheless, it provides us with reasons that are independent of moral reasons for wanting ourselves and others to develop our characters and live our lives in certain ways. When we take up this point of view and ask how much it would be good for an individual to act from the moral point of view, we do not find an obvious answer.<sup>3</sup>

The considerations of this paper suggest, at any rate, that the answer is not "as much as possible." This has implications both for the continued

development of moral theories and for the development of metamoral views and for our conception of moral philosophy more generally. From the moral point of view, we have reasons to want people to live lives that seem good from outside that point of view. If, as I have argued, this means that we have reason to want people to live lives that are not morally perfect, then any plausible moral theory must make use of some conception of supererogation.<sup>4</sup>

If moral philosophers are to address themselves at the most basic level to the question of how people should live, however, they must do more than adjust the content of their moral theories in ways that leave room for the affirmation of nonmoral values. They must examine explicitly the range and nature of these nonmoral values, and, in light of this examination, they must ask how the acceptance of a moral theory is to be understood and acted upon. For the claims of this paper do not so much conflict with the content of any particular currently popular moral theory as they call into question a metamoral assumption that implicitly surrounds discussions of moral theory more generally. Specifically, they call into question the assumption that it is always better to be morally better.

The role morality plays in the development of our characters and the shape of our practical deliberations need be neither that of a universal medium into which all other values must be translated nor that of an ever-present filter through which all other values must pass. This is not to say that moral value should not be an important, even the most important, kind of value we attend to in evaluating and improving ourselves and our world. It is to say that our values cannot be fully comprehended on the model of a hierarchical system with morality at the top.

The philosophical temperament will naturally incline, at this point, toward asking, "What, then, *is* at the top—or, if there is no top, how *are* we to decide when and how much to be moral?" In other words, there is a temptation to seek a metamoral—though not, in the standard sense, metaethical—theory that will give us principles, or, at least, informal directives on the basis of which we can develop and evaluate more comprehensive personal

ideals. Perhaps a theory that distinguishes among the various roles a person is expected to play within a life—as professional, as citizen, as friend, and so on—might give us some rules that would offer us, if nothing else, a better framework in which to think about and discuss these questions. I am pessimistic, however, about the chances of such a theory to yield substantial and satisfying results. For I do not see how a metamoral theory could be constructed which would not be subject to considerations parallel to those which seem inherently to limit the appropriateness of regarding moral theories as ultimate comprehensive guides for action.

This suggests that, at some point, both in our philosophizing and in our lives, we must be willing to raise normative questions from a perspective that is unattached to a commitment to any particular well-ordered system of values. It must be admitted that, in doing so, we run the risk of finding normative answers that diverge from the answers given by whatever moral theory one accepts. This, I take it, is the grain of truth in G. E. Moore's “open question” argument. In the background of this paper, then, there lurks a commitment to what seems to me to be a healthy form of intuitionism. It is a form of intuitionism which is not intended to take the place of more rigorous, systematically developed, moral theories—rather, it is intended to put these more rigorous and systematic moral theories in their place.

#### NOTES

1. Immanuel Kant, *The Doctrine of Virtue*, Mary J. Gregor, trans. (New York: Harper & Row, 1964), p. 71.

2. George Orwell makes a similar point in “Reflections on Gandhi,” in *A Collection of Essays by George Orwell* (New York: Harcourt Brace Jovanovich, 1945), p. 176: “sainthood is . . . a thing that human beings must avoid . . . It is too readily assumed that . . . the ordinary man only rejects it because it is too difficult; in other words, that the average human being is a failed saint. It is doubtful whether this is true. Many people genuinely do not wish to be saints, and it is probable that some who achieve or aspire to sainthood have never felt much temptation to be human beings.”

3. A similar view, which has strongly influenced mine, is expressed by Thomas Nagel in “The Fragmentation of Value,” in *Mortal Questions* (New York: Cambridge, 1979), pp. 128–141. Nagel focuses on the difficulties such apparently incommensurable points of view create for specific, isolable practical decisions that must be made both by individuals and by societies. In focusing on the way in which these points of view figure into the development of individual personal ideals, the questions with which I am concerned are more likely to lurk in the background of any individual’s life.

4. The variety of forms that a conception of supererogation might take, however, has not generally been noticed. Moral theories that make use of this notion typically do so by identifying some specific set of principles as universal moral requirements and supplement this list with a further set of directives which it is morally praiseworthy but not required for an agent to follow. [See, e.g., Charles Fried, *Right and Wrong* (Cambridge, Mass.: Harvard, 1979).] But it is possible that the ability to live a morally blameless life cannot be so easily or definitely secured as this type of theory would suggest. The fact that there are some situations in which an agent is morally required to do something and other situations in which it would be good but not required for an agent to do something does not imply that there are specific principles such that, in any situation, an agent is required to act in accordance with these principles and other specific principles such that, in any situation, it would be good but not required for an agent to act in accordance with those principles.



# Medical Professional and Patient

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# Paternalism and Patient Autonomy

On its face, the relationship between patient and health care provider seems technically simple and morally clear. The provider—physician, nurse, physician's assistant, or other professional—has a duty of beneficence toward the patient, an obligation to use her medical expertise to do him good and to avoid doing him harm. The patient has a right to this skilled beneficence and to respect for his autonomous choices regarding what the provider does. But below the surface, complications simmer. The principles of beneficence and autonomy are frequently at odds. The values of providers and patients can diverge. The cultures of patients, physicians, and nurses can clash. And often the stakes for everyone involved are extraordinarily high.

In this chapter we explore several moral issues arising from these conflicts, focusing on questions of medical paternalism, refusing treatment, and “futile” treatment. Chapter 4 delves into other aspects of patient–provider relationships, notably truth-telling, deception, and confidentiality. Chapter 5 examines the patient–provider relationship further by studying the many sides of informed consent and patient competence.

## SHADES OF AUTONOMY AND PATERNALISM

**Autonomy** is a person's rational capacity for self-governance or self-determination. It is an individual's power to deliberate about available options, to choose freely among those possibilities, and to act accordingly. We fully exercise our autonomy when our choices and actions are truly our own, free from the overriding pressure

of people and factors that rob us of control. The requirement to respect autonomy runs through all of bioethics, expressed in the *autonomy principle*, which we can state as *autonomous persons should be allowed to exercise their capacity for self-determination*. In bioethics it is considered a fundamental standard that can be violated only for good reasons and with explicit justification. In the name of the autonomy principle, medicine has developed the doctrine of informed consent and has devised countless procedures and guidelines to ensure that the principle is honored in the details.

Limitations on a person's autonomy can be physical or psychological, obvious or subtle, justified or unjustified, and generally accepted or widely controversial. Physically restraining a patient violates his autonomy, and so does misinforming him about the seriousness of his illness. Forcing a healthy woman to have a hysterectomy is obvious coercion. Using false information to persuade her to have the operation is a subtler kind of compulsion. We tend to think that physicians are sometimes justified in confining and treating a mentally ill man who is a danger to himself and others. We would not think so if the man were perfectly healthy. Giving a 12-year-old girl a blood transfusion to save her life seems like normal medical practice. Withholding the transfusion because her parents say it is an affront to their religious faith is controversial.

Conflicts between respect for patients' autonomy and providers' duty of beneficence usually raise the issue of **paternalism**, which we can define as the overriding of a person's actions or decision-making for his own good. Early medical

practice was strongly paternalistic, inspired by the Hippocratic tradition of devotion to the welfare of patients and fatherly insistence on deciding unilaterally what is best for them. The Hippocratic Oath and many later professional codes of medical practice had much to say about obligations to help and not to harm patients but little or nothing to declare about patients' rights to decide about their own medical care. But over the last few decades, this kind of heavy-handed paternalism has abated as society has placed more value on the rights of patients to know important facts about their medical care, to make choices regarding their medical treatment, and even to refuse treatment that physicians recommend.

We can distinguish between two kinds of paternalism. **Weak paternalism** refers to paternalism directed at persons who cannot act autonomously or whose autonomy is greatly diminished—who may be, for example, dangerously psychotic, intellectually disabled, extremely depressed, or acutely addicted. Weak paternalism is not usually considered an objectionable violation of autonomy because patients are already substantially nonautonomous to some degree. Generally it is thought to be morally acceptable because its purpose is to protect people from harm while they are nonautonomous, to determine if they are in fact nonautonomous, or to restore them to full autonomy. **Strong paternalism** is the overriding of a person's actions or choices, even though he is substantially autonomous. Cases involving strong paternalism often provoke debate and sometimes legal wrangling. A man who normally behaves autonomously and rationally is involuntarily committed to a mental institution because he occasionally becomes confused and disoriented and doctors fear that he might someday become a threat to himself or others. A physician discovers that his patient has a malignant breast tumor, but because he knows she is terrified of the disease, he tells her that the tumor is benign and should be surgically removed just in case. A woman who needs a

life-saving blood transfusion refuses it on religious grounds, but when she lapses into a coma, surgeons operate and give her the transfusion anyway. These and other scenarios play out more often than we might think and prompt not only ethical disagreement but also personal and professional anguish.

Many people are staunchly anti-paternalistic, condoning (as most do) acts of weak paternalism but rejecting all forms of strong paternalism. They argue that strong paternalism is wrong because it violates the rights of persons to determine for themselves what is good and what is right. Persons are sovereigns over their own lives, and overriding their sovereignty is impermissible regardless of the benefits gained by violating it. Others are more willing to countenance some acts of paternalism (including strong paternalism) on the grounds that the persons involved *would* consent to the acts if circumstances were ideal (if, say, the persons were thinking more rationally). These thinkers, for example, might be willing to commit a substantially autonomous person to a mental institution involuntarily if he would have trouble living independently and might be a danger to himself. Still others argue that the only satisfactory justification for paternalism is not consent but beneficence—intervening simply to promote someone's welfare. On this view, the benefits of paternalistic actions must be balanced against the importance of respecting autonomy. Actions that minimally restrict autonomy but benefit the person greatly would be justified; actions that seriously violate autonomy while offering only minor benefits would not be acceptable. Far less important would be concerns about what the individual would or would not consent to under different circumstances.<sup>1</sup>

## REFUSING TREATMENT

Patients want physicians to treat them; physicians want to treat patients. But often when patients (or their surrogates) refuse treatment,

patient autonomy and physician beneficence collide, sparking personal frustration and moral perplexity all around. In such cases the most vexing bioethical questions include: Is it ever morally permissible for a physician to treat a patient against her will? If so, what justifies the action, and under what conditions is it acceptable?

Until the late 1980s, the right of competent patients to turn down treatments ordered by physicians was unsettled. (Very roughly, competent patients are autonomous persons able to make decisions about treatment options.) In some situations, patients were thought to have no right to decline recommended treatments. Physicians sometimes forced pregnant patients to have cesarean deliveries if failure to do so put the fetuses at extreme risk. The courts frequently overruled the right to refuse treatment if the patient had dependent children or if the patient was not terminally ill. But later court rulings reversed the trend and carved out the bedrock principle that a competent patient has a right to reject recommended treatments, even life-saving ones. The legal principle now parallels the prevailing view in bioethics, which shifts the weight to patient autonomy over physician and nurse beneficence.

The courts have also stretched this right of competent patients to situations in which they become incompetent, as when they lapse into coma. Through advance directives or other evidence of their preferences, they can refuse life-sustaining treatment. This expression of prior intentions is now widely recognized as a legitimate exercise of autonomous choice.

The right to refuse treatment seems a relatively straightforward issue when the patient is a competent adult, but what if the patient is a child whose parents reject the recommended medical treatment on religious grounds? Consider the case of 11-year-old Ian Lundman of Minneapolis, Minnesota, who died on May 9, 1989, after slipping into a diabetic coma. His diabetes had remained medically untreated, his mother and

stepfather forgoing insulin in favor of prayers from Christian Science practitioners.<sup>2</sup> (Christian Scientists believe that disease is a spiritual disorder requiring spiritual healing, not medical treatment.) Or consider this scenario, typical of such cases: A 6-year-old girl is seriously injured in a traffic accident, and the only way to save her life is to give her a blood transfusion—which her Jehovah’s Witness parents reject because the procedure is explicitly forbidden by their faith. The physicians proceed with the transfusion and save the girl’s life, and the parents sue the physicians and the hospital.

Parents who for religious reasons reject medical treatment for their children insist on the right to decide what’s best for them and sincerely believe what’s best is avoiding medical interventions. They demand the freedom to practice their religion as they see fit. But others have argued (including the courts) that though parents may decide many matters on the well-being of their children, they do not have the right to bring serious harm to them, especially since children cannot decide such issues for themselves. This view was summed up in a famous 1944 Supreme Court decision: “Parents may be free to become martyrs themselves. But it does not follow they are free . . . to make martyrs of their children.”<sup>3</sup>

The situation takes on a different hue when children are considered competent to decide for themselves. States differ on whether an adolescent can be a “mature minor” to make health decisions, and the courts have waffled on the issue. Judges have ruled, for example, that a 15-year-old Jehovah’s Witness girl dying of leukemia could refuse a blood transfusion that would save her life—but that a 16-year-old boy injured in a train accident could not decline a transfusion needed during surgery to save his arm. Nevertheless, many argue that if adolescents are not competent to decide such things, competent adults (including physicians and nurses) should step in to protect their welfare, even if intervening means defying religious doctrine.

## IN DEPTH

### PHYSICIAN AUTONOMY

Patient autonomy is not the only kind of autonomy debated these days. There is also concern about *physician autonomy*, the freedom of doctors to determine the conditions they work in and the care they give to patients. Many factors can adversely affect physician autonomy. Here's a brief inventory of some that doctors believe are most problematic:

Both physicians and patients are inundated with arbitrary treatment regulations and financial punishments for “out-of-system treatments.” Physicians have added pressures from pharmaceutical industry inducements that encourage the use of expensive treatments of marginal efficacy. They are penalized for low productivity, which threatens their willingness to discuss complex patient problems, even those that are most likely to affect the patient’s health. Patterns of physician reimbursement encourage procedure-oriented interventions and minimize counseling, in spite of the greater benefit of brief counseling for patient health. . . .

As a result of all these complex, sometimes contradictory, often covert and self-interested

inducements from third parties, physicians often are confronted with resistance when they explain their treatment decisions to patients. The case of antibiotic treatment for viral infections is a prime example. Antibiotics have not been shown to improve medical outcomes for otherwise healthy patients with early symptoms of upper respiratory infections. In fact, patients incur the risk of side effects (allergic reactions, GI disturbance, and cost) without the potential for benefit. From the social justice point of view, prescribing antibiotics for URIs in otherwise healthy people wastes resources and could contribute to resistant bacteria in the population. Yet, patients frequently request, and sometimes demand, these antibiotics and interpret physicians’ withholding them as undermining their autonomy. . . .

In cases such as this, the value the patient places on having access to prescribed medication on demand appears to be in conflict with the physician’s obligation to put patient welfare first and to consider social justice in allocation of medical resources. . . .

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From Geoffrey C. Williams and Timothy E. Quill, “Physician Autonomy, Paternalism, and Professionalism: Finding Our Voice amid Conflicting Duties,” *AMA Journal of Ethics* 6, no. 2 (February 2004).

## FUTILE TREATMENT

The classic pattern of paternalism involves a physician who wants to treat a patient who prefers not to be treated. But sometimes things happen the other way around—when the patient or the patient’s family wants a treatment that the physician, typically from beneficent motives, does not want to provide. The main moral conflict is between patient autonomy and the physician’s view of what constitutes morally acceptable care.

The most dramatic (and heart-rending) of such cases center on whether to supply life-sustaining treatment to the patient. Consider the much discussed story of 85-year-old Helga

Wanglie, who in 1990 suddenly had to be placed on a ventilator because of serious breathing problems. Over the following weeks, her condition worsened as she sank into unconsciousness and then into a persistent vegetative state (a deep coma that is usually irreversible). She received round-the-clock life-sustaining treatment consisting of ventilator, antibiotics, tube feedings, and other measures. But physicians told Helga’s husband and two children that the treatment was not helping her and should be stopped. Her family, however, demanded that the treatment continue. They hoped for a miracle and asserted that Helga was not better off dead and that physicians should not play God.

**LEGAL BRIEF****Advance Directives**

What would happen if you were to become seriously ill, in an emergency or at the end of life, and were unable to make your own decisions about your medical care? Someone else (care providers, relatives, or lawyers perhaps) would have to make those decisions for you. Or, if you had specified your own preferences in an advance directive ahead of time, you would be the one deciding what should be done. An *advance directive* is a legal document that speaks for you if you are incapacitated. According to the National Institute on Aging,

An advance directive . . . allows you to express your values and desires related to end-of-life care. You might think of it as a living document—one that you can adjust as your situation changes because of new information or a change in your health. . . .

In considering treatment decisions, your personal values are key. Is your main desire to have the most days of life? Or, would your focus be on quality of life, as you see it? What if an illness leaves you paralyzed or in a permanent coma and you need to be on a ventilator? Would you want that?

What makes life meaningful to you? If your heart stops or you have trouble breathing, would you want to undergo life-saving measures

Her husband claimed that Helga had never expressed an opinion about life-sustaining treatment for herself. Later a second team of physicians confirmed the views of the first, calling the ventilator “nonbeneficial” because it could not ease Helga’s suffering, repair her body, or help her experience life.

The struggle over whether to discontinue Helga’s treatment eventually moved into court, but its decision did little to resolve the stalemate. Three days after the court ruling, Helga died.<sup>4</sup>

Such physician-patient conflicts are commonly described as confrontations about

if it meant that, in the future, you could be well enough to spend time with your family? Would you be content if the emergency leaves you simply able to spend your days listening to books on tape or gazing out the window?

But, there are many other scenarios. Here are a few. What would you decide?

- If a stroke leaves you unable to move and then your heart stops, would you want CPR? What if you were also mentally impaired by a stroke—does your decision change?
- What if you are in pain at the end of life? Do you want medication to treat the pain, even if it will make you more drowsy and lethargic?
- What if you are permanently unconscious and then develop pneumonia? Would you want antibiotics and to be placed on a ventilator?

For some people, staying alive as long as medically possible, or long enough to see an important event like a grandchild’s wedding, is the most important thing. An advance directive can help to make that possible. Others have a clear idea about when they would no longer want to prolong their life. An advance directive can help with that, too.

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National Institute on Aging, “Advance Care Planning: Healthcare Directives,” January 15, 2018, <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>.

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medical futility, the alleged pointlessness or ineffectiveness of administering particular treatments. Physicians may claim that a treatment is futile and therefore should not be used or continued. Patients or their surrogates may reject the label of futility and insist that everything be done that can be done. But physicians and patients often have different ideas about what constitutes futility. The former may judge a treatment futile if it cannot achieve a specified physiological benefit (cannot, for example, repair tissue, restore functioning, or ease suffering); the latter may think a treatment futile only

if it cannot keep the body alive. For both, the issue of futility is a question of values—of what should be done in the circumstances.

In tugs of war over the acceptability of treatment, physicians appeal to a widely recognized principle: Physicians are not obligated to provide treatments that are inconsistent with reasonable

standards of medical practice. They are not morally bound to comply, for example, when a patient requests that his legs be amputated for no reason or demands injections of a worthless and dangerous cancer remedy. Not every patient request must be regarded as legitimate, and not every medical technology must be supplied.

#### **LEGAL BRIEF**

### **Refusing Treatment for Children on Religious Grounds**

Since the 1970s, several children have died after their parents refused medical treatment because of religious beliefs. The deaths have sparked fierce debates and legal conflicts, with some jurisdictions offering religious parents exemptions from child abuse and neglect laws while medical organizations such as the American Academy of Pediatrics (AAP) and the American Medical Association (AMA) have opposed the laws. In its policy statement on the issue, the AAP declares, “Constitutional guarantees of freedom of religion do not permit children to be harmed through religious practices, nor do they allow religion to be a valid defense when an individual harms or neglects a child.” According to a recent tally of the religious exemptions:

- Thirty-eight states and the District of Columbia have religious exemptions in their civil codes on child abuse or neglect, largely because of a federal government policy from 1974 to 1983 requiring states to pass such exemptions in order to get federal funding for child protection work. The states are Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Utah, Vermont, Virginia, Washington,

Wisconsin, and Wyoming. Additionally, Tennessee exempts caretakers who withhold medical care from being adjudicated as negligent if they rely instead on nonmedical “remedial treatment” that is “legally recognized or legally permitted.”

- Sixteen states have religious defenses to felony crimes against children: Arkansas, Idaho, Indiana, Iowa, Louisiana, Minnesota, New Jersey, Ohio, Oklahoma, Tennessee, Texas, Utah, Virginia, Washington, West Virginia, and Wisconsin.
- Fifteen states have religious defenses to misdemeanors: Alabama, Alaska, California, Colorado, Delaware, Georgia, Kansas, Maine, Mississippi, Missouri, Nevada, New Hampshire, New York, South Carolina, and South Dakota.
- Florida has a religious exemption only in the civil code, but the Florida Supreme Court nevertheless held that it caused confusion about criminal liability and required overturning a felony conviction of Christian Scientists for letting their daughter die of untreated diabetes.

States with a religious defense to the most serious crimes against children include:

- Idaho, Iowa, and Ohio with religious defenses to manslaughter
- West Virginia with religious defenses to murder of a child and child neglect resulting in death
- Arkansas with a religious defense to capital murder

Many times in futility cases, physicians and surrogates find resolution. They agree to an extension of the treatment for a specified period or to reasonable goals that the treatment can achieve, or the surrogates eventually view the treatment as useless, or the patient dies. But sometimes resolution eludes everyone. The sharpest clash of values is likely to occur between physicians and those who argue for the

sacredness of human life. On this view, the moral imperative is to keep the body alive at all costs. For someone who accepts this principle, the physicians' claim that the treatment does not benefit the patient will carry little weight. A common argument against the position is that it makes no sense to treat a body when the person whose body it is no longer exists.

### IN DEPTH CPR AND DNR

The medical procedure used to restart a person's heart and breathing is known as cardiopulmonary resuscitation, or *CPR*. It typically consists of mouth-to-mouth resuscitation and external chest compression but may involve more advanced procedures such as defibrillation (electric shock to restore normal heart rhythm). A do-not-resuscitate order, or *DNR*, is a directive telling the medical staff to forgo CPR on a patient if his heart or breathing

stops. DNR orders are generally thought to be medically appropriate and morally permissible when the performing of CPR on seriously or terminally ill patients would be ineffective or futile and would only prolong dying or intensify the patient's pain and suffering. Patients can consent to DNR orders in person, in written instructions in an advance directive such as a living will, or through someone they designate as their representative, or proxy. The AMA declares, "The physician has an ethical obligation to honor the resuscitation preferences expressed by the patient. Physicians should not permit their personal value judgments about quality of life to obstruct the implementation of a patient's preferences regarding the use of CPR."

### IN DEPTH MORAL CONFLICTS IN NURSING

Critically important bioethical issues can arise for nurses from their relationships with patients, with physicians, and with the institutional ethic under which they serve.

As nurses interact with patients, they must come to terms with many of the same moral questions and principles that weigh so heavily on physicians: beneficence versus patient autonomy, patient-provider confidentiality, truth-telling, refusal of treatment, informed consent, and futile treatment.

The issues generated from physician–nurse interactions can be just as pressing. The traditional notion of a nurse is that of a caregiver subordinate to physicians and duty bound to carry out their directives for patient care and treatment. But for many nurses this model seems fraught with conflicts between the nurse's obligation to follow the doctor's orders and the nurse's duty of beneficence toward patients. Nurses may wonder whether they have this sort of duty to physicians even when doctors' orders seem clearly to be in error, or likely to harm patients, or obviously in violation of patients' autonomy, or evidently contrary to well-established standards of care.

Some writers have defended the traditional model of nursing, arguing that (at least in hospitals) physicians must always be the ultimate authority

(continued)

on treatment in urgent or serious cases. After all, only doctors have the requisite training and experience to deal with such situations, and for the sake of efficiency, their decisions should not be questioned. The nurse's proper role is therefore subservient.

But others reject the traditional model, arguing instead that the nurse's ultimate responsibility is to be an advocate for patients, that adopting a subservient role would likely harm patients, and that blindly following physicians' orders does not serve the patient well.

#### CLASSIC CASE FILE

### Elizabeth Bouvia

The central issue in this famous case—both moral and legal—is whether a competent patient has the right to refuse life-sustaining medical treatment. In *Bouvia v. Superior Court*, the California Court of Appeal answered the question with an emphatic yes, and other courts soon followed with similar rulings.

In 1983, Elizabeth Bouvia was 25 years old, bright, articulate, and mentally competent. But she had cerebral palsy from birth and was quadriplegic, her whole body paralyzed except for her right hand and a few muscles allowing minor face and head movements. She also suffered from degenerative arthritis, which, despite her paralysis, caused constant pain that could not be relieved entirely even with doses of morphine. She needed continuous care, but her family would not oblige. She had no job, no income, no home, and no hope of getting help except through public assistance.

She finally got her father to drive her to a public hospital in Riverside County, California, where she asked to be given pain medicine and hygienic care while she slowly committed suicide by starving herself to death. The hospital admitted her but refused to be part of her plan for suicide. She then asked for legal help from the American Civil Liberties Union (ACLU), and her case went before a judge in Riverside County.

Her attending physician at the hospital declared at the first hearing that he would not allow her to die by starvation and that if necessary he would force-feed her. Bouvia asked the judge to disallow

the force-feeding, but he ruled that it was permissible, saying that letting her starve to death would have a terrible effect on the hospital staff as well as on physically handicapped people generally. He asserted that she may have the right to commit suicide but not the right to compel others to help her do it. He said that society's interest in preserving life was more important than Elizabeth Bouvia's constitutional right to privacy, the right to be left alone.

So the force-feeding began. Liquid nourishment was pumped into her through a plastic tube snaked into her nose to her stomach, a procedure known as nasogastric feeding. Opinions among medical professionals about the practice were mixed, with some saying that it was necessary and others that it was horrible and coercive, amounting to battery.

Bouvia lost an appeal of the judge's decision, was later transferred to another hospital, and eventually ended up at High Desert Hospital, a public long-term care facility. At High Desert, her physicians ordered, against her will, that she be once again force-fed to head off possible starvation. They thought nasogastric feeding appropriate because her condition was life-threatening and because with adequate nutrition she could possibly live another 15 or 20 years.

She sued the hospital, asking the Superior Court of Los Angeles to order the force-feeding halted. But the court refused, saying that she clearly intended suicide and that the state could do whatever was necessary to preserve her life.

She appealed the decision to a higher court and, this time, won. In a 1986 ruling, the California Court of Appeal declared unequivocally that competent adults have a “constitutionally guaranteed right” to decide for themselves whether to submit to medical treatments:

[S]uch a patient has the right to refuse *any* medical treatment, even that which may save or prolong her life. . . . The right to refuse medical treatment is basic and fundamental. It is recognized as a part of the right of privacy protected by both the state and federal constitutions. . . . Its exercise requires no one’s approval. It is not merely one vote subject to being overridden by medical opinion. . . . A long line of cases, approved by the Supreme court in *Cobbs v. Grant* (1972) . . . have held that where a doctor performs treatment in the absence of informed consent, there is an actionable battery. The obvious corollary to this principle is that “*a competent patient has the legal right to refuse medical treatment.*”<sup>5</sup>

The court also held that the previous judge had put too much importance on the *length* of Elizabeth Bouvia’s life if treated (15 to 20 years) without considering the *quality* of that extended life:

We do not believe it is the policy of this State that all and every life must be preserved against the will of the sufferer. It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure, for “15 to 20 years.” We cannot conceive it to be the policy of this State to inflict such an ordeal upon anyone. . . . It is, therefore, immaterial that the removal of the nasogastric tube will hasten or cause Bouvia’s eventual death.<sup>6</sup>

Throughout Bouvia’s long ordeal, physicians had noted that her obvious intention was to commit suicide and that they did not want to be accomplices in such an act. But the court maintained that her intentions were irrelevant and that she had a right to refuse treatment regardless of her intentions. Moreover, caregivers who honored refusals of treatment in such cases would not be subject to legal penalty.

Thus, *Bouvia v. Superior Court* tilted the moral and legal scales from physician beneficence to patient autonomy. No other judicial ruling had so strongly and unequivocally asserted that competent patients have a right to reject treatments needed to keep them alive—and that this right supersedes the interests of doctors, hospitals, and the state.

### APPLYING MAJOR THEORIES

The major moral theories imply diverse stands on paternalism. As a theory driven by the principle of beneficence, utilitarianism demands that we maximize the good for everyone involved—a requirement that may justify paternalistic actions. To promote the greatest good for patients—to minimize suffering and maximize well-being—a physician or nurse may think it sometimes legitimate to breach confidentiality or mislead patients about their

condition or proposed treatment. She may believe it morally permissible to override a patient’s refusal of treatment or to reject the use of requested treatments thought to be futile.

Act- and rule-utilitarians can disagree dramatically on such matters. (They may also differ in their estimates of the probabilities involved and ideas about the nature of the good to be maximized.) In act-utilitarianism, the rightness of actions depends on the relative good produced by individual actions; in rule-utilitarianism, rightness depends on the good

maximized by rules governing categories of actions. On act-utilitarian grounds, a physician may judge that it is morally permissible to lie to a patient about a beneficial treatment to overcome the patient's refusal to be treated. But based on rule-utilitarianism, a physician may believe that in the long run, lies do more harm than good because they erode public trust in the medical profession. Better to adhere to a rule barring deceit as a means of getting patients to accept a treatment.

Utilitarians who follow John Stuart Mill's lead, however, would reject such paternalism. Mill believes that the principle of utility implies a strong respect for individual self-determination and asserts that no one may interfere with a person's liberty except to prevent harm to others. As Mill says, "[A person] cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right."<sup>7</sup> On this view people should typically be permitted to decide what is to be done to their own bodies, to refuse treatments, and to give their informed consent.

Generally, Kantian ethics also rejects paternalism. The means-end form of the categorical imperative insists on respect for the rights and autonomy of persons—respect that must not be weakened by calculations of utility and paternalistic urges to act for the patient's own good. The principle would require physicians to honor a patient's decision to refuse treatment, even when they believe the treatment is life-saving. Informed consent of the patient for any treatment would be mandatory, and misleading the patient about treatment would be out of the question. To ignore any of these requirements would be to treat the patient merely as a means and not as an end.

In cases of medical futility, a Kantian could argue that if a physician believes a treatment is pointless and that giving it would be unethical or inappropriate, then the physician's withholding or withdrawing the treatment is morally permissible. Forcing the physician to do what

she thinks is wrong would be a violation of her autonomy.

Natural law theory is more paternalistic than Kantian ethics, a characteristic we can see in cases involving euthanasia. A physician guided by the doctrine of double effect would deny a terminally ill patient's request to be given a lethal injection or to have ordinary life-sustaining measures stopped so she could die. The Roman Catholic corollary to this approach, however, is that a hopelessly ill patient has the right to refuse *extraordinary* life-sustaining treatments—measures that cause suffering or hardship but offer no medical benefit.

## KEY TERMS

autonomy  
medical futility  
paternalism  
strong paternalism  
weak paternalism

## SUMMARY

Autonomy is a person's rational capacity for self-governance or self-determination. The requirement to respect autonomy is expressed in the autonomy principle: Autonomous persons should be allowed to exercise their capacity for self-determination. In bioethics this principle is thought to be a fundamental standard that can be violated only for good reasons and with explicit justification.

Paternalism is the overriding of a person's actions or decision-making for his own good. Weak paternalism refers to paternalism directed at persons who cannot act autonomously or whose autonomy is greatly diminished. It is not usually considered an objectionable violation of autonomy because patients are already substantially nonautonomous and because the point is to protect people from harm while they are non-autonomous, to determine if they are in fact nonautonomous, or to restore them to full autonomy. Strong paternalism is the overriding of a person's actions or choices, even though he or she is substantially autonomous.

Patient autonomy and physician or nurse beneficence often conflict when patients refuse treatment. The central question in such cases is whether it is ever permissible for a provider to treat a patient against her will. Both physicians and the courts now recognize the right of competent patients to refuse treatment. But controversy arises when the patient is a child whose parents refuse medical treatment on religious grounds.

Physician-patient conflicts also surface when patients demand treatments that the physician thinks are inappropriate. These clashes are about medical futility, the alleged pointlessness or ineffectiveness of administering particular treatments. Physicians often appeal to the principle that they are not obligated to provide treatments that are inconsistent with reasonable standards of medical practice. Patients may appeal to other principles such as the sanctity of life.

Utilitarianism demands that we maximize the good for everyone involved—a requirement that may justify paternalistic actions. But utilitarian opinions on paternalism can vary depending on whether they are based on act- or rule-utilitarian approaches. Kantian ethics generally rejects paternalism, insisting on the rights and autonomy of persons. Natural law theory is more paternalistic, denying through the doctrine of double effect a terminally ill patient's request to be given a lethal injection or to have ordinary life-sustaining measures stopped so she could die.

## Cases for Evaluation

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### CASE I

#### Faith-Healing Parents Arrested for Death of Second Child

A religious couple already on probation for choosing prayer over medicine in the death of their toddler son may be facing similar charges in the death of their newest child. "They lost their 8-month-old

son, Brandon, last week after he suffered from diarrhea and breathing problems for at least a week, and stopped eating. Four years ago, another son died from bacterial pneumonia."

That boy, a two-year-old named Kent, died after the Schaibles refused to take him to the doctor when he became sick, relying instead on faith and prayer. The couple were convicted of involuntary manslaughter and sentenced to 10 years on probation.

In the latest tragedy, they told police that they prayed for God to heal Brandon instead of taking him to a doctor when he fell ill. Officials said that an autopsy will be performed on the child, and depending on those results, the parents may be charged with a crime.

The couple attend, and have taught at, Philadelphia's First Century Gospel Church, which cites Biblical scripture favoring prayer and faith over modern medicine. Other religions, including Followers of Christ Church, Christian Scientists, and Scientology, have doctrines that prohibit or discourage modern medicine and therapeutic interventions.

This is not the first time that parents have gone on trial for child abuse or neglect for refusing their children medical attention. Though freedom of religion is guaranteed by the First Amendment to the U.S. Constitution, the practice of that religion does not give followers license to break the law—especially when the result is injury or death to a child.\*

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*Do you agree with the court's sentence of 10 years of probation? Should the sentence have been harsher? Why or why not? Do you think that parents should have the right to reject medical treatment for their children on the basis of religious beliefs? What moral principle would support your judgment? Should religious liberty be construed to allow parents to do anything with their children as long as the actions are based on religious considerations? If not, what sorts of actions should and should not be allowed?*

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\*Discovery.com, April 24, 2013.

**CASE 2****State Paternalism and Pregnant Women**

(AP)—Public hospitals cannot test pregnant women for drugs and turn the results over to police without consent, the Supreme Court said Wednesday in a ruling that buttressed the Constitution's protection against unreasonable searches [*Ferguson v. City of Charleston*].

Some women who tested positive for drugs at a South Carolina public hospital were arrested from their beds shortly after giving birth.

The justices ruled 6-3 that such testing without patients' consent violates the Constitution even though the goal was to prevent women from harming their fetuses by using crack cocaine.

"It's a very, very important decision in protecting the right to privacy of all Americans," said Priscilla Smith, lawyer for the Center for Reproductive Law and Policy, who represented the South Carolina women. "It reaffirms that pregnant women have that same right to a confidential relationship with their doctors."

Justice John Paul Stevens wrote for the court that while the ultimate goal of the hospital's testing program may have been to get women into drug treatment, "the immediate objective of the searches was to generate evidence for law enforcement purposes in order to reach that goal."

When hospitals gather evidence "for the specific purpose of incriminating those patients, they have a special obligation to make sure that the patients are fully informed about their constitutional rights," Stevens said.

South Carolina Attorney General Charles Condon, who as a local prosecutor in Charleston began the testing program, issued a statement saying the program can continue if police get a search warrant or the patient's consent. "There is no right of a mother to jeopardize the health and safety of an unborn child through her own drug abuse," Condon wrote.

Condon developed the policy along with officials at the Medical University of South Carolina, a

Charleston hospital that treats indigent patients. The women were arrested under the state's child-endangerment law, but their lawyers contended the policy was counterproductive and would deter women from seeking prenatal care. . . .

The decision reversed a federal appeals court ruling that said the South Carolina hospital's drug-testing policy was a valid effort to reduce crack cocaine use by pregnant women.

The hospital began the drug testing in 1989 during the crack cocaine epidemic. If a woman's urine test indicated cocaine use, she was arrested for distributing the drug to a minor. In 1990 the hospital gave drug-using maternity patients a choice between arrest or enrolling for drug treatment.

Ten women sued the hospital in 1993, saying the policy violated the Constitution. The hospital dropped the policy the following year, but by then police had arrested 30 women.\*

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*Do you agree with the Supreme Court's decision? Why or why not? Should the state force pregnant women to behave in certain ways while carrying a fetus? If pregnant women can be legally punished for "fetal abuse," how should it be defined? Is a pregnant woman guilty of fetal abuse if she refuses to eat properly? Drinks any amount of alcohol? Forgoes prenatal care? Whose interests should be given greater weight—the woman's or the fetus's?*

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\*Associated Press, "Court: Consent Needed to Drug-Test Pregnant Women," CNN.com, March 21, 2001.

**CASE 3****Medical Futility**

(*Washington Post*)—A 17-month-old deaf, blind and terminally ill child on life support is the latest focus in an emotional fight against a Texas law that allows hospitals to withdraw care when a patient's ongoing treatment is declared "medically futile."

Since Dec. 28, baby Emilio Gonzales has spent his days in a pediatric intensive care unit, mostly asleep from the powerful drugs he is administered,

and breathing with the help of a respirator. Children's Hospital here declared his case hopeless last month and gave his mother 10 days, as legally required, to find another facility to take the baby. That deadline, extended once already, was due to expire Wednesday, at which time the hospital was to shut off Emilio's respirator. Without the machine, Emilio would die within minutes or hours, hospital officials have said.

But the child's mother, Catarina Gonzales, 23, and lawyers representing a coalition of state and national disability rights advocates and groups that favor prolonging life persuaded a Travis County judge Tuesday to force the hospital to maintain Emilio's care while the search for a facility to accept him continues. The group's attempt last week to persuade a federal judge to intervene in the case failed.

County Probate Judge Guy Herman appointed a guardian ad litem, or attorney, to represent Emilio's interests and issued a temporary restraining order prohibiting Children's Hospital from removing life-sustaining care from the child. He set an April 19 hearing on the mother's and lawyers' request for a temporary injunction against the hospital.

"I believe there is a hospital that is going to accept my son," said Gonzales following the brief hearing. "I just want to spend time with my son. . . . I want to let him die naturally without someone coming up and saying we're going to cut off on a certain day."

Michael Regier, senior vice president for legal affairs of the Seton Family of Hospitals, which includes Children's Hospital, said the child's condition continues to deteriorate although he has not met the criteria to be declared brain dead. He said the hospital has contacted 31 facilities "without any single indication of interest in taking the transfer."

Gonzales and her lawyers are seeking a transfer for the child, diagnosed with a terminal neurometabolic disorder called Leigh's disease, to a hospital that will perform a tracheotomy and insert a feeding tube so that he can live out his life in the facility or at home with his mother. But Children's Hospital doctors have declared that continuing treatment is potentially painful and is prolonging the child's suffering.

Emilio's case has drawn interest and support nationwide, including from the siblings of Terri

Schiavo, the Florida woman who was in a persistent vegetative state and who died in 2005 after doctors, acting on a court order, removed her life-sustaining feeding tube.

Texas's six-year-old "futile-care" law is one of two in the country that allow a hospital's ethics committee to declare the care of a terminally ill patient to be of no benefit and to discontinue care within a certain time frame. The patient's family or guardian must be informed in advance of the ethics committee meeting and must be allowed to participate. The family must also be given 10 days to find a medical facility willing to accept their terminal relative. After that period, the hospital may withdraw life support. Virginia gives a family 14 days to transfer a patient once a futile-care decision is made.\*

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*Do you agree with the hospital's reasons for wanting to withdraw care? Do you agree with the child's parents? Explain. Do you believe that life should be preserved at all costs (the sanctity of life view)? Why or why not? Do you believe that quality of life is more important than the preservation of life in cases like this? If so, how would you justify that view?*

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\*Sylvia Moreno, "Case Puts Futile-Treatment Law Under a Microscope," *Washington Post*, April 11, 2007.

## FURTHER READING

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#### NOTES

1. This summary of positions takes its inspiration from Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), 182–87.
2. Linda Greenhouse, "Supreme Court Roundup: Christian Scientists Rebuffed in Ruling by Supreme Court," *New York Times*, January 23, 1996.

#### READINGS

### Paternalism

GERALD DWORKIN

Dworkin accepts the notion (famously articulated by John Stuart Mill) that society may sometimes justifiably restrict a person's liberty for purposes of self-protection or the prevention of harm to others. But he takes issue with Mill's related anti-paternalistic idea that a person "cannot rightfully be compelled to do or forbear because it will be better for him to do so." He argues that some limited forms of state paternalism can be justified, for "[u]nder certain conditions it is rational for an individual to agree that others should force him to act in ways which, at the time of action, the individual may not see as desirable." In a representative government, rational people could agree to restrict their liberty even when the interests of others are not affected. But in such cases the state bears a heavy burden of proof to show "the exact nature of the harmful effects (or beneficial consequences) to be avoided (or achieved) and the probability of their occurrence."

Neither one person, nor any number of persons, is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it.

—MILL

I do not want to go along with a volunteer basis.  
I think a fellow should be compelled to become

From *The Monist: An International Quarterly Journal of General Philosophical Inquiry* 56, no. 4 (October 1972): 64–84.

3. *Prince v. Commonwealth of Massachusetts*, 321 U.S. 1958 (1944).
4. Steven H. Miles, "Informed Consent for 'Non-Beneficial' Medical Treatment," *The New England Journal of Medicine* 325, no. 7 (August 15, 1991), 512–15; "Brain Damaged Woman at Center of Lawsuit over Life-Support Dies," *New York Times* (July 6, 1991), 8.
5. John Stuart Mill, *On Liberty* (1859; rpt. Gateway ed., Chicago: Henry Regnery, 1955), 17–18.
6. *Bouvia v. Superior Court*, 179 Cal. 3d 1127, 1135–43, 225 Cal. Rptr. 297 (Ct. App. 1986).
7. Ibid.

better and not let him use his discretion whether he wants to get smarter, more healthy or more honest.

—GENERAL HERSHY

I take as my starting point the "one very simple principle" proclaimed by Mill in *On Liberty* . . . "That principle is, that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose

for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right."

This principle is neither "one" nor "very simple." It is at least two principles; one asserting that self-protection or the prevention of harm to others is sometimes a sufficient warrant and the other claiming that the individual's own good is *never* a sufficient warrant for the exercise of compulsion either by the society as a whole or by its individual members. I assume that no one with the possible exception of extreme pacifists or anarchists questions the correctness of the first half of the principle. This essay is an examination of the negative claim embodied in Mill's principle—the objection to paternalistic interferences with a man's liberty.

## I

By paternalism I shall understand roughly the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced. One is always well-advised to illustrate one's definitions by examples but it is not easy to find "pure" examples of paternalistic interferences. For almost any piece of legislation is justified by several different kinds of reasons and even if historically a piece of legislation can be shown to have been introduced for purely paternalistic motives, it may be that advocates of the legislation with an anti-paternalistic outlook can find sufficient reasons justifying the legislation without appealing to the reasons which were originally adduced to support it. Thus, for example, it may be the original legislation requiring motorcyclists to wear safety helmets was introduced for purely paternalistic reasons. But the Rhode Island Supreme Court recently upheld such legislation on the grounds that it was "not persuaded that the legislature is powerless to prohibit individuals from pursuing a course of conduct which could conceivably result in their becoming public charges," thus clearly introducing reasons of a quite different kind. Now I regard this

decision as being based on reasoning of a very dubious nature but it illustrates the kind of problem one has in finding examples. The following is a list of the kinds of interferences I have in mind as being paternalistic.

## II

1. Laws requiring motorcyclists to wear safety helmets when operating their machines.
2. Laws forbidding persons from swimming at a public beach when lifeguards are not on duty.
3. Laws making suicide a criminal offense.
4. Laws making it illegal for women and children to work at certain types of jobs.
5. Laws regulating certain kinds of sexual conduct, e.g. homosexuality among consenting adults in private.
6. Laws regulating the use of certain drugs which may have harmful consequences to the user but do not lead to anti-social conduct.
7. Laws requiring a license to engage in certain professions with those not receiving a license subject to fine or jail sentence if they do engage in the practice.
8. Laws compelling people to spend a specified fraction of their income on the purchase of retirement annuities. (Social Security)
9. Laws forbidding various forms of gambling (often justified on the grounds that the poor are more likely to throw away their money on such activities than the rich who can afford to).
10. Laws regulating the maximum rates of interest for loans.
11. Laws against duelling.

In addition to laws which attach criminal or civil penalties to certain kinds of action there are laws, rules, regulations, decrees, which make it either difficult or impossible for people to carry out their plans and which are also justified on paternalistic grounds. Examples of this are:

1. Laws regulating the types of contracts which will be upheld as valid by the courts, e.g. (an example of Mill's to which I shall return) no man may make a valid contract for perpetual involuntary servitude.

2. Not allowing as a defense to a charge of murder or assault the consent of the victim.
3. Requiring members of certain religious sects to have compulsory blood transfusions. This is made possible by not allowing the patient to have recourse to civil suits for assault and battery and by means of injunctions.
4. Civil commitment procedures when these are specifically justified on the basis of preventing the person being committed from harming himself. (The D. C. Hospitalization of the Mentally Ill Act provides for involuntary hospitalization of a person who "is mentally ill, and because of that illness, is likely to injure *himself* or others if allowed to remain at liberty." The term injure in this context applies to unintentional as well as intentional injuries.)
5. Putting fluorides in the community water supply.

All of my examples are of existing restrictions on the liberty of individuals. Obviously one can think of interferences which have not yet been imposed. Thus one might ban the sale of cigarettes, or require that people wear safety-belts in automobiles (as opposed to merely having them installed) enforcing this by not allowing motorists to sue for injuries even when caused by other drivers if the motorist was not wearing a seat-belt at the time of the accident....

### III

Bearing these examples in mind let me return to a characterization of paternalism. I said earlier that I meant by the term, roughly, interference with a person's liberty for his own good. But as some of the examples show the class of persons whose good is invoiced is not always identical with the class of persons whose freedom is restricted. Thus in the case of professional licensing it is the practitioner who is directly interfered with and it is the would-be patient whose interests are presumably being served. Not allowing the consent of the victim to be a defense to certain types of crime primarily affects the would-be aggressor but it is the interests of the willing victim that we are trying to protect. Sometimes a person may fall into both classes as would

be the case if we banned the manufacture and sale of cigarettes and a given manufacturer happened to be a smoker as well.

Thus we may first divide paternalistic interferences into "pure" and "impure" cases. In "pure" paternalism the class of persons whose freedom is restricted is identical with the class of persons whose benefit is intended to be promoted by such restrictions. Examples: the making of suicide a crime, requiring passengers in automobiles to wear seat-belts, requiring a Christian Scientist to receive a blood transfusion. In the case of "impure" paternalism in trying to protect the welfare of a class of persons we find that the only way to do so will involve restricting the freedom of other persons besides those who are benefited. Now it might be thought that there are no cases of "impure" paternalism since any such case could always be justified on non-paternalistic grounds, i.e. in terms of preventing harm to others. Thus we might ban cigarette manufacturers from continuing to manufacture their product on the grounds that we are preventing them from causing illness to others in the same way that we prevent other manufacturers from releasing pollutants into the atmosphere, thereby causing danger to the members of the community. The difference is, however, that in the former but not the latter case the harm is of such a nature that it could be avoided by those individuals affected if they so chose. The incurring of the harm requires, so to speak, the active co-operation of the victim. It would be mistaken theoretically and hypocritical in practice to assert that our interference in such cases is just like our interference in standard cases of protecting others from harm. At the very least someone interfered with in this way can reply that no one is complaining about his activities. It may be that impure paternalism requires arguments or reasons of a stronger kind in order to be justified since there are persons who are losing a portion of their liberty and they do not even have the solace of having it be done "in their own interest." Of course in some sense, if paternalistic justifications are ever correct then we are protecting others, we are preventing some from injuring others, but it is important to see the differences between this and the standard case.

Paternalism then will always involve limitations on the liberty of some individuals in their own interest but it may also extend to interferences with the liberty of parties whose interests are not in question.

#### IV

Finally, by way of some more preliminary analysis, I want to distinguish paternalistic interferences with liberty from a related type with which it is often confused. Consider, for example, legislation which forbids employees to work more than, say, 40 hours per week. It is sometimes argued that such legislation is paternalistic for if employees desired such a restriction on their hours of work they could agree among themselves to impose it voluntarily. But because they do not the society imposes its own conception of their best interests upon them by the use of coercion. Hence this is paternalism.

Now it may be that some legislation of this nature is, in fact, paternalistically motivated. I am not denying that. All I want to point out is that there is another possible way of justifying such measures which is not paternalistic in nature. It is not paternalistic because as Mill puts it in a similar context such measures are “required not to overrule the judgment of individuals respecting their own interest, but to give effect to that judgment they being unable to give effect to it except by concert, which concert again cannot be effectual unless it receives validity and sanction from the law.”

The line of reasoning here is a familiar one first found in Hobbes and developed with great sophistication by contemporary economists in the last decade or so. There are restrictions which are in the interests of a class of persons taken collectively but are such that the immediate interest of each individual is furthered by his violating the rule when others adhere to it. In such cases the individuals involved may need the use of compulsion to give effect to their collective judgment of their own interest by guaranteeing each individual compliance by the others. In these cases compulsion is not used to achieve some benefit which is not recognized to be a benefit by those concerned, but rather because it is the only feasible means of achieving some benefit which is recognized as such by all concerned. This way of viewing matters provides us with

another characterization of paternalism in general. Paternalism might be thought of as the use of coercion to achieve a good which is not recognized as such by those persons for whom the good is intended. Again while this formulation captures the heart of the matter—it is surely what Mill is objecting to in *On Liberty*—the matter is not always quite like that. For example when we force motorcyclists to wear helmets we are trying to promote a good—the protection of the person from injury—which is surely recognized by most of the individuals concerned. It is not that a cyclist doesn’t value his bodily integrity; rather, as a supporter of such legislation would put it, he either places, perhaps irrationally, another value or good (freedom from wearing a helmet) above that of physical well-being or, perhaps, while recognizing the danger in the abstract, he either does not fully appreciate it or he underestimates the likelihood of its occurring. But now we are approaching the question of possible justifications of paternalistic measures and the rest of this essay will be devoted to that question.

#### V

I shall begin for dialectical purposes by discussing Mill’s objections to paternalism and then go on to discuss more positive proposals. . . . The structure of Mill’s argument is as follows:

1. Since restraint is an evil the burden of proof is on those who propose such restraint.
2. Since the conduct which is being considered is purely self-regarding, the normal appeal to the protection of the interests of others is not available.
3. Therefore we have to consider whether reasons involving reference to the individual’s own good, happiness, welfare, or interests are sufficient to overcome the burden of justification.
4. We either cannot advance the interests of the individual by compulsion, or the attempt to do so involves evil which outweighs the good done.
5. Hence the promotion of the individual’s own interests does not provide a sufficient warrant for the use of compulsion.

Clearly the operative premise here is 4 and it is bolstered by claims about the status of the individual as judge and appraiser of his welfare, interests, needs, etc.

With respect to his own feelings and circumstances, the most ordinary man or woman has means of knowledge immeasurably surpassing those that can be possessed by anyone else.

He is the man most interested in his own well-being: the interest which any other person, except in cases of strong personal attachment, can have in it, is trifling, compared to that which he himself has.

These claims are used to support the following generalizations concerning the utility of compulsion for paternalistic purposes.

The interferences of society to overrule his judgment and purposes in what only regards himself must be grounded in general presumptions; which may be altogether wrong, and even if right, are as likely as not to be misapplied to individual cases.

But the strongest of all the arguments against the interference of the public with purely personal conduct is that when it does interfere, the odds are that it interferes wrongly and in the wrong place.

All errors which the individual is likely to commit against advice and warning are far outweighed by the evil of allowing others to constrain him to what they deem his good.

Performing the utilitarian calculation by balancing the advantages and disadvantages we find that:

Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each other to live as seems good to the rest.

From which follows the operative premise 4.

This classical case of a utilitarian argument with all the premises spelled out is not the only line of reasoning present in Mill's discussion. There are asides, and more than asides, which look quite different and I shall deal with them later. But this is clearly the main channel of Mill's thought and it is one which has been subjected to vigorous attack from the moment it appeared—most often by fellow Utilitarians. The link that they have usually seized on is, as Fitzjames Stephen put it, the absence of

proof that the “mass of adults are so well acquainted with their own interests and so much disposed to pursue them that no compulsion or restraint put upon them by any others for the purpose of promoting their interest can really promote them.” . . .

Now it is interesting to note that Mill himself was aware of some of the limitations on the doctrine that the individual is the best judge of his own interests. In his discussion of government intervention in general (even where the intervention does not interfere with liberty but provides alternative institutions to those of the market) after making claims which are parallel to those just discussed, e.g.

People understand their own business and their own interests better, and care for them more, than the government does, or can be expected to do.

He goes on to an intelligent discussion of the “very large and conspicuous exceptions” to the maxim that:

Most persons take a juster and more intelligent view of their own interest, and of the means of promoting it than can either be prescribed to them by a general enactment of the legislature, or pointed out in the particular case by a public functionary.

Thus there are things

of which the utility does not consist in ministering to inclinations, nor in serving the daily uses of life, and the want of which is least felt where the need is greatest. This is peculiarly true of those things which are chiefly useful as tending to raise the character of human beings. The uncultivated cannot be competent judges of cultivation. Those who most need to be made wiser and better, usually desire it least, and, if they desired it, would be incapable of finding the way to it by their own lights.

. . . A second exception to the doctrine that individuals are the best judges of their own interest, is when an individual attempts to decide irrevocably now what will be best for his interest at some future and distant time. The presumption in favor of individual judgment is only legitimate, where the judgment is grounded on actual, and especially on present, personal experience; not where it is formed antecedently to experience, and not suffered to be reversed even after experience has condemned it.

The upshot of these exceptions is that Mill does not declare that there should never be government interference with the economy but rather that

... in every instance, the burden of making out a strong case should be thrown not on those who resist but on those who recommend government interference. Letting alone, in short, should be the general practice: every departure from it, unless required by some great good, is a certain evil.

In short, we get a presumption not an absolute prohibition. The question is why doesn't the argument against paternalism go the same way?

A consistent Utilitarian can only argue against paternalism on the grounds that it (as a matter of fact) does not maximize the good. It is always a contingent question that may be refuted by the evidence. But there is also a non-contingent argument which runs through *On Liberty*. When Mill states that "there is a part of the life of every person who has come to years of discretion, within which the individuality of that person ought to reign uncontrolled either by any other person or by the public collectively" he is saying something about what it means to be a person, an autonomous agent. It is because coercing a person for his own good denies this status as an independent entity that Mill objects to it so strongly and in such absolute terms. To be able to choose is a good that is independent of the wisdom of what is chosen. A man's "mode" of laying out his existence is the best, not because it is the best in itself, but because it is his own mode.

It is the privilege and proper condition of a human being, arrived at the maturity of his faculties, to use and interpret experience in his own way.

As further evidence of this line of reasoning in Mill consider the one exception to his prohibition against paternalism.

In this and most civilised countries, for example, an engagement by which a person should sell himself, or allow himself to be sold, as a slave, would be null and void; neither enforced by law nor by opinion. The ground for thus limiting his power of voluntarily disposing of his own lot in life, is apparent, and is very clearly seen in this extreme case. The reason for not interfering, unless for the sake of others, with a person's voluntary acts, is

consideration for his liberty. His voluntary choice is evidence that what he so chooses is desirable, or at least durable, to him, and his good is on the whole best provided for by allowing him to take his own means of pursuing it. But by selling himself for a slave, he abdicates his liberty; he foregoes any further use of it beyond that single act.

He therefore defeats, in his own case, the very purpose which is the justification of allowing him to dispose of himself. He is no longer free; but is thenceforth in a position which has no longer the presumption in its favour, that would be afforded by his voluntarily remaining in it. The principle of freedom cannot require that he should be free not to be free. It is not freedom to be allowed to alienate his freedom.

Now leaving aside the fudging on the meaning of freedom in the last line it is clear that part of this argument is incorrect. While it is true that *future* choices of the slave are not reasons for thinking that what he chooses then is desirable for him, what is at issue is limiting his immediate choice; and since this choice is made freely, the individual may be correct in thinking that his interests are best provided for by entering such a contract. But the main consideration for not allowing such a contract is the need to preserve the liberty of the person to make future choices. This gives us a principle—a very narrow one, by which to justify some paternalistic interferences. Paternalism is justified only to preserve a wider range of freedom for the individual in question. How far this principle could be extended, whether it can justify all the cases in which we are inclined upon reflection to think paternalistic measures justified remains to be discussed. What I have tried to show so far is that there are two strains of argument in Mill—one a straightforward Utilitarian mode of reasoning and one which relies not on the goods which free choice leads to but on the absolute value of the choice itself. The first cannot establish any absolute prohibition but at most a presumption and indeed a fairly weak one given some fairly plausible assumptions about human psychology; the second while a stronger line of argument seems to me to allow on its own grounds a wider range of paternalism than might be suspected. I turn now to a consideration of these matters.

**VI**

We might begin looking for principles governing the acceptable use of paternalistic power in cases where it is generally agreed that it is legitimate. Even Mill intends his principles to be applicable only to mature individuals, not those in what he calls "non-age." What is it that justifies us in interfering with children? The fact that they lack some of the emotional and cognitive capacities required in order to make fully rational decisions. It is an empirical question to just what extent children have an adequate conception of their own present and future interests but there is not much doubt that there are many deficiencies. For example it is very difficult for a child to defer gratification for any considerable period of time. Given these deficiencies and given the very real and permanent dangers that may befall the child it becomes not only permissible but even a duty of the parent to restrict the child's freedom in various ways. There is however an important moral limitation on the exercise of such parental power which is provided by the notion of the child eventually coming to see the correctness of his parents' interventions. Parental paternalism may be thought of as a wager by the parent on the child's subsequent recognition of the wisdom of the restrictions. There is an emphasis on what could be called future-oriented consent—on what the child will come to welcome, rather than on what he does welcome.

The essence of this idea has been incorporated by idealist philosophers into various types of "real-will" theory as applied to fully adult persons. Extensions of paternalism are argued for by claiming that in various respects, chronologically mature individuals share the same deficiencies in knowledge, capacity to think rationally, and the ability to carry out decisions that children possess. Hence in interfering with such people we are in effect doing what they would do if they were fully rational. Hence we are not really opposing their will, hence we are not really interfering with their freedom. The dangers of this move have been sufficiently exposed by Berlin in his "Two Concepts of Liberty." I see no gain in theoretical clarity nor in practical advantage in trying to pass over the real nature of the interferences with liberty that we impose on

others. Still the basic notion of consent is important and seems to me the only acceptable way of trying to delimit an area of justified paternalism.

Let me start by considering a case where the consent is not hypothetical in nature. Under certain conditions it is rational for an individual to agree that others should force him to act in ways which, at the time of action, the individual may not see as desirable. If, for example, a man knows that he is subject to breaking his resolves when temptation is present, he may ask a friend to refuse to entertain his request at some later stage.

A classical example is given in the *Odyssey* when Odysseus commands his men to tie him to the mast and refuse all future orders to be set free because he knows the power of the Sirens to enchant men with their songs. Here we are on relatively sound ground in later refusing Odysseus' request to be set free. He may even claim to have changed his mind but since it is just such changes that he wishes to guard against we are entitled to ignore them.

A process analogous to this may take place on a social rather than individual basis. An electorate may mandate its representatives to pass legislation which when it comes time to "pay the price" may be unpalatable. I may believe that a tax increase is necessary to halt inflation though I may resent the lower pay check each month. However in both this case and that of Odysseus the measure to be enforced is specifically requested by the party involved and at some point in time there is genuine consent and agreement on the part of those persons whose liberty is infringed. Such is not the case for the paternalistic measures we have been speaking about. What must be involved here is not consent to specific measures but rather consent to a system of government, run by elected representatives, with an understanding that they may act to safeguard our interests in certain limited ways.

I suggest that since we are all aware of our irrational propensities, deficiencies in cognitive and emotional capacities and avoidable and unavoidable ignorance it is rational and prudent for us to in effect take out "social insurance policies." We may argue for and against proposed paternalistic measures in terms of what fully rational individuals would accept as forms of protection. Now, clearly

since the initial agreement is not about specific measures we are dealing with a more-or-less blank check and therefore there have to be carefully defined limits. What I am looking for are certain kinds of conditions which make it plausible to suppose that rational men could reach agreement to limit their liberty even when other men's interests are not affected.

Of course as in any kind of agreement schema there are great difficulties in deciding what rational individuals would or would not accept. Particularly in sensitive areas of personal liberty, there is always a danger of the dispute over agreement and rationality being a disguised version of evaluative and normative disagreement.

Let me suggest types of situations in which it seems plausible to suppose that fully rational individuals would agree to having paternalistic restrictions imposed upon them. It is reasonable to suppose that there are "goods" such as health which any person would want to have in order to pursue his own good—no matter how that good is conceived. This is an argument that is used in connection with compulsory education for children but it seems to me that it can be extended to other goods which have this character. Then one could agree that the attainment of such goods should be promoted even when not recognized to be such, at the moment, by the individuals concerned.

An immediate difficulty that arises stems from the fact that men are always faced with competing goods and that there may be reasons why even a value such as health—or indeed life—may be overridden by competing values. Thus the problem with the Christian Scientist and blood transfusions. It may be more important for him to reject "impure substances" than to go on living. The difficult problem that must be faced is whether one can give sense to the notion of a person irrationally attaching weights to competing values.

Consider a person who knows the statistical data on the probability of being injured when not wearing seat-belts in an automobile and knows the types and gravity of the various injuries. He also insists that the inconvenience attached to fastening the belt every time he gets in and out of the car outweighs for him the possible risks to himself.

I am inclined in this case to think that such a weighing is irrational. Given his life plans which we are assuming are those of the average person, his interests and commitments already undertaken, I think it is safe to predict that we can find inconsistencies in his calculations at some point. I am assuming that this is not a man who for some conscious or unconscious reasons is trying to injure himself nor is he a man who just likes to "live dangerously." I am assuming that he is like us in all the relevant respects but just puts an enormously high negative value on inconvenience—one which does not seem comprehensible or reasonable.

It is always possible, of course to assimilate this person to creatures like myself. I, also, neglect to fasten my seat-belt and I concede such behavior is not rational but not because I weigh the inconvenience differently from those who fasten the belts. It is just that having made (roughly) the same calculation as everybody else I ignore it in my actions. [Note: a much better case of weakness of the will than those usually given in ethics texts.] A plausible explanation for this deplorable habit is that although I know in some intellectual sense what the probabilities and risks are I do not fully appreciate them in an emotionally genuine manner.

We have two distinct types of situation in which a man acts in a non-rational fashion. In one case he attaches incorrect weights to some of his values; in the other he neglects to act in accordance with his actual preferences and desires. Clearly there is a stronger and more persuasive argument for paternalism in the latter situation. Here we are really not—by assumption—imposing a good on another person. But why may we not extend our interference to what we might call evaluative delusions? After all in the case of cognitive delusions we are prepared, often, to act against the expressed will of the person involved. If a man believes that when he jumps out the window he will float upwards—Robert Nozick's example—would not we detain him, forcibly if necessary? The reply will be that this man doesn't wish to be injured and if we could convince him that he is mistaken as to the consequences of his actions he would not wish to perform the action. But part of what is involved in claiming that a man who doesn't fasten his seat-belts is

attaching an irrational weight to the inconvenience of fastening them is that if he were to be involved in an accident and severely injured he would look back and admit that the inconvenience wasn't as bad as all that. So there is a sense in which if I could convince him of the consequences of his actions he also would not wish to continue his present course of action. Now the notion of consequences being used here is covering a lot of ground. In one case it's being used to indicate what will or can happen as a result of a course of action and in the other it's making a prediction about the future evaluation of the consequences—in the first sense—of a course of action. And whatever the difference between facts and values—whether it be hard and fast or soft and slow—we are genuinely more reluctant to consent to interferences where evaluative differences are the issue. Let me now consider another factor which comes into play in some of these situations which may make an important difference in our willingness to consent to paternalistic restrictions.

Some of the decisions we make are of such a character that they produce changes which are in one or another way irreversible. Situations are created in which it is difficult or impossible to return to anything like the initial stage at which the decision was made. In particular some of these changes will make it impossible to continue to make reasoned choices in the future. I am thinking specifically of decisions which involve taking drugs that are physically or psychologically addictive and those which are destructive of one's mental and physical capacities.

I suggest we think of the imposition of paternalistic interferences in situations of this kind as being a kind of insurance policy which we take out against making decisions which are far-reaching, potentially dangerous and irreversible. . . .

A second class of cases concerns decisions which are made under extreme psychological and socio-psychological pressure. I am not thinking here of the making of the decision as being something one is pressured into—e.g. a good reason for making duelling illegal is that unless this is done many people might have to manifest their courage and integrity in ways in which they would rather not do so—but rather of decisions such as that to commit suicide which are usually made at a point where the

individual is not thinking clearly and calmly about the nature of his decision. In addition, of course, this comes under the previous heading of all-too-irrevocable decision. Now there are practical steps which a society could take if it wanted to decrease the possibility of suicide—for example not paying social security benefits to the survivors or as religious institutions do, not allowing such persons to be buried with the same status as natural deaths. I think we may count these as interferences with the liberty of persons to attempt suicide and the question is whether they are justifiable.

Using my argument schema the question is whether rational individuals would consent to such limitations. I see no reason for them to consent to an absolute prohibition but I do think it is reasonable for them to agree to some kind of enforced waiting period. Since we are all aware of the possibility of temporary states, such as great fear or depression, that are inimical to the making of well-informed and rational decisions, it would be prudent for all of us if there were some kind of institutional arrangement whereby we were restrained from making a decision which is (all too) irreversible. What this would be like in practice is difficult to envisage and it may be that if no practical arrangements were feasible then we would have to conclude that there should be no restriction at all on this kind of action. But we might have a "cooling off" period, in much the same way that we now require couples who file for divorce to go through a waiting period. Or, more far-fetched, we might imagine a Suicide Board composed of a psychologist and another member picked by the applicant. The Board would be required to meet and talk with the person proposing to take his life, though its approval would not be required.

A third class of decisions—these classes are not supposed to be disjoint—involves dangers which are either not sufficiently understood or appreciated correctly by the persons involved. Let me illustrate, using the example of cigarette smoking, a number of possible cases.

1. A man may not know the facts—e.g. smoking between 1 and 2 packs a day shortens life expectancy 6.2 years, the cost and pain of the illness caused by smoking, etc.

2. A man may know the facts, wish to stop smoking, but not have the requisite willpower.
3. A man may know the facts but not have them play the correct role in his calculation because, say, he discounts the danger psychologically because it is remote in time and/or inflates the attractiveness of other consequences of his decision which he regards as beneficial.

In case 1 what is called for is education, the posting of warnings, etc. In case 2 there is no theoretical problem. We are not imposing a good on someone who rejects it. We are simply using coercion to enable people to carry out their own goals. (Note: There obviously is a difficulty in that only a subclass of the individuals affected wish to be prevented from doing what they are doing.) In case 3 there is a sense in which we are imposing a good on someone since given his current appraisal of the facts he doesn't wish to be restricted. But in another sense we are not imposing a good since what is being claimed—and what must be shown or at least argued for—is that an accurate accounting on his part would lead him to reject his current course of action. Now we all know that such cases exist, that we are prone to disregard dangers that are only possibilities, that immediate pleasures are often magnified and distorted.

If in addition the dangers are severe and far-reaching we could agree to allowing the state a certain degree of power to intervene in such situations. The difficulty is in specifying in advance, even vaguely, the class of cases in which intervention will be legitimate.

A related difficulty is that of drawing a line so that it is not the case that all ultra-hazardous activities are ruled out, e.g. mountain-climbing, bull-fighting, sports-car racing, etc. There are some risks—even very great ones—which a person is entitled to take with his life.

A good deal depends on the nature of the deprivation—e.g. does it prevent the person from engaging in the activity completely or merely limit his participation—and how important to the nature of the activity is the absence of restriction when this

is weighed against the role that the activity plays in the life of the person. In the case of automobile seatbelts, for example, the restriction is trivial in nature, interferes not at all with the use or enjoyment of the activity, and does, I am assuming, considerably reduce a high risk of serious injury. Whereas, for example, making mountain climbing illegal prevents completely a person engaging in an activity which may play an important role in his life and his conception of the person he is.

In general the easiest cases to handle are those which can be argued about in the terms which Mill thought to be so important—a concern not just for the happiness or welfare, in some broad sense, of the individual but rather a concern for the autonomy and freedom of the person. I suggest that we would be most likely to consent to paternalism in those instances in which it preserves and enhances for the individual his ability to rationally consider and carry out his own decisions.

I have suggested in this essay a number of types of situations in which it seems plausible that rational men would agree to granting the legislative powers of a society the right to impose restrictions on what Mill calls “self-regarding” conduct. However, rational men knowing something about the resources of ignorance, ill-will and stupidity available to the lawmakers of a society—a good case in point is the history of drug legislation in the United States—will be concerned to limit such intervention to minimum. I suggest in closing two principles designed to achieve this end.

In all cases of paternalistic legislation there must be a heavy and clear burden of proof placed on the authorities to demonstrate the exact nature of the harmful effects (or beneficial consequences) to be avoided (or achieved) and the probability of their occurrence. The burden of proof here is twofold—what lawyers distinguish as the burden of going forward and the burden of persuasion. That the authorities have the burden of going forward means that it is up to them to raise the question and bring forward evidence of the evils to be avoided. Unlike the case of new drugs where the manufacturer must produce some evidence that the drug has been tested and found not harmful, no citizen has to show with respect to self-regarding conduct that it is not harmful

or promotes his best interests. In addition the nature and cogency of the evidence for the harmfulness of the course of action must be set at a high level. To paraphrase a formulation of the burden of proof for criminal proceedings—better 10 men ruin themselves than one man be unjustly deprived of liberty.

Finally I suggest a principle of the least restrictive alternative. If there is an alternative way of accomplishing the desired end without restricting liberty then although it may involve great expense, inconvenience, etc. the society must adopt it.

## The Refutation of Medical Paternalism

ALAN GOLDMAN

Except in a few extraordinary cases, strong paternalism in medicine is unjustified, Goldman argues. Patients have a right of self-determination, a right of freedom to make their own choices. Decisions regarding their own futures should be left up to them because persons are the best judges of their own interests and because self-determination is valuable for its own sake regardless of its generally positive effects. This right implies “the right to be told the truth about one’s condition, and the right to accept or refuse or withdraw from treatment on the basis of adequate information regarding alternatives, risks and uncertainties.” The faulty premise in the argument for medical paternalism, says Goldman, is that health and prolonged life can be assumed to be the top priorities for patients (and so physicians may decide for patients accordingly). But very few people always prioritize these values in this way.

There are two ways to attack an argument in favor of paternalistic measures (while accepting our criteria for justified paternalism). One is to argue that honoring rather than overriding the right of the person will not in fact harm him. The other is to admit that the satisfaction of the person’s right may harm in some way, but argue that the harm does not merit exception to the right, all things considered. The first is principally an empirical, the second a moral counterargument.

The latter is not a perfectly clear-cut distinction, either in general or in application to the question of paternalism. For one thing, the most inclusive notion of harm is relative to the values and preferences of the particular individual. (This point will

be important in the argument to follow.) A person is harmed when a state of affairs below a certain level on his preference scale is realized rather than one higher up. Our notion of harm derives what objectivity it has from two sources, again one principally empirical and the other more purely moral. The first is the fact that certain states of affairs are such that the vast majority of us would wish to avoid them in almost all conceivable contexts: physical injury, hastened death, or depression itself for example. It is an empirical question whether these states of affairs result from certain courses of conduct, hence, when they are predicted results, principally an empirical question whether harm ensues. The second source of a concept of harm independent of individual differences in subjective preferences is ideal-regarding: when the development of an individual capable of freely and creatively formulating and acting to realize central life projects is blocked, that person is harmed, whether

or not he realizes it, and whether or not any of his present desires are frustrated.

The first argument against paternalistic interference holds that allowing an individual free choice is not most likely to result in harm taken in its objective sense. The second argument is somewhat more complex. It admits likely harm in the objective sense—worsened health, depression, or even hastened death in the examples we are considering—but holds that even greater harm to the individual is likely to ensue from the interference, harm in the more inclusive sense that takes account of his whole range of value orderings and the independent value of his integrity as an individual. In this latter situation there is one sense in which the individual is likely to suffer harm no matter what others do, since a state of affairs will be realized that he would wish to avoid, other things being equal, a state of affairs well below the neutral level in his preference orderings. But from the point of view of others, they impose harm only by interfering, since only that action results in a state of affairs lower on his scale of preferences than would otherwise be realized. In this sense harm is a relative notion, first because it is relative to subjective value orderings, and second because it is imposed only when a situation *worse* than what would otherwise occur is caused. We appeal to this second more inclusive notion in the second type of argument against paternalism.

### **Empirical Arguments**

Returning to the medical context, other philosophers have recently questioned the degree of truth in the empirical premise that patients are likely to be harmed when doctors fully inform them. Sissela Bok, for example, has noted that in general it appears to be false that patients do not really want bad news, cannot accept or understand it, or are harmed by it. Yet she does not deny that information can sometimes harm patients, can cause depression, prolong illness, or even hasten death; and she explicitly allows for concealment when this can be shown in terminal cases. Allen Buchanan questions the ability of the doctor to make a competent judgment on the probability of harm to the patient, a judgment that would require both psychiatric expertise and intimate knowledge of the patient

himself. Doctors are not generally trained to judge long-term psychological reactions, and even if they were, they would require detailed psychological histories of patients in order to apply this expertise in particular cases. As medical practices tend to become more impersonal, certainly a trend in recent years, such intimate knowledge of patients, even on a nontheoretical level, will normally be lacking. Physicians would then have to rely upon loose generalizations, based on prior impressions of other patients and folklore from colleagues, in order to predict the effect of information on particular patients.

Buchanan appears to consider this point sufficient to refute the argument for paternalism, eschewing appeal to patients' rights. But unless we begin with a strong presumption of a right of the patient to the truth, I do not see why the difficulties for the doctor in judging the effect of information on the patient recommends a practice of disclosure. If the decision is to be based upon risk-benefit calculation (as it would be without consideration of rights), then, just as in other decisions regarding treatment, no matter how difficult to make, it seems that the doctor should act on his best estimate. The decision on what to say must be made by him one way or the other; and without a right-based presumption in favor of revealing the truth, its difficulty is no argument for one outcome rather than the other. In fact, the difficulty might count against revelation, since telling the truth is generally more irreversible than concealment or delay.

One could, it is true, attempt to make out a case for full disclosure on strict risk-benefit grounds, without appeal to rights. As we have seen in earlier chapters, utilitarians can go to great lengths to show that their calculations accord with the intuitive recognition of particular rights. In the case of lying or deceiving, they standardly appeal to certain systematic disutilities that might be projected, e.g. effects upon the agent's trustworthiness and upon the trust that other people are willing to accord him if his lies are discovered. In the doctor's case, he might fear losing patients or losing the faith of patients who continue to consult him, if he is caught in lies or deceptions. A utilitarian could argue further that, even in situations in which

these disutilities appear not to figure, this appearance tends to be misleading, and that potential liars should therefore resist the temptation on this ground. One problem with this argument, as pointed out in the chapter on political ethics, is that it is empirically falsified in many situations. It is not always so difficult to foretell the utilitarian effects of deception, at least no more difficult than is any other future-looking moral calculation. In the case of terminally ill patients, for example, by the time they realize that their doctors have been deceiving them, they will be in no condition to communicate this fact to other patients or potential patients, even if such communication were otherwise commonplace. Thus the doctor has little to fear in the way of losing patients or patients' faith from his policy of disclosure or concealment from the terminally ill. He can safely calculate risks and benefits with little regard for such systematic disutilities. Again we have little reason to prefer honoring a right, in this case a right to be told the truth, without appealing to the right itself. The only conclusion that I would draw from the empirical points taken in themselves is that doctors should perhaps be better trained in psychology in order to be better able to judge the effects of disclosure upon patients, not that they should make a practice of full disclosure and of allowing patients full control over decisions on treatment. These conclusions we must reach by a different rights-based route.

I shall then criticize the argument for paternalistic strong role differentiation on the more fundamental moral ground. To do so I shall restrict attention to cases in which there is a definite risk or probability of eventual harm (in the objective sense) to the patient's health from revealing the truth about his condition to him, or from informing him of all risks of alternative treatments and allowing him a fully informed decision. These cases are those in which the high probability of harm can be supported or demonstrated, but in which the patient asks to know the truth. Such cases are not decided by the points of Bok or Buchanan, and they are the crucial ones for the question of strong role differentiation. The issue is whether such projected harm is sufficient to justify concealment. If the patient's normal right to self-determination prevails, then

the doctor, in having to honor this right, is acting within the same moral framework as the rest of us. If the doctor acquires the authority to decide for the patient, a normally competent adult, or to withhold the truth about his own condition from him, then he has special professional license to override otherwise obtaining rights, and his position is strongly differentiated.

Before presenting the case against strong role differentiation on this basis, I want to dispense quickly with a possible conceptual objection. One might claim that the justification of medical paternalism would not in itself satisfy the criteria for strong role differentiation as defined. Since paternalism is justified as well in other contexts, the exceptions to the rights in question need not be seen to derive from a special principle unique to medical ethics, but can be held simply to instantiate a generally recognized ground for restricting rights or freedoms. If serious harm to a person himself generally can be counted as overriding evidence that the projected action is contrary to his own true preferences or values, and if this generally justifies paternalistic interference or delegation of authority for decisions to others, if, for example, legislators assume authority to apply coercive sanctions to behavior on these grounds, then the authority to be paternalistic would not uniquely differentiate doctors.

The above may be true in so far as paternalism is sometimes justified in other than medical contexts, but that does not alter the import of the argument for medical paternalism to our perception of the doctor's role. If the argument were sound, the medical profession might still be the only one, or one of only a few, paternalistic in this way. This would differentiate medical ethics sufficiently. I argued earlier that legislators must in fact honor normal moral rights. While paternalistic legislation is sometimes justified, as in the requirement that motorcycle riders wear helmets, such legislation is so relatively small a part of the legislator's concerns, and the amount of coercion justified itself so relatively light, that this does not alter our perception of the legislator's general moral framework. If the paternalist argument were sound in relation to doctors, on the other hand, this would substantially alter the nature

of their practice and our perception of their authority over certain areas of our lives. We can therefore view the paternalist argument as expressing the underlying moral purposes that elevate the Hippocratic principle and augment the doctor's authority to ignore systematically rights that would obtain against all but those in the medical profession. The values expressed and elevated are viewed by doctors themselves as central to their role, which again distinguishes this argument from claims of justified paternalism in other contexts. Furthermore, viewing the argument in this way brings out the interesting relations between positions of doctors and those in other professions and social roles. It brings out that doctors tend to assume broader moral responsibility for decisions than laymen, while those in certain other professions tend to assume less. In any case, while I shall not in the end view the doctor's role as strongly differentiated, I do not want to rely upon this terminological point, but rather to refute the argument for overriding patients' rights to further the medical goal of optimal treatment.

### The Moral Argument

In order to refute an argument, we of course need to refute only one of its premises. The argument for medical paternalism, stripped to its barest outline, was:

1. Disclosure of information to the patient will sometimes increase the likelihood of depression and physical deterioration, or result in choice of medically inoptimal treatment.
2. Disclosure of information is therefore sometimes likely to be detrimental to the patient's health, perhaps even to hasten his death.
3. Health and prolonged life can be assumed to have priority among preferences for patients who place themselves under physicians' care.
4. Worsening health or hastening death can therefore be assumed to be contrary to patients' own true value orderings.
5. Paternalism is therefore justified: doctors may sometimes override patients' *prima facie* rights to information about risks and treatments or about their own conditions in order to prevent harm to their health.

### The Relativity of Values: Health and Life

The fundamentally faulty premise in the argument for paternalistic role differentiation for doctors is that which assumes that health or prolonged life must take absolute priority in the patient's value orderings. In order for paternalistic interference to be justified, a person must be acting irrationally or inconsistently with his own long-range preferences. The value ordering violated by the action to be prevented must either be known to be that of the person himself, as in the train example, or else be uncontroversially that of any rational person, as in the motorcycle helmet case. But can we assume that health and prolonged life have top priority in any rational ordering? If these values could be safely assumed to be always overriding for those who seek medical assistance, then medical expertise would become paramount in decisions regarding treatment, and decisions on disclosure would become assimilated to those within the treatment context. But in fact very few of us act according to such an assumed value ordering. In designing social policy we do not devote all funds or efforts toward minimizing loss of life, on the highways or in hospitals for example.

If our primary goal were always to minimize risk to health and life, we should spend our entire federal budget in health-related areas. Certainly such a suggestion would be ludicrous. We do not in fact grant to individuals rights to minimal risk in their activities or to absolutely optimal health care. From another perspective, if life itself, rather than life of a certain quality with autonomy and dignity, were of ultimate value, then even defensive wars could never be justified. But when the quality of life and the autonomy of an entire nation is threatened from without, defensive war in which many lives are risked and lost is a rational posture. To paraphrase Camus, anything worth living for is worth dying for. To realize or preserve those values that give meaning to life is worth the risk of life itself. Such fundamental values (and autonomy for individuals is certainly among them), necessary within a framework in which life of a certain quality becomes possible, appear to take precedence over the value of mere biological existence.

In personal life too we often engage in risky activities for far less exalted reasons, in fact just for the pleasure or convenience. We work too hard, smoke, exercise too little or too much, eat what we know is bad for us, and continue to do all these things even when informed of their possibly fatal effects. To doctors in their roles as doctors all this may appear irrational, although they no more act always to preserve their own health than do the rest of us. If certain risks to life and health are irrational, others are not. Once more the quality and significance of one's life may take precedence over maximal longevity. Many people when they are sick think of nothing above getting better; but this is not true of all. A person with a heart condition may decide that important unfinished work or projects must take priority over increased risk to his health; and his priority is not uncontroversially irrational. Since people's lives derive meaning and fulfillment from their projects and accomplishments, a person's risking a shortened life for one more fulfilled might well justify actions detrimental to his health. . . .

To doctors in their roles as professionals whose ultimate concern is the health or continued lives of patients, it is natural to elevate these values to ultimate prominence. The death of a patient, inevitable as it is in many cases, may appear as an ultimate defeat to the medical art, as something to be fought by any means, even after life has lost all value and meaning for the patient himself. The argument in the previous section for assuming this value ordering was that health, and certainly life, seem to be necessary conditions for the realization of all other goods or values. But this point, even if true, leaves open the question of whether health and life are of ultimate, or indeed any, intrinsic value, or whether they are valuable *merely* as means. It is plausible to maintain that life itself is not of intrinsic value, since surviving in an irreversible coma seems no better than death. It therefore again appears that it is the quality of life that counts, not simply being alive. Although almost any quality might be preferable to none, it is not irrational to trade off quantity for quality, as in any other good.

Even life with physical health and consciousness may not be of intrinsic value. Consciousness and

health may not be sufficient in themselves to make the life worth living, since some states of consciousness are intrinsically good and others bad. Furthermore, if a person has nothing before him but pain and depression, then the instrumental worth of being alive may be reversed. And if prolonging one's life can be accomplished only at the expense of incapacitation or ignorance, perhaps preventing lifelong projects from being completed, then the instrumental value of longer life again seems overbalanced. It is certainly true that normally life itself is of utmost value as necessary for all else of value, and that living longer usually enables one to complete more projects and plans, to satisfy more desires and derive more enjoyments. But this cannot be assumed in the extreme circumstances of severe or terminal illness. Ignorance of how long one has left may block realization of such values, as may treatment with the best chance for cure, if it also risks incapacitation or immediate death.

Nor is avoidance of depression the most important consideration in such circumstances, as a shallow hedonism might assume. Hedonistic theories of value, which seek only to produce pleasure or avoid pain and depression, are easily disproven by our abhorrence at the prospect of a "brave new world," or our unwillingness, were it possible, to be plugged indefinitely into a "pleasure machine." The latter prospect is abhorrent not only from an ideal-regarding viewpoint, but, less obviously, for want-regarding reasons (for most persons) as well. Most people would in fact be unwilling to trade important freedoms and accomplishments for sensuous pleasures, or even for the illusion of greater freedoms and accomplishments. As many philosophers have pointed out, while satisfaction of wants may bring pleasurable sensations, wants are not primarily *for* pleasurable sensations, or even for happiness more broadly construed, *per se*. Conversely, the avoidance of negative feelings or depression is not uppermost among primary motives. Many people are willing to endure frustration, suffering, and even depression in pursuit of accomplishment, or in order to complete projects once begun. Thus information relevant to such matters, such as medical information about one's own condition or possible adverse effects of various treatments, may well be

worth having at the cost of psychological pain or depression.

### The Value of Self-Determination

We have so far focused on the inability of the doctor to assume a particular value ordering for his patient in which health, the prolonging of life, or the avoidance of depression is uppermost. The likelihood of error in this regard makes it probable that the doctor will not know the true interests of his patient as well as the patient himself. He is therefore less likely than the patient himself to make choices in accord with that overall interest, and paternalistic assumption of authority to do so is therefore unjustified. There is in addition another decisive consideration mentioned earlier, namely the independent value of self-determination or freedom of choice. Personal autonomy over important decisions in one's life, the ability to attempt to realize one's own value ordering, is indeed so important that normally no amount of other goods, pleasures or avoidance of personal evils can take precedence. This is why it is wrong to contract oneself into slavery, and another reason why pleasure machines do not seem attractive. Regarding the latter, even if people were willing to forego other goods for a life of constant pleasure, the loss in variety of other values, and in the creativity that can generate new sources of value, would be morally regrettable. The value of self-determination explains also why there is such a strong burden of proof upon those who advocate paternalistic measures, why they must show that the person would otherwise act in a way inconsistent with his own value ordering, that is irrationally. A person's desires are not simply evidence of what is in his interest—they have extra weight.

Especially when decisions are important to the course of our lives, we are unwilling to relinquish them to others, even in exchange for a higher probability of happiness or less risk of suffering. Even if it could be proven, for example, that some scientific method of matching spouses greatly increased chances of compatibility and happiness, we would insist upon retaining our rights over marriage decisions. Given the present rate of success in marriages, it is probable that we could in fact find some better method of matching partners in terms of increasing

that success rate. Yet we are willing to forego increased chances of success in order to make our own choices, choices that tend to make us miserable in the long run. The same might be true of career choices, choices of schools, and others central to the course of our lives. Our unwillingness to delegate these crucial decisions to experts or computers, who might stand a better chance of making them correctly (in terms of later satisfactions), is not to be explained simply in terms of our (sometimes mistaken) assumptions that we know best how to satisfy our own interests, or that we personally will choose correctly, even though most other people do not. If our retaining such authority for ourselves is not simply irrational, and I do not believe it is, this can only be because of the great independent value of self-determination. We value the exercise of free choice itself in personally important decisions, no matter what the effects of those decisions upon other satisfactions. The independent value of self-determination in decisions of great personal importance adds also to our reluctance to relinquish medical decisions with crucial effects on our lives to doctors, despite their medical expertise.

Autonomy or self-determination is independently valuable, as argued before, first of all because we value it in itself. But we may again add to this want-regarding or utilitarian reason a second ideal-regarding or perfectionist reason. What has value does so because it is valued by a rational and autonomous person. But autonomy itself is necessary to the development of such valuing individual persons or agents. It is therefore not to be sacrificed to other derivative values. To do so as a rule is to destroy the ground for the latter. Rights in general not only express and protect the central interests of individuals (the *raison d'être* usually emphasized in their exposition); they also express the dignity and inviolability of individuality itself. For this reason the most fundamental right is the right to control the course of one's life, to make decisions crucial to it, including decisions in life-or-death medical contexts. The other side of the independent value of self-determination from the point of view of the individual is the recognition of him by others, including doctors, as an individual with his own possibly unique set of values and priorities. His dignity demands a right to make personal decisions that express those values.

## Why Doctors Should Intervene

TERRENCE F. ACKERMAN

Respect for patient autonomy is distorted when autonomy is understood as mere noninterference, says Ackerman. On this prevalent hands-off view, “[t]he doctor need be only an honest and good technician, providing relevant information and dispensing professionally competent care.” But this approach fails to respect autonomy genuinely, he argues, for it does not recognize that many factors can compromise autonomy, including illness and a host of psychological, social, and cultural constraints. At times, true respect for autonomy may require the physician to intervene, to deviate from the patient’s stated preferences. The goal of the physician–patient relationship should be “to resolve the underlying physical (or mental) defect, and to deal with cognitive, psychological, and social constraints in order to restore autonomous functioning.”

Patient autonomy has become a watchword of the medical profession. According to the revised 1980 AMA Principles of Medical Ethics,<sup>1</sup> no longer is it permissible for a doctor to withhold information from a patient, even on grounds that it may be harmful. Instead the physician is expected to “deal honestly with patients” at all times. Physicians also have a duty to respect the confidentiality of the doctor-patient relationship. Even when disclosure to a third party may be in the patient’s interests, the doctor is instructed to release information only when required by law. Respect for the autonomy of patients has given rise to many specific patient rights—among them the right to refuse treatment, the right to give informed consent, the right to privacy, and the right to competent medical care provided with “respect for human dignity.”

While requirements of honesty, confidentiality, and patients’ rights are all important, the underlying moral vision that places exclusive emphasis upon these factors is more troublesome. The profession’s notion of respect for autonomy makes noninterference its essential feature. As the Belmont Report has described it, there is an obligation to “give weight to autonomous persons’ considered opinions and choices while refraining from

obstructing their actions unless they are clearly detrimental to others.”<sup>2</sup> Or, as Tom Beauchamp and James Childress have suggested, “To respect autonomous agents is to recognize with due appreciation their own considered value judgments and outlooks even when it is believed that their judgments are mistaken.” They argue that people “are entitled to autonomous determination without limitation on their liberty being imposed by others.”<sup>3</sup>

When respect for personal autonomy is understood as noninterference, the physician’s role is dramatically simplified. The doctor need be only an honest and good technician, providing relevant information and dispensing professionally competent care. Does noninterference really respect patient autonomy? I maintain that it does not, because it fails to take account of the transforming effects of illness.

“Autonomy,” typically defined as self-governance, has two key features. First, autonomous behavior is governed by plans of action that have been formulated through deliberation or reflection. This deliberative activity involves processes of both information gathering and priority setting. Second, autonomous behavior issues, intentionally and voluntarily, from choices people make based upon their own life plans.

But various kinds of constraints can impede autonomous behavior. There are physical constraints—confinement in prison is an example—where internal

or external circumstances bodily prevent a person from deliberating adequately or acting on life plans. Cognitive constraints derive from either a lack of information or an inability to understand that information. A consumer's ignorance regarding the merits or defects of a particular product fits the description. Psychological constraints, such as anxiety or depression, also inhibit adequate deliberation. Finally, there are social constraints—such as institutionalized roles and expectations ("a woman's place is in the home," "the doctor knows best") that block considered choices.

Edmund Pellegrino suggests several ways in which autonomy is specifically compromised by illness:

In illness, the body is interposed between us and reality—it impedes our choices and actions and is no longer fully responsive. . . . Illness forces a reappraisal and that poses a threat to the old image; it opens up all the old anxieties and imposes new ones—often including the real threat of death or drastic alterations in life-style. This ontological assault is aggravated by the loss of . . . freedoms we identify as peculiarly human. The patient . . . lacks the knowledge and skills necessary to cure himself or gain relief of pain and suffering. . . . The state of being ill is therefore a state of "wounded humanity," of a person compromised in his fundamental capacity to deal with his vulnerability.<sup>4</sup>

The most obvious impediment is that illness "interposes" the body or mind between the patient and reality, obstructing attempts to act upon cherished plans. An illness may not only temporarily obstruct long-range goals; it may necessitate permanent and drastic revision in the patient's major activities, such as working habits. Patients may also need to set limited goals regarding control of pain, alteration in diet and physical activity, and rehabilitation of functional impairments. They may face considerable difficulties in identifying realistic and productive aims.

The crisis is aggravated by a cognitive constraint—the lack of "knowledge and skills" to overcome their physical or mental impediment. Without adequate medical understanding, the patient cannot assess his or her condition accurately. Thus the choice of goals is seriously hampered and subsequent decisions by the patient are not well founded.

Pellegrino mentions the anxieties created by illness, but psychological constraints may also include denial, depression, guilt, and fear. I recently visited an eighteen-year-old boy who was dying of a cancer that had metastasized extensively throughout his abdomen. The doctor wanted to administer further chemotherapy that might extend the patient's life a few months. But the patient's nutritional status was poor, and he would need intravenous feedings prior to chemotherapy. Since the nutritional therapy might also encourage tumor growth, leading to a blockage of the gastrointestinal tract, the physician carefully explained the options and the risks and benefits several times, each time at greater length. But after each explanation the young man would say only that he wished to do whatever was necessary to get better. Denial prevented him from exploring the alternatives.

Similarly, depression can lead patients to make choices that are not in harmony with their life plans. Recently, a middle-aged woman with a history of ovarian cancer in remission returned to the hospital for the biopsy of a possible pulmonary metastasis. Complications ensued and she required the use of an artificial respirator for several days. She became severely depressed and soon refused further treatment. The behavior was entirely out of character with her previous full commitment to treatment. Fully supporting her overt wishes might have robbed her of many months of relatively comfortable life in the midst of a very supportive family around which her activities centered. The medical staff stalled for time. Fortunately, her condition improved.

Fear may also cripple the ability of patients to choose. Another patient, diagnosed as having a cerebral tumor that was probably malignant, refused life-saving surgery because he feared the cosmetic effects of neurosurgery and the possibility of neurological damage. After he became comatose and new evidence suggested that the tumor might be benign, his family agreed to surgery and a benign tumor was removed. But he later died of complications related to the unfortunate delay in surgery. Although while competent he had agreed to chemotherapy, his fears (not uncommon among candidates for neurosurgery) prevented him from accepting the medical intervention that might have secured him the health he desired.

Social constraints may also prevent patients from acting upon their considered choices. A recent case involved a twelve-year-old boy whose rhabdomyosarcoma had metastasized extensively. Since all therapeutic interventions had failed, the only remaining option was to involve him in a phase 1 clinical trial. (A phase 1 clinical trial is the initial testing of a drug in human subjects. Its primary purpose is to identify toxicities rather than to evaluate therapeutic effectiveness.) The patient's course had been very stormy, and he privately expressed to the staff his desire to quit further therapy and return home. However, his parents denied the hopelessness of his condition, remaining steadfast in their belief that God would save their child. With deep regard for his parents' wishes, he refused to openly object to their desires and the therapy was administered. No antitumor effect occurred and the patient soon died.

Various social and cultural expectations also take their toll. According to Talcott Parsons, one feature of the sick role is that the ill person is obligated "...to seek *technically competent* help, namely, in the most usual case, that of a physician and to *cooperate* with him in the process of trying to get well."<sup>5</sup> Parsons does not describe in detail the elements of this cooperation. But clinical observation suggests that many patients relinquish their opportunity to deliberate and make choices regarding treatment in deference to the physician's superior educational achievement and social status ("Whatever you think, doctor!"). The physical and emotional demands of illness reinforce this behavior.

Moreover, this perception of the sick role has been socially taught from childhood—and it is not easily altered even by the physician who ardently tries to engage the patient in decision making. Indeed, when patients are initially asked to participate in the decision-making process, some exhibit considerable confusion and anxiety. Thus, for many persons, the institutional role of patient requires the physician to assume the responsibilities of making decisions.

Ethicists typically condemn paternalistic practices in the therapeutic relationship, but fail to investigate the features that incline physicians to be paternalistic. Such behavior may be one way to

assist persons whose autonomous behavior has been impaired by illness. Of course, it is an open moral question whether the constraints imposed by illness ought to be addressed in such a way. But only by coming to grips with the psychological and social dimensions of illness can we discuss how physicians can best respect persons who are patients.

### **Returning Control to Patients**

In the usual interpretation of respect for personal autonomy, noninterference is fundamental. In the medical setting, this means providing adequate information and competent care that accords with the patient's wishes. But if serious constraints upon autonomous behavior are intrinsic to the state of being ill, then noninterference is not the best course, since the patient's choices will be seriously limited. Under these conditions, real respect for autonomy entails a more inclusive understanding of the relationship between patients and physicians. Rather than restraining themselves so that patients can exercise whatever autonomy they retain in illness, physicians should actively seek to neutralize the impediments that interfere with patients' choices.

In *The Healer's Art*, Eric Cassell underscored the essential feature of illness that demands a revision in our understanding of respect for autonomy:

If I had to pick the aspect of illness that is most destructive to the sick, I would choose the loss of control. Maintaining control over oneself is so vital to all of us that one might see all the other phenomena of illness as doing harm not only in their own right but doubly so as they reinforce the sick person's perception that he is no longer in control.<sup>6</sup>

Cassell maintains, "The doctor's job is to return control to his patient." But what is involved in "returning control" to patients? Pellegrino identifies two elements that are preeminent duties of the physician: to provide technically competent care and to fully inform the patient. The noninterference approach emphasizes these factors, and their importance is clear. Loss of control in illness is precipitated by a physical or mental defect. If technically competent therapy can fully restore previous health, then the patient will again be in control. Consider a patient who is treated with antibiotics for a routine

throat infection of streptococcal origin. Similarly, loss of control is fueled by lack of knowledge—not knowing what is the matter, what it portends for life and limb, and how it might be dealt with. Providing information that will enable the patient to make decisions and adjust goals enhances personal control.

If physical and cognitive constraints were the only impediments to autonomous behavior, then Pellegrino's suggestions might be adequate. But providing information and technically competent care will not do much to alter psychological or social impediments. Pellegrino does not adequately portray the physician's role in ameliorating these.

How can the doctor offset the acute denial that prevented the adolescent patient from assessing the benefits and risk of intravenous feedings prior to his additional chemotherapy? How can he deal with the candidate for neurosurgery who clearly desired that attempts be made to restore his health, but feared cosmetic and functional impairments? Here strategies must go beyond the mere provision of information. Crucial information may have to be repeatedly shared with patients. Features of the situation that the patient has brushed over (as in denial) or falsely emphasized (as with acute anxiety) must be discussed in more detail or set in their proper perspective. And the physician may have to alter the tone of discussions with the patient, emphasizing a positive attitude with the overly depressed or anxious patient, or a more realistic, cautious attitude with the denying patient, in order to neutralize psychological constraints.

The physician may also need to influence the beliefs or attitudes of other people, such as family members, that limit their awareness of the patient's perspective. Such a strategy might have helped the parents of the dying child to conform with the patient's wishes. On the other hand, physicians may need to modify the patient's own understanding of the sick role. For example, they may need to convey that the choice of treatment depends not merely upon the physician's technical assessment, but on the quality of life and personal goals that the patient desires.

Once we admit that psychological and social constraints impair patient autonomy, it follows that physicians must carefully assess the psychological and social profiles and needs of patients. Thus, Pedro

Lain-Entralgo insists that adequate therapeutic interaction consists in a combination of "objectivity" and "cooperation." Cooperation "is shown by psychologically reproducing in the mind of the doctor, insofar as that is possible, the meaning the patient's illness has for him."<sup>7</sup> Without such knowledge, the physician cannot assist patients in restoring control over their lives. Ironically, some critics have insisted that physicians are not justified in acting for the well-being of patients because they possess no "expertise" in securing the requisite knowledge about the patient.<sup>8</sup> But knowledge of the patient's psychological and social situation is also necessary to help the patient to act as a fully autonomous person.

### **Beyond Legalism**

Current notions of respect for autonomy are undergirded by a legal model of doctor-patient interaction. The relationship is viewed as a typical commodity exchange—the provision of technically competent medical care in return for financial compensation. Moreover, physicians and patients are presumed to have an equal ability to work out the details of therapy, *provided that* certain moral rights of patients are recognized. But the compromising effects of illness, the superior knowledge of physicians, and various institutional arrangements are also viewed as giving the physician an unfair power advantage. Since the values and interests of patients may conflict with those of the physician, the emphasis is placed upon noninterference.<sup>9</sup>

This legal framework is insufficient for medical ethics because it fails to recognize the impact of illness upon autonomous behavior. Even if the rights to receive adequate information and to provide consent are secured, affective and social constraints impair the ability of patients to engage in contractual therapeutic relationships. When people are sick, the focus upon equality is temporally misplaced. The goal of the therapeutic relationship is the "development" of the patient—helping to resolve the underlying physical (or mental) defect, and to deal with cognitive, psychological, and social constraints in order to restore autonomous functioning. In this sense, the doctor-patient interaction is not unlike the parent-child or teacher-student relationship.

The legal model also falls short because the therapeutic relationship is not a typical commodity exchange in which the parties use each other to accomplish mutually compatible goals, without taking a direct interest in each other. Rather, the status of patients as persons whose autonomy is compromised constitutes the very stuff of therapeutic art. The physician is attempting to alter the fundamental ability of patients to carry through their life plans. To accomplish this delicate task requires a personal knowledge about and interest in the patient. If we accept these points, then we must reject the narrow focus of medical ethics upon noninterference and emphasize patterns of interaction that free patients from constraints upon autonomy.

I hasten to add that I am criticizing the legal model only as a *complete* moral framework for therapeutic interaction. As case studies in medical ethics suggest, physicians and patients *are* potential adversaries. Moreover, the disability of the patient and various institutional controls provide physicians with a distinct "power advantage" that can be abused. Thus, a legitimate function of medical ethics is to formulate conditions that assure noninterference in patient decision making. But various positive interventions must also be emphasized, since the central task in the therapeutic process is assisting patients to reestablish control over their own lives.

In the last analysis, the crucial matter is how we view the patient who enters into the therapeutic relationship. Cassell points out that in the typical view ". . . the sick person is seen simply as a well person with a disease, rather than as qualitatively different, not only physically but also socially, emotionally, and even cognitively." In this view, ". . . the physician's role in the care of the sick is primarily the application of technology . . . and health can be seen as a commodity."<sup>10</sup> But if, as I believe, illness renders sick persons "qualitatively different," then respect for personal autonomy requires a therapeutic interaction considerably more complex than the noninterference strategy.

Thus the current "Principles of Medical Ethics" simply exhort physicians to be honest. But the crucial requirement is that physicians tell the truth in a way, at a time, and in whatever increments are

necessary to allow patients to effectively use the information in adjusting their life plans.<sup>11</sup> Similarly, respecting a patient's refusal of treatment maximizes autonomy only if a balanced and thorough deliberation precedes the decision. Again, the "Principles" suggest that physicians observe strict confidentiality. But the more complex moral challenge is to use confidential information in a way that will help to give the patient more freedom. Thus, the doctor can keep a patient's report on family dynamics private, and still use it to modify attitudes or actions of family members that inhibit the patient's control.

At its root, illness is an evil primarily because it compromises our efforts to control our lives. Thus, we must preserve an understanding of the physician's art that transcends noninterference and addresses this fundamental reality.

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## Autonomy, Futility, and the Limits of Medicine

ROBERT L. SCHWARTZ

Does respecting the principle of autonomy require physicians to provide any treatment that an autonomous patient requests? Schwartz says that physicians are not obligated to give scientifically futile treatment (a worthless cancer therapy, for example). More importantly, neither are they morally required to provide treatment that is outside the scope of medical practice (such as surgical amputation of a limb for purely religious reasons). In many instances (including the famous Wanglie case), the central question was not whether the treatment requested by the patient was futile, but whether the treatment was beyond the proper limits of medicine. Schwartz contends that defining the scope of medicine should be left to physicians themselves.

SURGEON: I don't seem to understand; why, precisely, have you come to see me today?

PATIENT: I am here because I need to have my right arm amputated, and I have been told that you are one of the finest surgeons in town.

SURGEON: That is, of course, correct. Tell me, though—I do not see a referral here—what makes you think that you need your arm amputated?

PATIENT: It is the only way I can expiate my sins. I could describe those sins to you in detail, and I could tell you why this is the only way I can seek expiation, but that hardly seems appropriate or necessary. In any case, I am sure that the only way I can

expiate them is by having my right arm amputated.

SURGEON: Do I understand this? You came to see me because you want a good surgeon to amputate your right arm so that you can expiate your sins.

PATIENT: Exactly; I knew you would understand. By the way, I am fully insured.

SURGEON: Are you crazy? You've come to a surgeon just because you want your arm lopped off?

PATIENT: I would be crazy if I went any place else. I mean, you wouldn't recommend a butcher or a chiropractor, would you?

SURGEON: I'm sorry; your request is simply unacceptable. My values do not permit me to provide the services you seek. I just don't think it would be right.

PATIENT: Wait just a minute. I am not hiring you for your ability to make moral

judgments. I am hiring you because of your technical skill in removing limbs. We are talking about my arm, my life, and my values. I have decided I need the surgery and I ask you merely to respect my autonomy and to apply your medical skill so that my values can be served. If you want to expiate your sins in some other way, that's just fine with me. I don't want your religious and ethical peccadillos to interfere with a high-quality technical medical service that I am paying you to provide for me.

Most of us find the surgeon's surprise at this patient's request understandable, and it is hard to imagine any surgeon acceding to this patient's demand. On the other hand (the one left), the patient is right—the surgeon is denying his technical skill because his values are different from those of the patient, whose values the surgeon does not respect.<sup>1</sup> The autonomy of the patient is being limited by the values of the doctor whose own interests, other than his interest in practicing medicine according to his own ethical values, would remain unaffected by his decision to provide the service.

### **Autonomy and Patient Control of Medical Decision Making**

Autonomy is the authority to make decisions in accord with one's own values, unrestrained by the values of others who do not suffer the consequences of the decision. Ordinarily, the principle of autonomy authorizes patients to make healthcare decisions unrestrained by the values of their physicians, others in the healthcare industry, or the rest of society. Despite this, even the strongest supporters of the primacy of the principle of autonomy in healthcare decision making—even those who believe that autonomy virtually always trumps beneficence—would be likely to support (or even require) the surgeon's decision *not* to offer surgery in this case. But why?

The principle of autonomy has never been understood to authorize patients to choose from among an unrestricted range of alternatives. As Fenella Rouse points out in the next note on the *Wanglie* case, autonomy has often been misconstrued and

improperly applied by courts in cases involving medical decision making. In any case, there are at least three kinds of limitations on the exercise of autonomy by those making healthcare choices. First, patients may not require that they be treated by nonmedical means. Second, patients may not require that they be given scientifically futile treatment. Finally, and most significantly, patients may not require that they be treated in ways that are inconsistent with the ends of medicine, that is, in ways that are outside of the scope of medicine.

First, for example, a tense and depressed street-car operator is not denied autonomy by our healthcare system if he is not given the option of choosing three weeks on the beach in Tahiti as a cure for his condition, even though it may well be effective. Three weeks on the beach in Tahiti is simply not a medical means of treatment—it is not among the medical alternatives for the treatment of that (or any other) condition.

Second, where the issue is one of scientific futility, i.e., whether a medical procedure will have the scientific consequences that are expected, the issue is left entirely to the medical profession. Physicians are not required to prescribe pasque-flower tea for the treatment of cancer, for example, because, as a scientific matter, there is simply no efficacy in treatment by pasque-flower tea. From a purely scientific perspective, the treatment of cancer by pasque-flower tea really is futile.

Unlike beach rest, amputation is within the therapeutic arsenal of the medical profession; it is a medical procedure. Unlike pasque-flower tea as a cure for cancer, surgical amputation is a proven effective way of removing a limb; thus, it is not futile in a scientific sense. Despite this, though, we would not allow the patient in the opening vignette to demand that his arm be amputated because patients are not permitted to demand surgery that is inconsistent with the definition of the scope of medical practice accepted by the surgeon.<sup>2</sup> In their exercise of autonomy, patients may choose only from among reasonable medical alternatives. The hard question is how doctors, patients, and others define which medically and scientifically proven procedures are among the reasonable medical alternatives.

### The Wanglie Case

The limitations on a patient's autonomy to choose healthcare has come to the forefront of the bioethics debate over the past year. In December 1989, Helga Wanglie, an 87-year-old retired school teacher in Minneapolis, tripped on a rug in her home and fractured her hip.<sup>3</sup> One month later, after surgery in one hospital, she was transferred to Hennepin County Medical Center, where her doctors determined she needed assistance in breathing and placed her on a ventilator. Three months later, in May 1990, she was transferred to yet another hospital to see if she could be weaned from her ventilator. While there, she suffered cardiac arrest and was resuscitated, but only after she suffered severe and irreversible brain damage that put her in a persistent vegetative state. She was moved back to Hennepin County Medical Center, where she was maintained on a ventilator and fed through a gastrostomy tube. Mrs. Wanglie remained in a persistent vegetative state for several months before her physicians determined that the continuation of high-tech medical intervention was inappropriate. In essence, the doctors determined that the care Mrs. Wanglie was receiving was no longer among the reasonable medical alternatives for a person in her condition—it was, to her doctors, morally analogous to amputating a limb to expiate sins.

Mrs. Wanglie's husband and her two children disagreed. As Mrs. Wanglie's husband pointed out, "Only He who gave life has the right to take life." He also pointed out, "I am a pro-lifer. I take the position that human life is sacred."<sup>4</sup> He and the children agreed that Mrs. Wanglie would want treatment continued, even if the doctors believed that there were no chance of recovery. This was, as the family pointed out, a determination based on the patient's values, and there was no reason to defer to the doctors' collective ethical judgment.

The physicians and the hospital searched in vain for some healthcare facility in Minnesota that would be willing to take Mrs. Wanglie and continue to provide her care. None came forward. Frustrated by what they considered the continued inappropriate use of medicine, the hospital sought a court order appointing a conservator to replace Mr. Wanglie to make healthcare decisions for Mrs. Wanglie. On 1

July 1991, the trial court judge refused to issue an order and effectively confirmed Mr. Wanglie's right to continue to make healthcare decisions for his wife of 53 years.<sup>5</sup> Three days after the order was issued, Mrs. Wanglie died "of natural causes." Her hospitalization cost nearly 1 million dollars, which was paid by Medicare and her private medigap insurance carrier. Neither objected to the care for financial or cost-benefit reasons, and the cost properly did not enter into the judicial analysis of the case.

### Asking the Wrong Question: Substitute Decision Makers and the Wanglie Court

Unfortunately, the litigation in this case obscured the real issue. The hospital's decision to seek a conservatorship did nothing more than raise the issue of whether Mr. Wanglie was the best decision maker for his wife. The lawsuit asked nothing more than whether Mr. Wanglie was the most able to apply his wife's values to the medical facts in this case.<sup>6</sup> Indeed, the hospital supplied no evidence that anyone else would be more likely to be able to determine and apply Mrs. Wanglie's values. To the extent that the litigation focused on how best to carry to fruition Mrs. Wanglie's autonomy, not on the limits of that autonomy, the hospital was left without a prayer of success.

The real question, however, should not have been what Mrs. Wanglie would have desired (or what was in her "best personal medical interest")—there was no reason to doubt her family on that point—but whether the continuation of ventilator support and gastrostomy feeding were among the reasonable medical alternatives that should have been available to Mrs. Wanglie or her surrogate decision maker, whoever that might be. The question, really, was whether the provision of this kind of treatment in this kind of case was outside the limits of medicine and, thus, beyond her power of choice.

Mrs. Wanglie's healthcare providers should have argued that medical practice simply did not include providing a ventilator and gastrostomy feeding under circumstances of this case, and that no surrogate decision maker—whether it be Mr. Wanglie or another substituted by the court—should be able to choose this option. If, for example, Mr. Wanglie requested that his wife be frozen and cryopreserved so that she could be brought back to life and "cured"

when there were sufficient advances in the science of her underlying ailments, there is no doubt that this request would not have to be honored by Mrs. Wanglie's medical team. A request for cryopreservation, like a request for surgery that a patient believes will expiate his sins, may well reflect the true desires of the patient, but it is a request that asks something that is beyond the limits of medicine.<sup>7</sup> Why is the Wanglie family request in this case any different? The real question in the *Wanglie* case was whether the continuation of life-sustaining treatment for an 87-year-old woman in a persistent vegetative state with no hope of return to sentience constitutes treatment outside of the limits of medicine.

Although the question of the propriety of treatment for Mrs. Wanglie has been discussed as if it were a question of "futility," there is no doubt that the treatment was *not* futile in the purely scientific sense. The treatment was designed to keep Mrs. Wanglie alive, and it served this end effectively. Those who have viewed the *Wanglie* case as one dealing with futility in a scientific sense have brought the wrong perspective to the case. The question is not whether the treatment offered would successfully do what Mrs. Wanglie's family said she desired—keep her alive—but whether keeping her alive, under the circumstances, was beyond the proper scope of medicine. Like most questions in medicine, this is not purely a question of science or a question of values, but a hybrid question.

### **The Role of the Physician in Healthcare Decision Making**

Even when the question is not a purely scientific one, even when it involves a determination of whether medical treatment justifies the quality of life that results, our society has generally left to physicians the determination of whether a particular treatment is among the reasonable medical alternatives. There are, of course, problems with this approach.<sup>8</sup> Why should physicians have the exclusive authority to define the extent of their own professional conduct? Does this lead to too much variation from doctor to doctor and from hospital to hospital? Could doctors decide that providing treatment to HIV-positive patients is beyond the limits of medicine? Leaving the question of what

constitutes a reasonable medical alternative in the hands of Dr. Kevorkian yields a very different result than leaving that same question in the hands of the doctors who are associated with the right-to-life movement. As the national debate over euthanasia has demonstrated, doctors disagree over the appropriate scope of medicine with as much vigor, and probably with more concern, than the rest of us.

In the end, though, that is exactly why these decisions should be left to physicians. If a patient who desires a particular course of treatment can find a healthcare provider—*any* healthcare provider—who believes that the proposed course of treatment is within the realm of reasonable medical alternatives, that patient will have access to that course of treatment. It is only when a patient desires treatment that not a single healthcare provider believes to be within the limits of medicine that the patient will be denied that course of treatment. If a patient seeks amputation for the expiation of sins, for example, it is unlikely that the patient will find any surgeon willing to perform the task. When there is universal agreement among healthcare providers that the patient's request seeks something beyond the limits of medicine, that should constitute very strong evidence that the request is inappropriate.

The Wanglie family could not find any healthcare provider in Minnesota who would offer the medical services the family thought appropriate. Although the technical services that were sought (the ventilator, for example) were clearly within the scope of medical practice, there was no healthcare provider in Minnesota who believed that the provision of those services in Mrs. Wanglie's circumstance was within the range of reasonable medical alternatives—at least, no one who was capable of providing the services was willing to do so. In effect, the court required Hennepin County Medical Center to provide a service that was, in the universal conclusion of Minnesota healthcare providers, inappropriate.

### **Asking the Right Question: The Courts and Ethics Committees**

Courts focus only on the best way to serve the autonomy of patients; after all, the courts are largely responsible for making the principle of autonomy the guiding principle for medical decision-making.

The *Wanglie* court was simply unable to get beyond the question of who could best identify the values and interests of the patient and move on to the question of whether the proposed treatment was within the limits of medicine. The court did not decide that continued use of the ventilator and the continued gastrostomy feedings were reasonable medical alternatives for Mrs. Wanglie; it did not address these questions at all. Similarly, in October 1991, an Atlanta judge finessed the same issue in just the same way when she determined in the *Jane Doe* case that a 13-year-old with a degenerative neurologic condition must be continued on a treatment dictated by her father, who believed in miracles, despite the testimony of her pediatric neurologist that it was "ethically and morally unconscionable" to do so.<sup>4</sup>

If the courts continue to miss the real issue in these cases, as they will, that issue will have to be addressed in some other forum where there is both the moral and medical sophistication to understand the limits of medicine and the sensitivity to understand (and help define) society's reasonable expectations of medicine. Within their roles as educators, as mediators, and as sources for discussion of exactly these questions, broadly interdisciplinary ethics committees seem particularly well suited to the task. When a court is forced to face a determination by such a committee that a particular treatment, in a particular case, is beyond the limits of medicine—even though this treatment is exactly what the patient desires, even though the treatment employs a clearly medical procedure, and even though the treatment is not scientifically futile—that court may be forced to take the real question seriously.

#### NOTES

1. One might argue that the surgeon's only real concern is over the competency of the patient, but there is no reason outside of this medical request itself to question that competency. Indeed, we accept the fact that competent people can make unusual requests—requests that the vast majority of us find strange—and still be competent. We are even more likely to find unusual behavior (such as various kinds of abstinence and abnegation) consistent with competence when the behavior is religious, or quasi-religious, as it is here. In any case, there is very little left to any meaningful notion of competence if we determine a patient's competence to choose a particular form of treatment solely by reference to the treatment choice he makes.

2. Analogously, the American Medical Association has found it unacceptable to have physicians administer lethal doses of drugs to execute condemned prisoners, even if the condemned prisoners request the administration of the drugs because the alternative methods of execution are more painful or degrading. Although the administration of the relevant drugs is appropriately limited to physicians, their use *for this purpose* is simply outside of the scope of medicine, whatever the prisoner-patient may desire.

3. A great deal has been written about the *Wanglie* case. Several relevant articles are found in the July–August 1991 issue of the *Hastings Center Report*, which includes a summary of the facts prepared by Ronald Cranford of the Department of Neurology at the hospital in which Mrs. Wanglie remained a patient at her death. The facts are fleshed out in various newspaper articles: Colen. Fight over life. *Newsday* (1991 Jan. 29): City p. 57; Belkin. As family protests, hospital seeks an end to woman's life support. *New York Times* (1991 Jan. 10): Sec. A, p. 1; Steinbrook Hospital or family: who decides right to die? *Los Angeles Times* (1991 Feb. 17): Part A, p. 1.

4. See note 3. Colen (1991): 57.

5. *Conservatorship of Wanglie*, No. PX-91-283 (Minn., Hennepin Co. Dist. Ct., July 1, 1991).

6. The hospital argued that Mr. Wanglie should be disqualified from making the decision for his wife because his decision was not in the "patient's best personal medical interest." Cranford. Helga Wanglie's ventilator. *Hastings Center Report* (1991; Jul.–Aug.): 23–4.

7. The courts have been unsympathetic to those who seek cryopreservation, as you might guess. For a description of the case of Thomas Donaldson, who did not convince a court to allow the removal and freezing of his head before his certain death from a brain tumor, see Corwin. Tumor victim loses bid to freeze head before death. *Los Angeles Times* (1990 Sept. 15): Sec. A, p. 28. As one might expect, the case was subsequently turned into an episode of *L.A. Law* (#7Do8, copyright 1990).

8. To the extent these problems flow from the use of a "futility" exception to normal requirements of consent, they are cogently and thoughtfully expressed in Scofield. Is consent useful when resuscitation isn't. *Hastings Center Report* (1991; Nov.–Dec.): 28–6. As Scofield points out (in the context of CPR):

In reality the futility exception is a dishonest solution to the tragic choice that decisions to limit treatment represent. It purports to represent, but in fact departs from the fundamental values consent is intended to serve. It will not generate the conversation we need if we are to attain consensus about limiting treatment; nor will it make physicians sensitive in their dealings with patients, especially dying patients. It promotes a model of consent that is antithetical to setting limits in a democratic, caring manner. (p. 30)

9. Colen. Judge bars letting girl in coma die. *Newsday* (1991 Oct. 18): News p. 4.1.

## Four Models of the Physician-Patient Relationship

EZEKIEL J. EMANUEL AND LINDA L. EMANUEL

The Emanuels outline four ways that the physician–patient relationship could be arranged based on different understandings of (1) the goals of physician–patient interaction, (2) the physician’s obligations, (3) the patient’s values, and (4) the moral principle of patient autonomy. They discuss four models of physician–patient interaction, which they call the paternalistic, the informative, the interpretive, and the deliberative. They identify the advantages of each model and examine possible objections, ultimately arguing for the deliberative model, in which “the aim of the physician–patient interaction is to help the patient determine and choose the best health-related values that can be realized in the clinical situation.” In this approach, “the physician acts as a teacher or friend, engaging the patient in dialogue on what course of action would be best. Not only does the physician indicate what the patient could do, but, knowing the patient and wishing what is best, the physician indicates what the patient should do, what decision regarding medical therapy would be admirable.”

During the last two decades or so, there has been a struggle over the patient’s role in medical decision making that is often characterized as a conflict between autonomy and health, between the values of the patient and the values of the physician. Seeking to curtail physician dominance, many have advocated an ideal of greater patient control.<sup>1,2</sup> Others question this ideal because it fails to acknowledge the potentially imbalanced nature of this interaction when one party is sick and searching for security, and when judgments entail the interpretation of technical information.<sup>3,4</sup> Still others are trying to delineate a more mutual relationship.<sup>5,6</sup> This struggle shapes the expectations of physicians and patients as well as the ethical and legal standards for the physician’s duties, informed consent, and medical malpractice. This struggle forces us to ask, What should be the ideal physician–patient relationship?

We shall outline four models of the physician–patient interaction, emphasizing the different understandings of (1) the goals of the physician–patient interaction, (2) the physician’s obligations, (3) the

role of patient values, and (4) the conception of patient autonomy. To elaborate the abstract description of these four models, we shall indicate the types of response the models might suggest in a clinical situation. Third, we shall also indicate how these models inform the current debate about the ideal physician–patient relationship. Finally, we shall evaluate these models and recommend one as the preferred model.

As outlined, the models are Weberian ideal types. They may not describe any particular physician–patient interactions but highlight, free from complicating details, different visions of the essential characteristics of the physician–patient interaction.<sup>7</sup> Consequently, they do not embody minimum ethical or legal standards, but rather constitute regulative ideals that are “higher than the law” but not “above the law.”<sup>8</sup>

### The Paternalistic Model

First is the *paternalistic* model, sometimes called the parental<sup>9</sup> or priestly<sup>10</sup> model. In this model, the physician–patient interaction ensures that patients receive the interventions that best promote their health and well-being. To this end, physicians use their skills to determine the patient’s medical condition and his

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or her stage in the disease process and to identify the medical tests and treatments most likely to restore the patient's health or ameliorate pain. Then the physician presents the patient with selected information that will encourage the patient to consent to the intervention the physician considers best. At the extreme, the physician authoritatively informs the patient when the intervention will be initiated.

The paternalistic model assumes that there are shared objective criteria for determining what is best. Hence the physician can discern what is in the patient's best interest with limited patient participation. Ultimately, it is assumed that the patient will be thankful for decisions made by the physician even if he or she would not agree to them at the time.<sup>11</sup> In the tension between the patient's autonomy and well-being, between choice and health, the paternalistic physician's main emphasis is toward the latter.

In the paternalistic model, the physician acts as the patient's guardian, articulating and implementing what is best for the patient. As such, the physician has obligations, including that of placing the patient's interest above his or her own and soliciting the views of others when lacking adequate knowledge. The conception of patient autonomy is patient assent, either at the time or later, to the physician's determinations of what is best.

### **The Informative Model**

Second is the *informative* model, sometimes called the scientific,<sup>9</sup> engineering,<sup>10</sup> or consumer model. In this model, the objective of the physician-patient interaction is for the physician to provide the patient with all relevant information, for the patient to select the medical interventions he or she wants, and for the physician to execute the selected interventions. To this end, the physician informs the patient of his or her disease state, the nature of possible diagnostic and therapeutic interventions, the nature and probability of risks and benefits associated with the interventions, and any uncertainties of knowledge. At the extreme, patients could come to know all medical information relevant to their disease and available interventions and select the interventions that best realize their values.

The informative model assumes a fairly clear distinction between facts and values. The patient's

values are well defined and known; what the patient lacks is facts. It is the physician's obligation to provide all the available facts, and the patient's values then determine what treatments are to be given. There is no role for the physician's values, the physician's understanding of the patient's values, or his or her judgment of the worth of the patient's values. In the informative model, the physician is a purveyor of technical expertise, providing the patient with the means to exercise control. As technical experts, physicians have important obligations to provide truthful information, to maintain competence in their area of expertise, and to consult others when their knowledge or skills are lacking. The conception of patient autonomy is patient control over medical decision making.

### **The Interpretive Model**

The third model is the *interpretive* model. The aim of the physician-patient interaction is to elucidate the patient's values and what he or she actually wants, and to help the patient select the available medical interventions that realize these values. Like the informative physician, the interpretive physician provides the patient with information on the nature of the condition and the risks and benefits of possible interventions. Beyond this, however, the interpretive physician assists the patient in elucidating and articulating his or her values and in determining what medical interventions best realize the specified values, thus helping to interpret the patient's values for the patient.

According to the interpretive model, the patient's values are not necessarily fixed and known to the patient. They are often inchoate, and the patient may only partially understand them; they may conflict when applied to specific situations. Consequently, the physician working with the patient must elucidate and make coherent these values. To do this, the physician works with the patient to reconstruct the patient's goals and aspirations, commitments and character. At the extreme, the physician must conceive the patient's life as a narrative whole, and from this specify the patient's values and their priority.<sup>12,13</sup> Then the physician determines which tests and treatments best realize these values. Importantly, the physician does not dictate to the

### Comparing the Four Models

	<b>Informative</b>	<b>Interpretive</b>	<b>Deliberative</b>	<b>Paternalistic</b>
Patient values	Defined, fixed, and known to the patient	Inchoate and conflicting, requiring elucidation	Open to development and revision through moral discussion	Objective and shared by physician and patient
Physician's obligation	Providing relevant factual information and implementing patient's selected intervention	Elucidating and interpreting relevant patient values as well as informing the patient and implementing the patient's selected intervention	Articulating and persuading the patient of the most admirable values as well as informing the patient and implementing the patient's selected intervention	Promoting the patient's well-being independent of the patient's current preferences
Conception of patient's autonomy	Choice of, and control over, medical care	Self-understanding relevant to medical care	Moral self-development relevant to medical care	Assenting to objective values
Conception of physician's role	Competent technical expert	Counselor or adviser	Friend or teacher	Guardian

patient; it is the patient who ultimately decides which values and course of action best fit who he or she is. Neither is the physician judging the patient's values; he or she helps the patient to understand and use them in the medical situation.

In the interpretive model, the physician is a counselor, analogous to a cabinet minister's advisory role to a head of state, supplying relevant information, helping to elucidate values and suggesting what medical interventions realize these values. Thus the physician's obligations include those enumerated in the informative model but also require engaging the patient in a joint process of understanding. Accordingly, the conception of patient autonomy is self-understanding; the patient comes to know more clearly who he or she is and how the various medical options bear on his or her identity.

#### The Deliberative Model

Fourth is the *deliberative* model. The aim of the physician-patient interaction is to help the patient determine and choose the best health-related values that can be realized in the clinical situation. To this end, the physician must delineate information on the patient's clinical situation and then help

elucidate the types of values embodied in the available options. The physician's objectives include suggesting why certain health-related values are more worthy and should be aspired to. At the extreme, the physician and patient engage in deliberation about what kind of health-related values the patient could and ultimately should pursue. The physician discusses only health-related values, that is, values that affect or are affected by the patient's disease and treatments; he or she recognizes that many elements of morality are unrelated to the patient's disease or treatment and beyond the scope of their professional relationship. Further, the physician aims at no more than moral persuasion; ultimately, coercion is avoided, and the patient must define his or her life and select the ordering of values to be espoused. By engaging in moral deliberation, the physician and patient judge the worthiness and importance of the health-related values.

In the deliberative model, the physician acts as a teacher or friend,<sup>14</sup> engaging the patient in dialogue on what course of action would be best. Not only does the physician indicate what the patient could do, but, knowing the patient and wishing what is best, the physician indicates what the patient should

do, what decision regarding medical therapy would be admirable. The conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness, and their implications for treatment.

### Comparing the Four Models

The Table compares the four models on essential points. Importantly, all models have a role for patient autonomy; a main factor that differentiates the models is their particular conceptions of patient autonomy. Therefore, no single model can be endorsed because it alone promotes patient autonomy. Instead the models must be compared and evaluated, at least in part, by evaluating the adequacy of their particular conceptions of patient autonomy.

The four models are not exhaustive. At a minimum there might be added a fifth: the *instrumental* model. In this model, the patient's values are irrelevant; the physician aims for some goal independent of the patient, such as the good of society or furtherance of scientific knowledge. The Tuskegee syphilis experiment<sup>15–17</sup> and the Willowbrook hepatitis study<sup>18,19</sup> are examples of this model. As the moral condemnation of these cases reveals, this model is not an ideal but an aberration. Thus we have not elaborated it herein.

### A Clinical Case

To make tangible these abstract descriptions and to crystallize essential differences among the models, we will illustrate the responses they suggest in a clinical situation, that of a 43-year-old premenopausal woman who has recently discovered a breast mass. Surgery reveals a 3.5-cm ductal carcinoma with no lymph node involvement that is estrogen receptor positive. Chest roentgenogram, bone scan, and liver function tests reveal no evidence of metastatic disease. The patient was recently divorced and has gone back to work as a legal aide to support herself. What should the physician say to this patient?

In the paternalistic model a physician might say, "There are two alternative therapies to protect against recurrence of cancer in your breast: mastectomy or radiation. We now know that the survival

with lumpectomy combined with radiation therapy is equal to that with mastectomy. Because lumpectomy and radiation offers the best survival and the best cosmetic result, it is to be preferred. I have asked the radiation therapist to come and discuss radiation treatment with you. We also need to protect you against the spread of the cancer to other parts of your body. Even though the chance of recurrence is low, you are young, and we should not leave any therapeutic possibilities untried. Recent studies involving chemotherapy suggest improvements in survival without recurrence of breast cancer. Indeed, the National Cancer Institute recommends chemotherapy for women with your type of breast cancer. Chemotherapy has side effects. Nevertheless, a few months of hardship now are worth the potential added years of life without cancer."

In the informative model a physician might say, "With node-negative breast cancer there are two issues before you: local control and systemic control. For local control, the options are mastectomy or lumpectomy with or without radiation. From many studies we know that mastectomy and lumpectomy with radiation result in identical overall survival, about 80% 10-year survival. Lumpectomy without radiation results in a 30% to 40% chance of tumor recurrence in the breast. The second issue relates to systemic control. We know that chemotherapy prolongs survival for premenopausal women who have axillary nodes involved with tumor. The role for women with node-negative breast cancer is less clear. Individual studies suggest that chemotherapy is of no benefit in terms of improving overall survival, but a comprehensive review of all studies suggests that there is a survival benefit. Several years ago, the NCI suggested that for women like yourself, chemotherapy can have a positive therapeutic impact. Finally, let me inform you that there are clinical trials, for which you are eligible, to evaluate the benefits of chemotherapy for patients with node-negative breast cancer. I can enroll you in a study if you want. I will be happy to give you any further information you feel you need."

The interpretive physician might outline much of the same information as the informative physician, then engage in discussion to elucidate the patient's wishes, and conclude, "It sounds to me as if you have

conflicting wishes. Understandably, you seem uncertain how to balance the demands required for receiving additional treatment, rejuvenating your personal affairs, and maintaining your psychological equilibrium. Let me try to express a perspective that fits your position. Fighting your cancer is important, but it must leave you with a healthy self-image and quality time outside the hospital. This view seems compatible with undergoing radiation therapy but not chemotherapy. A lumpectomy with radiation maximizes your chance of surviving while preserving your breast. Radiotherapy fights your breast cancer without disfigurement. Conversely, chemotherapy would prolong the duration of therapy by many months. Further, the benefits of chemotherapy in terms of survival are smaller and more controversial. Given the recent changes in your life, you have too many new preoccupations to undergo months of chemotherapy for a questionable benefit. Do I understand you? We can talk again in a few days."

The deliberative physician might begin by outlining the same factual information, engage in a conversation to elucidate the patient's values, but continue, "It seems clear that you should undergo radiation therapy. It offers maximal survival with minimal risk, disfigurement, and disruption of your life. The issue of chemotherapy is different, fraught with conflicting data. Balancing all the options, I think the best one for you is to enter a trial that is investigating the potential benefit of chemotherapy for women with node-negative breast cancer. First, it ensures that you receive excellent medical care. At this point, we do not know which therapy maximizes survival. In a clinical study the schedule of follow-up visits, tests, and decisions is specified by leading breast cancer experts to ensure that all the women receive care that is the best available anywhere. A second reason to participate in a trial is altruistic; it allows you to contribute something to women with breast cancer in the future who will face difficult choices. Over decades, thousands of women have participated in studies that inform our current treatment practices. Without those women, and the knowledge they made possible, we would probably still be giving you and all other women with breast cancer mastectomies. By enrolling in a trial you participate in a tradition in

which women of one generation receive the highest standard of care available but also enhance the care of women in future generations because medicine has learned something about which interventions are better. I must tell you that I am not involved in the study; if you elect to enroll in this trial, you will initially see another breast cancer expert to plan your therapy. I have sought to explain our current knowledge and offer my recommendation so you can make the best possible decision."

Lacking the normal interchange with patients, these statements may seem contrived, even caricatures. Nevertheless, they highlight the essence of each model and suggest how the objectives and assumptions of each inform a physician's approach to his or her patients. Similar statements can be imagined for other clinical situations such as an obstetrician discussing prenatal testing or a cardiologist discussing cholesterol-reducing interventions.

### **The Current Debate and the Four Models**

In recent decades there has been a call for greater patient autonomy or, as some have called it, "patient sovereignty,"<sup>20</sup> conceived as patient *choice* and *control* over medical decisions. This shift toward the informative model is embodied in the adoption of business terms for medicine, as when physicians are described as health care providers and patients as consumers. It can also be found in the propagation of patient rights statements,<sup>21</sup> in the promotion of living will laws, and in rules regarding human experimentation. For instance, the opening sentences of one law state: "The Rights of the Terminally Ill Act authorizes an adult person to *control* decisions regarding administration of life-sustaining treatment. . . . The Act merely provides one way by which a terminally-ill patient's *desires* regarding the use of life-sustaining procedures can be legally implemented" (emphasis added).<sup>22</sup> Indeed, living will laws do not require or encourage patients to discuss the issue of terminating care with their physicians before signing such documents. Similarly, decisions in "right-to-die" cases emphasize patient control over medical decisions. As one court put it<sup>23</sup>:

The right to refuse medical treatment is basic and fundamental. . . . Its exercise requires no one's approval. . . . [T]he controlling decision belongs to a

*competent informed patient. . . It is not a medical decision for her physicians to make. . . It is a moral and philosophical decision that, being a competent adult, is [the patient's] alone.* (emphasis added)

Probably the most forceful endorsement of the informative model as the ideal inheres in informed consent standards. Prior to the 1970s, the standard for informed consent was “physician based.”<sup>24–26</sup> Since 1972 and the *Canterbury* case, however, the emphasis has been on a “patient-oriented” standard of informed consent in which the physician has a “duty” to provide appropriate medical facts to empower the patient to use his or her values to determine what interventions should be implemented.<sup>25–27</sup>

True consent to what happens to one’s self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. . . . *[I]t is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie.* To enable the patient to chart his course understandably, some familiarity with the therapeutic alternatives and their hazards becomes essential.<sup>27</sup> (emphasis added)

### Shared Decision Making

Despite its dominance, many have found the informative model “arid.”<sup>28</sup> The President’s Commission and others contend that the ideal relationship does not vest moral authority and medical decision-making power exclusively in the patient but must be a process of shared decision making constructed around “mutual participation and respect.”<sup>28,29</sup> The President’s Commission argues that the physician’s role is “to help the patient understand the medical situation and available courses of action, and the patient conveys his or her concerns and wishes.”<sup>29</sup> Brock and Wartman<sup>29</sup> stress this fact-value “division of labor”—having the physician provide information while the patient makes value decisions—by describing “shared decision making” as a collaborative process

in which both physicians and patients make active and essential contributions. Physicians bring their medical training, knowledge, and expertise—including an understanding of the available

treatment alternatives—to the diagnosis and management of patients’ condition. Patients bring knowledge of their own subjective aims and values, through which risks and benefits of various treatment options can be evaluated. With this approach, selecting the best treatment for a particular patient requires the contribution of both parties.

Similarly, in discussing ideal medical decision making, Eddy<sup>30</sup> argues for this fact-value division of labor between the physician and patient as the ideal:

It is important to separate the decision process into these two steps. . . . The first step is a question of facts. The anchor is empirical evidence. . . . [T]he second step is a question not of facts but of personal values or preferences. The thought process is not analytic but personal and subjective. . . . [I]t is the patient’s preferences that should determine the decision. . . . Ideally, you and I [the physicians] are not in the picture. What matters is what Mrs. Smith thinks.

This view of shared decision making seems to vest the medical decision-making authority with the patient while relegating physicians to technicians “transmitting medical information and using their technical skills as the patient directs.”<sup>29</sup> Thus, while the advocates of “shared decision making” may aspire toward a mutual dialogue between physician and patient, the substantive view informing their ideal reembodies the informative model under a different label.

Other commentators have articulated more mutual models of the physician-patient interaction.<sup>5,6,25</sup> Prominent among these efforts is Katz<sup>31</sup> *The Silent World of the Doctor and Patient*. Relying on a Freudian view in which self-knowledge and self-determination are inherently limited because of unconscious influences, Katz views dialogue as a mechanism for greater self-understanding of one’s values and objectives. According to Katz, this view places a duty on physicians and patients to reflect and communicate so that patients can gain a greater self-understanding and self-determination. Katz’ insight is also available on grounds other than Freudian psychological theory and is consistent with the interpretive model.<sup>13</sup>

### **Objections to the Paternalistic Model**

It is widely recognized that the paternalistic model is justified during emergencies when the time taken to obtain informed consent might irreversibly harm the patient.<sup>1,2,20</sup> Beyond such limited circumstances, however, it is no longer tenable to assume that the physician and patient espouse similar values and views of what constitutes a benefit. Consequently, even physicians rarely advocate the paternalistic model as an ideal for routine physician-patient interactions.<sup>32</sup>

### **Objections to the Informative Model**

The informative model seems both descriptively and prescriptively inaccurate. First, this model seems to have no place for essential qualities of the ideal physician-patient relationship. The informative physician cares for the patient in the sense of competently implementing the patient's selected interventions. However, the informative physician lacks a caring approach that requires understanding what the patient values or should value and how his or her illness impinges on these values. Patients seem to expect their physician to have a caring approach; they deem a technically proficient but detached physician as deficient, and properly condemned. Further, the informative physician is proscribed from giving a recommendation for fear of imposing his or her will on the patient and thereby competing for the decision-making control that has been given to the patient.<sup>25</sup> Yet, if one of the essential qualities of the ideal physician is the ability to assimilate medical facts, prior experience of similar situations, and intimate knowledge of the patient's view into a recommendation designed for the patient's specific medical and personal condition,<sup>3-5,25</sup> then the informative physician cannot be ideal.

Second, in the informative model the ideal physician is a highly trained subspecialist who provides detailed factual information and competently implements the patient's preferred medical intervention. Hence, the informative model perpetuates and accentuates the trend toward specialization and impersonalization within the medical profession.

Most importantly, the informative model's conception of patient autonomy seems philosophically untenable. The informative model presupposes that

persons possess known and fixed values, but this is inaccurate. People are often uncertain about what they actually want. Further, unlike animals, people have what philosophers call "second order desires,"<sup>33-35</sup> that is, the capacity to reflect on their wishes and to revise their own desires and preferences. In fact, freedom of the will and autonomy inhere in having "second order desires" and being able to change our preferences and modify our identity. Self-reflection and the capacity to change what we want often require a "process" of moral deliberation in which we assess the value of what we want. And this is a process that occurs with other people who know us well and can articulate a vision of who we ought to be that we can assent to.<sup>13</sup> Even though changes in health or implementation of alternative interventions can have profound effects on what we desire and how we realize our desires, self-reflection and deliberation play no essential role in the informative physician-patient interaction. The informative model's conception of autonomy is incompatible with a vision of autonomy that incorporates second-order desires.

### **Objections to the Interpretive Model**

The interpretive model rectifies this deficiency by recognizing that persons have second-order desires and dynamic value structures and placing the elucidation of values in the context of the patient's medical condition at the center of the physician-patient interaction. Nevertheless, there are objections to the interpretive model.

Technical specialization militates against physicians cultivating the skills necessary to the interpretive model. With limited interpretive talents and limited time, physicians may unwittingly impose their own values under the guise of articulating the patient's values. And patients, overwhelmed by their medical condition and uncertain of their own views, may too easily accept this imposition. Such circumstances may push the interpretive model toward the paternalistic model in actual practice.

Further, autonomy viewed as self-understanding excludes evaluative judgment of the patient's values or attempts to persuade the patient to adopt other values. This constrains the guidance and recommendations the physician can offer. Yet in practice,

especially in preventive medicine and risk-reduction interventions, physicians often attempt to persuade patients to adopt particular health-related values. Physicians frequently urge patients with high cholesterol levels who smoke to change their dietary habits, quit smoking, and begin exercise programs before initiating drug therapy. The justification given for these changes is that patients should value their health more than they do. Similarly, physicians are encouraged to persuade their human immunodeficiency virus (HIV)-infected patients who might be engaging in unsafe sexual practices either to abstain or, realistically, to adopt “safer sex” practices. Such appeals are not made to promote the HIV-infected patient’s own health, but are grounded on an appeal for the patient to assume responsibility for the good of others. Consequently, by excluding evaluative judgments, the interpretive model seems to characterize inaccurately ideal physician-patient interactions.

### **Objections to the Deliberative Model**

The fundamental objections to the deliberative model focus on whether it is proper for physicians to judge patients’ values and promote particular health-related values. First, physicians do not possess privileged knowledge of the priority of health-related values relative to other values. Indeed, since ours is a pluralistic society in which people espouse incommensurable values, it is likely that a physician’s values and view of which values are higher will conflict with those of other physicians and those of his or her patients.

Second, the nature of the moral deliberation between physician and patient, the physician’s recommended interventions, and the actual treatments used will depend on the values of the particular physician treating the patient. However, recommendations and care provided to patients should not depend on the physician’s judgment of the worthiness of the patient’s values or on the physician’s particular values. As one bioethicist put it:<sup>36</sup>

The hand is broken; the physician can repair the hand; therefore the physician must repair the hand—as well as possible—with regard to personal values that might lead the physician to think ill of the patient or of the patient’s values. . . . [A]t

the level of clinical practice, medicine should be value-free in the sense that the personal values of the physician should not distort the making of medical decisions.

Third, it may be argued that the deliberative model misconstrues the purpose of the physician-patient interaction. Patients see their physicians to receive health care, not to engage in moral deliberation or to revise their values. Finally, like the interpretive model, the deliberative model may easily metamorphose into unintended paternalism, the very practice that generated the public debate over the proper physician-patient interaction.

### **The Preferred Model and the Practical Implications**

Clearly, under different clinical circumstances different models may be appropriate. Indeed, at different times all four models may justifiably guide physicians and patients. Nevertheless, it is important to specify one model as the shared, paradigmatic reference; exceptions to use other models would not be automatically condemned, but would require justification based on the circumstances of a particular situation. Thus, it is widely agreed that in an emergency where delays in treatment to obtain informed consent might irreversibly harm the patient, the paternalistic model correctly guides physician-patient interactions. Conversely, for patients who have clear but conflicting values, the interpretive model is probably justified. For instance, a 65-year-old woman who has been treated for acute leukemia may have clearly decided against reinduction chemotherapy if she relapses. Several months before the anticipated birth of her first grandchild, the patient relapses. The patient becomes torn about whether to endure the risks of reinduction chemotherapy in order to live to see her first grandchild or whether to refuse therapy, resigning herself to not seeing her grandchild. In such cases, the physician may justifiably adopt the interpretive approach. In other circumstances, where there is only a one-time physician-patient interaction without an ongoing relationship in which the patient’s values can be elucidated and compared with ideals, such as in a walk-in center, the informative model may be justified.

Descriptively and prescriptively, we claim that the ideal physician-patient relationship is the deliberative model. We will adduce six points to justify this claim. First, the deliberative model more nearly embodies our ideal of autonomy. It is an oversimplification and distortion of the Western tradition to view respecting autonomy as simply permitting a person to select, unrestricted by coercion, ignorance, physical interference, and the like, his or her preferred course of action from a comprehensive list of available options.<sup>34,35</sup> Freedom and control over medical decisions alone do not constitute patient autonomy. Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the values. The process of deliberation integral to the deliberative model is essential for realizing patient autonomy understood in this way.

Second, our society's image of an ideal physician is not limited to one who knows and communicates to the patient relevant factual information and competently implements medical interventions. The ideal physician—often embodied in literature, art, and popular culture—is a caring physician who integrates the information and relevant values to make a recommendation and, through discussion, attempts to persuade the patient to accept this recommendation as the intervention that best promotes his or her overall well-being. Thus, we expect the best physicians to engage their patients in evaluative discussions of health issues and related values. The physician's discussion does not invoke values that are unrelated or tangentially related to the patient's illness and potential therapies. Importantly, these efforts are not restricted to situations in which patients might make "irrational and harmful" choices<sup>29</sup> but extend to all health care decisions.

Third, the deliberative model is not a disguised form of paternalism. Previously there may have been category mistakes in which instances of the deliberative model have been erroneously identified as physician paternalism. And no doubt, in practice, the deliberative physician may occasionally lapse into paternalism. However, like the ideal teacher, the deliberative physician attempts to *persuade* the

patient of the worthiness of certain values, not to *impose* those values paternalistically; the physician's aim is not to subject the patient to his or her will, but to persuade the patient of a course of action as desirable. In the *Laws*, Plato<sup>37</sup> characterizes this fundamental distinction between persuasion and imposition for medical practice that distinguishes the deliberative from the paternalistic model:

A physician to slaves never gives his patient any account of his illness . . . the physician offers some orders gleaned from experience with an air of infallible knowledge, in the brusque fashion of a dictator. . . . The free physician, who usually cares for free men, treats their diseases first by thoroughly discussing with the patient and his friends his ailment. This way he learns something from the sufferer and simultaneously instructs him. Then the physician does not give his medications until he has persuaded the patient; the physician aims at complete restoration of health by persuading the patient to comply with his therapy.

Fourth, physician values are relevant to patients and do inform their choice of a physician. When a pregnant woman chooses an obstetrician who does not routinely perform a battery of prenatal tests or, alternatively, one who strongly favors them; when a patient seeks an aggressive cardiologist who favors procedural interventions or one who concentrates therapy on dietary changes, stress reduction, and life-style modifications, they are, consciously or not, selecting a physician based on the values that guide his or her medical decisions. And, when disagreements between physicians and patients arise, there are discussions over which values are more important and should be realized in medical care. Occasionally, when such disagreements undermine the physician-patient relationship and a caring attitude, a patient's care is transferred to another physician. Indeed, in the informative model the grounds for transferring care to a new physician is either the physician's ignorance or incompetence. But patients seem to switch physicians because they do not "like" a particular physician or that physician's attitude or approach.

Fifth, we seem to believe that physicians should not only help fit therapies to the patients' elucidated values, but should also promote health-related

values. As noted, we expect physicians to promote certain values, such as “safer sex” for patients with HIV or abstaining from or limiting alcohol use. Similarly, patients are willing to adjust their values and actions to be more compatible with health-promoting values.<sup>38</sup> This is in the nature of seeking a caring medical recommendation.

Finally, it may well be that many physicians currently lack the training and capacity to articulate the values underlying their recommendations and persuade patients that these values are worthy. But, in part, this deficiency is a consequence of the tendencies toward specialization and the avoidance of discussions of values by physicians that are perpetuated and justified by the dominant informative model. Therefore, if the deliberative model seems most appropriate, then we need to implement changes in medical care and education to encourage a more caring approach. We must stress understanding rather than mere provisions of factual information in keeping with the legal standards of informed consent and medical malpractice; we must educate physicians not just to spend more time in physician-patient communication but to elucidate and articulate the values underlying their medical care decisions, including routine ones; we must shift the publicly assumed conception of patient autonomy that shapes both the physician’s and the patient’s expectations from patient control to moral development. Most important, we must recognize that developing a deliberative physician-patient relationship requires a considerable amount of time. We must develop a health care financing system that properly reimburses—rather than penalizes—physicians for taking the time to discuss values with their patients.

### Conclusion

Over the last few decades, the discourse regarding the physician-patient relationship has focused on two extremes: autonomy and paternalism. Many have attacked physicians as paternalistic, urging the empowerment of patients to control their own care. This view, the informative model, has become dominant in bioethics and legal standards. This model embodies a defective conception of patient autonomy, and it reduces the physician’s role to that

of a technologist. The essence of doctoring is a fabric of knowledge, understanding, teaching, and action, in which the caring physician integrates the patient’s medical condition and health-related values, makes a recommendation on the appropriate course of action, and tries to persuade the patient of the worthiness of this approach and the values it realizes. The physician with a caring attitude is the ideal embodied in the deliberative model, the ideal that should inform laws and policies that regulate the physician-patient interaction.

Finally, it may be worth noting that the four models outlined herein are not limited to the medical realm; they may inform the public conception of other professional interactions as well. We suggest that the ideal relationships between lawyer and client,<sup>14</sup> religious mentor and laity, and educator and student are well described by the deliberative model, at least in some of their essential aspects.

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## Confronting Death: Who Chooses, Who Controls?

A Dialogue Between Dax Cowart and Robert Burt

DAX COWART AND ROBERT BURT

In 1973, Dax Cowart was severely injured in a horrific accident, leaving him blind, without the use of his hands, and burned over two-thirds of his body. The treatment for his burns was so excruciatingly painful that in his agony he refused to consent to the treatments, demanding that they be stopped and that he be allowed to die. His request was repeatedly denied, even though his psychiatrist pronounced him competent. He eventually recovered, and his story provoked serious debate about patient autonomy and a patient's right to refuse treatment and to die. Here is a respectful dialogue on the issues between Cowart and Robert Burt, who had long-term correspondence with him and disagreed with part of Cowart's view.

On 21 November 1996, Dax Cowart and Robert Burt jointly delivered the Heather Koller Memorial Lecture at Pacific Lutheran University. This was the first time that they spoke together in a public forum. Dax Cowart now lives and practices law in Corpus Christi, Texas. In the summer of 1973, he was critically injured in a propane gas explosion that took his father's life and very deeply burned more than two-thirds of his own body. He was left blind and without the use of his hands. For more than a year Dax underwent extraordinarily painful treatments in the acute burn ward of two hospitals. Throughout his ordeal he demanded to die by refusing consent to his disinfectant treatments. Despite repeated declarations of competence by his psychiatrist, all his pleas were rejected. In 1974, while still hospitalized, he helped make the famous "Please Let Me Die" video, and in 1984 a second video, "Dax's Case." In 1986 Dax Cowart received a law degree from Texas Tech University.

Burt and Cowart have corresponded over the course of several years on the subject of Dax's case and related issues. They met for the first time during their trip to Tacoma, Washington for the Koller Memorial Lecture. The following is an edited transcript of their public remarks.

**Robert Burt:** Let me start at a place where I think we agree. Before 1974, the dominant attitude of physicians toward patients was by and large intensely disrespectful of patients' autonomy. The basic posture was paternalistic. Physicians knew what was best for patients, and the patient's job was just to go along. Dax himself has been a critically important actor and symbol in identifying the wrongdoing in that attitude, and raising into high social visibility the proposition that autonomy is a vitally important value; patients are the central actors here and physicians must attend to them in a respectful and careful way. On that point we agree.

The place at which I get troubled or confused is what exactly follows if we embrace this important

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norm of autonomy. Start with a simple version of two alternatives, perhaps extreme alternatives, to try and sharpen what the issues are. One version of autonomy says: well, it's the physician's job, like it's anybody's job who needs to respect autonomy, to say to a patient, "What do you want?"; the patient says "I want A, B, C," or "I don't want A, B, and C," and then it's just the physician's job to implement that. That is a possible interpretation of the law and way of proceeding.

I find that interpretation of the law, however, to be quite unsatisfactory. It is not only permissible, but important—I would even say essential—that a somewhat different step be taken by a physician (or anyone dealing with a patient). "What do you want?" Dax says, "I don't want treatment." At that point I think it is not only permissible but imperative that whoever hears that respond not with "OK, great, let's go ahead," but instead with, "Well, why exactly do you want that? Why have you come to that conclusion? I want to explore that with you." Now imagine the next step. Dax says, "None of your business." I think it is then both permissible and essential for the doctor to say, "No, no, it is my business, and not because I'm a doctor but because I am another human being who is necessarily involved in your life. We define one another in important kinds of ways, and while, of course, I can't define you, we have to negotiate together what our shared meanings are about, what it is that you want me to do or not to do." It is correct not only for me to say, "Why do you want to do that?" but also permissible for me to argue with you if I disagree, and to argue strenuously with you on a variety of grounds.

Now come the end of the day, yes, it's your life, it's not my life. But the question is, When have we reached the end of the day? When may we terminate this conversation so that I believe that the choice that you're making is as considerate a choice as I think it is morally obligatory for you to make? I know that this can become a kind of trick, and it shouldn't be that; this is only the first step in a conversation.

Why do I think it's not just important but imperative that anybody hearing such a request on Dax's part explore it with him and even quarrel with him? I think we define one another for one

another. We are not isolated creatures, popped into this world, who chart ourselves only by what's in our head. We are intensely social creatures. Dax himself has become more than just an individual, he has become a symbol and independent force that shapes our way of thinking about ourselves when we imagine ourselves to be patients. We are mutually shaped by our expectation in lots of ways.

There is one way I want to particularize that in Dax's case. All of us, as members of a society, have attitudes toward people with disabilities. Those of us who are able-bodied or, as they say correctly among disability advocates, those of us who are temporarily able-bodied, often spend an enormous amount of energy denying the fact that our able-bodied status is, in fact, temporary. It is for many, many of us an unattractive, if not to say frightening, possibility to think of ourselves as significantly disabled. Many people in this society, for lots of different reasons, have stereotypical views of disabled people and what their possibilities are. You correct me if I misstep here, Dax, but just on the face of the matter, it seems to me that until your accident you were a member of the able-bodied community, and a very able-bodied member at that, for whom your physical prowess was a matter of great importance and pride to you. Suddenly and deeply beyond your control, in a way that can happen frighteningly to any of us, you found yourself pushed over this divide between the able-bodied and the not-able-bodied. But you inevitably brought with you attitudes that were shaped at a time when you were comfortably, happily, proudly a member of the able-bodied community.

Now it seems to me that having been pushed over that divide in physical terms, there still was a question, at least, about your attitudinal concerns, your attitudinal shift.

Let me read one passage from this initial conversation that Dax had with Dr. White.<sup>1</sup> Dr. White said to Dax, "From the very beginning, according to what you've told me, and what's been written in your hospital record, you had very strong feelings that you didn't want the doctors to go on with your treatment, that you wanted them to leave you alone and not attempt to sustain your life. How do you feel about that at this point?" Dax said in response,

"At this point I feel much the same way. If I felt that I could be rehabilitated to where I could walk and do other things normally, I might have a different feeling about it. I don't know. But being blind itself is one big factor that influences my thinking on the matter. I know that there's no way that I want to go on as a blind and a cripple."

Now human communication is a chancy and somewhat crude thing. I only have your words. Dr. White only had Dax's words. Reading those words and putting myself imaginatively in the shoes of your physician, or your lawyer asked to represent you, I have a whole series of questions. How realistic was your perception at that point, just a few months after your accident? How realistic was it of the full range of capacities that could be held out to you, even if you were permanently blind, and even if you were permanently unable to walk (which it turns out, of course, you were not)? How much contact had you had with people with significant disabilities of these sorts? How much were you devaluing your own capacity, thinking that in fact you would be able to do nothing more than your mother's observation in the subsequent videotape interview. She said that you said at one point, "You know, all I'm going to be able do is to sit on a street corner and sell pencils." Well, of course we see today that you are very active and don't sell pencils. But this is a very common fear of able-bodied people who have had no substantial contact with people with disabilities.

So I would ask myself first of all, how realistic is someone like Dax's sense of the real possibilities open for him? But then second of all, how can I as a helper, someone who wants to be useful and helpful to him, communicate in a way that is fully understandable and believable what the real range of options are to him, disabled, that he, formerly able-bodied and now still able-bodied in his image of himself, is not able to see. What do you do? There are many possibilities. You bring people to talk, you discuss, you challenge. All this takes time. It's not something that you can just say to Dax, "Well, how realistic are you? Let's have a brief discussion." In the kind of immensely difficult, immensely traumatic situation in which he found himself, in the midst of his treatment and with the physical pain

that he was feeling, and with the psychological pain of his losses including the loss of his father in the same accident, this is not a conversation that can take place in ten minutes or one day. Over how much time and with what kind of constraints?

**Dax Cowart:** Now I know how it feels to be killed with kindness. It makes it more difficult to take the opposing position, but being the good lawyer that I am I will do my best (audience laughter).

The right to control your own body is a right you're born with, not something that you have to ask anyone else for, not the government, not your treating physician, not your next-of-kin. No one has the right to amputate your arms or your legs without your consent. No one has the right to remove your internal organs without your consent. No one has the right to force other kinds of medical treatment upon you without your consent. There is no legitimate law, there is no legitimate authority, there is no legitimate power anywhere on the face of this earth that can take the right away from a mentally competent human being and give it to a state, to a federal government, or to any other person.

A number of quotations constitute a brief overview of what others have said throughout history and also give insight into my own feelings. In *A Connecticut Yankee in King Arthur's Court*, the leading character and one of his companions come across a whole family which has almost died of smallpox. The mother appears to be the only one still alive. Later on they discover she has a fifteen-year-old daughter up in a sleeping loft who is in a near-comatose state and almost dead. So they rushed the young girl down and began administering aid to her. I'll pick up the quotation there. "I snatched my liquor flask from my knapsack, but the woman forbade me and said: 'No, she does not suffer; it is better so. It might bring her back to life. None that be so good and kind as ye are would do her that cruel hurt. Thou go on thy way, and be merciful friends that will not hinder.'"

I was asking my own physicians to be merciful friends who go on their way and do not hinder. But they would not listen. In the first part of this century, Justice Louis Brandeis wrote in one of his Supreme Court opinions: "The makers of our Constitution

sought to protect Americans, and their beliefs, their thoughts, their emotions, and their sensations. They conferred as against the government the right to be left alone, the most comprehensive of rights and the right most valued by civilized man."

Warren Burger, who later became chief justice, referred to Justice Brandeis: "Nothing suggests that Justice Brandeis thought an individual possessed these rights only as to sensible beliefs, valid thoughts, reasonable emotions or well-founded sensations. I suggest that he intended to include a great many foolish, unreasonable and even absurd ideas that do not conform, such as refusing medical treatment even at great risk."

Justice Burger did not want to encourage foolish, unreasonable, or absurd conduct, but he did recognize the importance that the individual has in making his or her own decision. He understood that what some of us might think of as foolish, unreasonable, or absurd can also be something that is very precious and dear to someone else.

The English poet John Keats, almost 200 years ago, wrote simply, "Until we are sick, we understand not." That is so true—until we are the ones who are feeling the pain, until we are the ones who are on the sick bed, we cannot fully appreciate what the other person is going through. And even having been there myself, today I cannot fully appreciate what someone who has been badly burned is going through on the burn ward. Our mind mercifully blocks out much of that pain.

When I was in the second grade, a popular joke concerned a mother who severely reprimanded her young son for coming home late from school. He said, "Mom, now that I'm a Boy Scout, I stopped to do my good deed for the day and helped this little old granny lady cross the street." She said, "Young man, it sure doesn't take an hour to help one little old granny lady cross the street." He said, "Well, it sure did this one, 'cause she didn't want to go." I was like that little old granny lady; I didn't want to go. And even today there are many patients who are being forced to endure things that they do not wish to endure, while being taken places that they don't even want to go.

John Stuart Mill, the English philosopher, in his essay *On Liberty*, came down on the side of the right

to self-determination by dividing acts into those that are self-regarding and those that are other-regarding in nature. Mill concluded that when the act is self-regarding in nature, the individual should be left to make his or her own decisions. That is precisely my view. In a medical context, I am saying that before a physician is allowed to pick up a saw and saw off a patient's fingers or pick up a scalpel and cut out a patient's eyes, we must make sure that the physician has first obtained that patient's informed consent. I always like to stick the word "voluntary" in there—*informed and voluntary consent*—because consent that is obtained through coercion or by telling half-truths or withholding the full measure of risk and benefit is not truly consent. Medical providers need to understand that patients do not lose their constitutional rights simply because they find themselves behind a hospital wall. They have the same constitutional rights that the rest of us have, that we expect and enjoy outside hospital walls.

Fortunately today we have many protections that we did not have when I was in the hospital in 1973 and 1974. We have legally enforceable advance directives such as durable power of attorney and other health care proxies. Studies, though, have shown that even when these advance directives are part of the patient's hospital records, over half the time they are ignored by the patient's physician.

When I was in the hospital there were many reasons I wanted to refuse treatment, but one was overriding—the pain. The pain was so excruciating, it was so far beyond any pain that I ever knew was possible, that I simply could not endure it. I was very naive. I had always thought in that day and age, 1973, that a doctor would not let his or her patient undergo that kind of pain; they would be given whatever was needed to control it. Then I found out that was not true. I found out later that much more could have been done for my pain.

There were other important issues, too. One, though it was a distant second, was what Dr. Burt mentioned, my quality of life. I just did not feel that living my life blind, disfigured, with my fingers amputated and at that time not even able to walk, would be worthwhile. With that quality of life it did not seem that I would ever want to live. I have freely admitted for many years now that I was wrong about that.

I want to clarify this, though. Freedom, true freedom, not only gives us the right to make the correct choices; it also has to give us the right sometimes to make the wrong choices. In my case, however, it was a moot point whether I was wrong as far as my quality of life went, because that was a secondary issue. The immediate issue, the urgent issue, was that my pain was not being taken care of. That was why I wanted to die.

Today I'm happy; in fact I even feel that I'm happier than most people. I'm more active physically than I thought I ever would be. I've taken karate for a couple of years. I've climbed a 50-foot utility pole with the assistance of a belay line on the ropes course. I do other mental things, like write poetry and practice law. That is not to say, though, that the doctors were right. To say that would reflect a mentality that says, all's well that ends well, or the ends justify the means—whatever means necessary to achieve the results are okay to use. That totally ignores the pain that I had to go through. I check myself on this very often, several times a year, since I do speak so much. I ask if the same thing were to happen today under identical circumstances, would I still want the freedom? Knowing what I know now, would I still want the freedom to refuse treatment and die? And the answer is always yes, a resounding yes. If I think about having to go through that kind of pain again, I know that it's not something I would want. Another individual may well make a different decision. That's the beauty of freedom; that's his or her choice to do so.

**Burt:** You said at the end of your remarks that if you had to, if it happened all over again to you, you would nonetheless come to the same conclusion. If instead of this happening to you, imagine for a minute that there would be somebody in exactly the same situation that you were in, but that today you were called in to talk with this person. This person had also said to his or her physicians, "I don't want to be treated. Stop now." What would you say to that person?

**Cowart:** I would say to that person, just as you suggested earlier, "What are your concerns?" I do not urge, when a physician goes to a patient's bedside and the patient says, "Doc, I don't want to be treated, leave me alone," that the physician say, "It's your

decision" and walk away. The physician has a duty to inform the patient, as well as he or she can, what in all honesty can be done and then solicit the patient's concerns. I'm not talking about painting some rosy scenario that is really not accurate. So to answer your specific question, were I called to that patient's bedside, I would want to ask why he or she wanted to refuse treatment. I would expect that one of the answers might be the pain. I would then say, "If that were addressed, would that change things for you?" They may say yes, and they may say no. I would try to give that person the benefit of my own experiences—not just the positive points, but the negative ones, because it took me seven years following the explosion before I even began to get on my feet again and life became really worth living. But I would try to reaffirm the person, let him or her know what I thought was possible, what I thought could help, but I would not skirt the problems. One of the problems we have today, for example, is that once patients are out of the multimillion-dollar hospital facilities and away from all the nurses and doctors there, they don't often have good support. They have understaffed and underfunded government agencies to rely on in most cases, and often they fall far short of what they should be.

**Burt:** That's interesting. I continue to be puzzled about whether we significantly disagree. I completely buy your proposition that there is a right here, a right of autonomous choice. The only point that I keep pushing is your old question of how that is implemented. Let me, if you will, try to push you a bit more just on this point. To me it is the crucial question. This imaginary patient says to you that first of all there's a pain problem and it's not being addressed. I take it that given what you now know about the possibilities of pain control, you would then start moving around and see to it that such treatment would be available—the kind that at the time you were in the hospital wasn't made available to you. Am I right?

**Cowart:** Yes.

**Burt:** So you would fight for them. What, though, if they said to you, "Don't fight for me. Go away. My

life isn't worth living. I don't care what the possibility of getting on top of this pain is, just go away." What would you say then?

**Cowart:** At some point you have to say, "Okay, it's your decision."

**Burt:** Yes, at some point, but that day? The next week? If not right away, are you comfortable in arguing with them?

**Cowart:** I would feel comfortable in confronting them. I would not say argue, but I would discuss it with them, even confront them.

**Burt:** What do you mean by confront?

**Cowart:** Take an opposing position, discuss it, and have a lively debate about it. I have no problem with that.

**Burt:** I have another question. The observation that you just made, that it took you seven years to get to the point where life seemed fully worthwhile is a very powerful one. Would you say to our imaginary patient, "You know, the seven years time, it was hard time. Looked at from the other side, it now feels to me worth it, and it might feel like that to you, too"?

**Cowart:** That would be the honest way to do it.

**Burt:** What if they said, "No, you're different from me, it just can't be. I can't do it, I can't do it"? Is there anything you would do then?

**Cowart:** This goes back to your question, When is the end of the day? Is the end of the day at the end of one day, at the end of one week, or at the end of one year? To answer truthfully, I don't think I can say when it is without knowing more about the circumstances. For me, one hour was an eternity, with the pain I was going through. Certainly no longer than one day under those circumstances. There may be times when we would want to extend that to a week or maybe a month, depending on how severe the pain was. But the problem I see in doing that is that I don't believe our health care providers would be honest about letting go of a patient earlier than whatever we set up as the maximum time. Our health care providers have been entrenched in paternalism since

probably the beginning of the profession, and until we break out of the paternalistic mode, I can't see our physicians allowing patients to exercise their free choice unless they're legally bound to.

**Audience Question:** Mr. Burt, when is it okay for a doctor to say to a patient who refuses lifesaving treatment, "I agree with you"? The patient's in a lot of pain, she's suffering, and has a chronic illness. When is it okay to say, "All right, you can call an end to it"? When is the end of the day? When is it appropriate to acknowledge that to the patient?

**Burt:** I agree that there must be an end of the day. Otherwise one is disrespectful of the person who is saying "No, no, no—enough." I also agree that you should make it clear to patients from the beginning that ultimately it's their choice. But then I would say it's appropriate to say, "Give me time. Give me an opportunity, at least." Now once you say that, you're on the line and you must continue to spend time with this person—respectful time, extensive time. That itself is a very risky thing for you to do. It's a very considerable commitment, and you can't go into it lightly. You can't go into it lightly as a friend, and you can't go into it lightly as a professional. So you've got to be prepared to follow through by saying, in effect, "I'm here with you, I'm going to stay with you." But also, "I would hope and expect that as we struggle together it will become clearer to the both of us when that end of the day is. But at least right now it's not clear to me that we're there." Then see what the person says. This is not saying something and then vanishing for two weeks, because you're going on vacation somewhere or have other things to do. The commitment is enormously burdensome for a caretaker to take on in these situations. But that to me is the heart of caretaking. Is that an answer?

**Same Questioner:** Not really. As Dax said earlier, he had torturous pain. Are you saying that this patient should go through such suffering for this delayed, extended dialogue that you want?

**Burt:** Well, look, when I say "Give me, time," I would hope, particularly on these pain issues, that one would also take some action. The provision of adequate pain control in this culture today is a disgrace, but it shouldn't be. Medical technology that

is extraordinarily responsive in lots of ways is available. It's a great puzzle in a way—part of the sense of isolation and disregard for patients—that we are doing so little to implement what we know about addressing issues of pain. Lots of pain, though, is complicated to deal with. So when I ask for time, I don't mean, give me time because I'm going down to the cafeteria since I'm hungry. What I mean is, give me time to get the resources that I know exist that can address this in some way. If it turns out that there aren't those resources, or I really tried to get them and they did not work, then I come back to the patient and say, "Okay, I failed on that score; now we have to go from here." At that point, it does make sense for me to say, "Okay, this is intolerable for you. That's it, that's enough." So the time that I was asking for, was time to address your problem in the best way a doctor is trained to do. To the patient who said, "What do you mean, give you time?" I'd say, "Give me time to do my job. I acknowledge that we're not meeting your needs right now, but I think we can, though it will take some time for me to do that." If you insist now that you're not going to give me that time, it frustrates what I know I can do as a caretaker. Look, a discussion needs to take place; that's what I want, rather than people talking as if they are in isolation booths.

**Cowart:** A physician has to establish rapport with his or her patient, treat that patient as a human being, let the patient know that he or she really cares. I don't know whether it's taught or whether it's just picked up or by watching other physicians, but I think there is a professional distance, a real displacement, by physicians that is counterproductive for good medical treatment. I'll give you an example. When I was in the hospital, the director of the burn ward wanted to do surgery on my fingers. He felt I could probably get some use out of my hand, but I wouldn't do it, because the surgery I had had before on my hands was so painful.

There was a medical student, though, who was assigned to work with me. He'd come by every day. We'd have friendly, heart-to-heart talks, and I liked the guy a lot. He wanted me to have my hands operated on and asked me why I would not allow the doctor to do it. I explained to him about the pain.

He said, "Well if I guaranteed you that you would be kept out of pain, would you?" I told him I'd consider it, but I just didn't see how he could guarantee that, especially since he was a medical student. But he continued to talk with me until finally I agreed to talk to the director of the burn ward about it, who then came in and assured me that he would do everything he could to keep me out of pain. He would give me as much pain medication as he possibly could and not jeopardize my life. It wasn't until then that I agreed to the surgery, and he did keep his word on the pain control. That is more the model of what should take place. But the physician should not have the power to force upon the patient a long, ongoing discussion like that over an extended period of time, whether it be days or weeks.

**Audience Question:** Mr. Cowart, you have focused a lot on the physicians up to this point. How were you treated by your nurses?

**Cowart:** Overall, I was very impressed by their good care. Nurses tend to understand, to have a very caring and compassionate side to them that I don't see nearly as often in physicians. Sometimes you can have nurses who are barracudas, though, and a physician who is very loving and compassionate. I don't know how much of the general difference is gender-based, or how much of it is in the training; I suspect it's some of both. Above all, nurses are there with the patients; they're in the trenches working with the patients, seeing what the patient's going through on a minute-to-minute, hour-to-hour basis. They seem to have a much better understanding of and empathy for the patient than I've seen in most physicians.

**Audience Question:** Mr. Burt, I'm an RN and a hospice nurse. I have two patients right now; both of them have recliners, both of them have TV remotes, both of them have morphine, and both of them have pain. In the last two weeks, one patient said, "I have everything I need. I have my recliner, my remote, my morphine, and I'm fine." The other patient said, "I hate my life. All I have is this stinking recliner and TV and my morphine. This isn't a life." Now in the last week, one of those patients has died because he made a decision to stop all of his

medication except his morphine, and he died. I was not ready for him to die, but he was ready to die. If I had argued with him, whose need would be met? It would not be his need, would it?

**Burt:** I guess I would say that if you had stopped him, that would be inappropriate. But this word "arguing," maybe we get hung up on it. Importuning, offering to explore, not just taking this patient's statement in a way that I'm sure you didn't—that is appropriate to move into.

**Same Questioner:** I mean, we talked a lot!

**Burt:** Good—that's right. The root of this is in the particularity of individual interaction. It sounds to me, even in the minute in which I have heard you describe this, that you reached what I would agree is the end of the day. That is, the end of an involved, caring, committed relationship in which it was very clear that you were not going to walk away. That's the most that you can offer. You've got to offer that, and you did. And hospice care generally does. I see the forces of disregard, of speedy resolution, of turning away from patients, of being aversive to death and dying, for example, as so strong generally in the medical profession that by contrast hospice is a wonderful exception.

So, too, is the caregiver who may lovingly challenge a patient's requests. You ask, whose needs are such caregivers meeting? Do they do it only for their patients? Or do they do it for their patients and themselves? There's a mix in these things. Who can draw a strict line and say, "Hey, I know that I'm just doing this for you and not for me"? I would turn the question around. A patient is complaining and saying, "Everything that you do is wrong. You give me the recliner and I don't like it. You give me the morphine and I don't like it. So let me out of here." If you say "Right," what and who would you be doing that for? Many people whom I've talked to involving the care of "difficult" patients, when they are honest with themselves, say it's very hard to make sure that what they're doing is not for themselves but for the patients. Sometimes, in hanging in there, it's a mix—no, it's always a mix. The goal is only that it should be principally for the patient and only secondarily for you. But that's not an easy goal

to get to either. You get closest to it by struggle, sweat, honesty, reflection.

**Audience Question:** Mr. Cowart, I'm trying to understand your thinking. You were in the hospital and kept saying you wanted to die, and then you were released home without much care. You said it took seven years for you to turn your life around, but you did. You didn't kill yourself. At what point did you say, "I want to live"?

**Cowart:** I don't know where or when that point was. When I was in the burn ward and was told I was going to live regardless of whether I had that last skin graft operation or not, I told myself, I'm just going to do whatever I can to make the best of a bad situation. I didn't really live up to that. Subsequently, and within that seven-year period, I tried to take my own life twice—three times if you count the time I crawled over the hospital bed rails trying to get to the window to jump out of an eight-story window. But in 1980, and all during the entire seven years after I was in the hospital, I was not able to sleep very well at all. I'd stay awake most of the night and then could hardly stay awake during the day. I was trying to go to law school, too, and every time I felt like I was getting something going, I couldn't sleep then and I couldn't function. I felt just slammed right down to the ground again. In 1980 Dr. White was able to help me sleep better. Then I really saw my life turn around.

**Audience Question:** Mr. Cowart, it seems to me that you are a perfect example of what now seems to be success in spite of any physical disability. Do you now feel at all grateful, thinking back? Are you glad that the doctors fought your request to die?

**Cowart:** I do not feel grateful to anyone for fighting my request to die. What I do feel grateful to them for is that I believe they honestly felt they were acting in my best interest. But no, I'm not glad they forcibly treated me because the pain that I went through was pure hell. We lose sight of how painful pain can be. Einstein apparently once talked about comparing sitting five minutes on a park bench beside a beautiful girl with sitting five minutes on a hot plate and said, "that's relativity!"

**Audience Question:** In fighting for your right to choose your fate, were you also fighting physically against the care that was forced upon you? Were you physically trying to refuse treatment?

**Cowart:** Oh yes! I would have done anything to keep them away from me. I used everything I had at my disposal to try to do that.

**Same Questioner:** Do you suppose that this fight within you, this struggle, this energy you were putting out, actually made you live?

**Cowart:** Yes. I think it was, ironically, counterproductive for what I wanted. There was a burn ward nurse I later learned of who left the hospital before I got there. She would not take anything off her patients, no matter how badly they were burned and what their expectation was about living. She also wouldn't take any lip from them, and even the other nurses were appalled by how rough and how rude she was to these patients. Her patients were so angry that they would, literally, have killed her on the spot. The other nurses began to notice that some of her patients were living, who would not normally have lived. What may have been at work there—this is only my hunch—is that such passion, even when it's negative, helps. When people die, it can be just lack of any passion, negative or positive—just the languishing.

**Audience Question:** Mr. Cowart, at the time that you were fighting against treatment, your mother was fighting for continued treatment. Did you consider getting an attorney at that time?

**Cowart:** I asked the attorney who was representing me in a personal injury suit against the oil company whose duty it had been to maintain the pipeline properly to help me. He had been a long-time friend of my father's, and he also knew me. He would not help me get the legal resources. He did go to the doctors, though, and say, "You have got to do more to keep him out of pain. It's ridiculous that you're not doing more." I tried to get family members, relatives, friends to find another attorney for me. I wasn't able to do that. I asked the hospital staff to take me to a pay phone there on the floor to call one, and they said there weren't any pay phones. I said,

"Take me to the lobby, then." They said, "Burn patients can't leave the ward." I said, "Well let me use the phone at the nurses' station. I know you have a phone there because I hear it ringing all the time." They said, "No, patients aren't allowed to use it. It's only for staff." I wrote at least one letter privately with a nurse. I dictated a letter to that nurse, and he apparently addressed it to my uncle. The letter (I don't know whether it was the original or a copy) ended up in the doctor's file, without my knowledge. The patient may have a right not to be treated, but without an advocate—someone at the hospital who has the authority and power to act on behalf of the patient—it's hard to enforce that right. Finally it was Dr. White, the psychiatrist who was brought in to declare me incompetent, who both declared me competent and contacted an attorney for me. The attorney finally came down from Dallas. We talked. He said he'd do what he could, but I never heard back from him.

**Audience Question:** Mr. Cowart, when you were first injured, if your intractable pain had been effectively managed, do you think that your attitude would have been different? Do you think you might have had a very different outlook as to prolonging your life? Do you think that the pain was really the main issue that wasn't being addressed by your physicians and the medical community, and that that interfered with your ability to really look at the future?

**Cowart:** Your concern is what I hear time after time from many people in the health care professions. Dr. White, the psychiatrist who was called in, expressed that same type of concern. Another concern Dr. White had was whether I had a major issue with control, whether once I showed that I was in control, then I would want to be treated. That just was not the case. It was not the future that I was concerned with; it was the present moment, the pain that I was undergoing. I knew that the physical pain would be gone eventually, but I was not willing to tolerate it for long enough to get beyond it. Even if my pain had been competently managed, I still don't think that I would want to have been treated, because of my physical condition and what I did see as the future. Possibly without the pain, and

possibly with much better professional support, maybe I could have been persuaded to go ahead and accept treatment. But you know, a psychiatrist was not called in to try to help me with these concerns until almost a year into my hospitalization. And then they called the psychiatrist in, not for the purpose of helping me, but to have me declared incompetent. He refused to do it and in fact found me competent, and so did the second psychiatrist, as you know.

**Audience Question:** Mr. Burt, I get the impression that both the medical profession and the society assume a temporary incompetence in anybody who is in severe pain or in severe emotional grief. Do you take the word of somebody in severe pain as at that moment truly their decision? Is a presumption of temporary incompetence justifiable?

**Burt:** I don't like the language, "presumption of temporary incompetence." It has a disrespectful and excessive quality to it. I don't think we should operate on such a premise. What I do think is that people in grief or extraordinary pain deserve a response by a whole range of caretakers, personal and professional: "I'm with you and I'll stick with you, and I'll be as helpful as I possibly can in working this through with you. I won't abandon you." Sometimes, in fact maybe even frequently, I think people who are in severe grief or severe pain have trouble, because they feel so hopeless, believing that people are responding to them in this way. So it takes an awful lot of assurance—not just words but being there when it counts, and it's not something that you can just say once and have it sink in to someone in great physical or psychological pain. Now I don't call that incompetence; I call that humanity—our human condition. It's naturally how people respond in times of enormous stress, woe, and trouble. In organizing caretaking we should be thinking of ourselves as responding to that—not just in cheap words, and that takes time.

**Audience Question:** It seems to me that you, Mr. Cowart, actually made a very articulate defense of Mr. Burt's position when you so ably identified the essentials of informed consent, making the very clear point, well respected and recognized in

medical-legal law, that informed volitional consent demands a full appraisal and understanding of the risks and benefits of the therapy. The difficulty that I see Mr. Burt focusing on here is that these decisions don't take place instantaneously in time. Even a patient who is not in pain, to make a fully informed decision about the risks versus benefits of treatment, has to be able to appropriate a different set of attitudes and expectations, and the process for that is one of knowledge and dialogue and information. Setting aside the pain issue, which ought to be aggressively manageable, how does your own experience help us understand how to balance respecting the patient's request with confidence that enough time has been given to the patient to allow a truly informed personal assessment of what the risks and benefits are?

**Cowart:** Assuming that pain is not an issue and that there's not some other issue present analogous to pain as far as the immediacy of the situation goes, I would not be nearly as inclined to favor a very short time period. I probably would favor a longer period of time, maybe weeks, maybe even

months, but I don't think that I would be in favor of years. As far as physicians being able to work with a patient during that time, I think it would probably be good in instances where you don't have the immediacy that something like severe physical pain requires. The trouble I have is how you go about assessing what is sufficient time from the patient's viewpoint, since we're all different. I just know that for myself I would like to have the right to make my own decisions at zero point in time. At the same time I'm willing to forgo some of my own autonomy in the interest of better decisions being made. What I don't know is how to determine always, as Dr. Burt calls it, when the end of the day has come. If the patient gives away some of that autonomy, I just don't know how you go about protecting the patient so he or she can still say, "Okay, I've heard you out, I've tried what you said, and it's not for me."

#### REFERENCES

1. From the transcript made of the initial videotape and published as an appendix to Robert Burt, *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations* (New York: The Free Press, 1979), pp. 174–180.

## Bouvia v. Superior Court

CALIFORNIA COURT OF APPEAL

In this 1986 ruling, the court asserted that competent adults have a “constitutionally guaranteed right” to decide for themselves whether to submit to medical treatments, a right that outweighs the interests of physicians, hospitals, and the state. A competent patient may refuse treatments even if they are needed to keep her alive.

Petitioner, Elizabeth Bouvia, a patient in a public hospital, seeks the removal from her body of a nasogastric tube inserted and maintained against her will and without her consent by physicians who so placed it for the purpose of keeping her alive through involuntary forced feeding.

From California Court of Appeal, *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ctr. App. 1986).

Petitioner has here filed a petition for writ of mandamus and other extraordinary relief after the trial court denied her a preliminary injunction requiring that the tube be removed and that the hospital and doctors be prohibited from using any other similar procedures. We issued an alternative writ. We have heard oral argument from the parties and now order issuance of a peremptory writ, granting petitioner, Elizabeth Bouvia, the relief for which she prayed. . . .

The trial court denied petitioner's request for the immediate relief she sought. It concluded that leaving the tube in place was necessary to prolong petitioner's life, and that it would, in fact, do so. With the tube in place petitioner probably will survive the time required to prepare for trial, a trial itself and an appeal, if one proved necessary. The real party-physicians also assert, and the trial court agreed, that physically petitioner tolerates the tube reasonably well and thus is not in great physical discomfort.

Real parties' counsel therefore argue that the normal course of trial and appeal provide a sufficient remedy. But petitioner's ability to tolerate physical discomfort does not diminish her right to immediate relief. Her mental and emotional feelings are equally entitled to respect. She has been subjected to the forced intrusion of an artificial mechanism into her body against her will. She has a right to refuse the increased dehumanizing aspects of her condition created by the insertion of a permanent tube through her nose and into her stomach.

To petitioner it is a dismal prospect to live with this hated and unwanted device attached to her, through perhaps years of the law's slow process. She has the right to have it removed immediately. This matter constitutes a perfect paradigm of the axiom: "Justice delayed is justice denied."

By refusing petitioner the relief which she sought, the trial court, with the most noble intentions, attempted to exercise its discretion by issuing a ruling which would uphold what it considered a lawful object, i.e., keeping Elizabeth Bouvia alive by a means which it considered ethical. Nonetheless, it erred for it had no discretion to exercise. Petitioner sought to enforce only a right which was exclusively hers and over which neither the medical profession nor the judiciary have any veto power. The trial court could but recognize and protect her exercise of that right.

In explanation of its ruling, the trial court stated that it considered petitioner's "motives" to be indicative of an attempt to commit suicide with the state's help rather than a bona fide exercise of her right to refuse medical treatment. No evidence supports this conclusion.

As previously noted, the legal remedies available to petitioner through the normal course of trial and appeal are wholly inadequate. Therefore, a prompt resolution, even though based upon a provisional ruling, is justified, particularly when it will probably completely resolve this tragic case.

Petitioner is a 28-year-old woman. Since birth she has been afflicted with and suffered from severe cerebral palsy. She is quadriplegic. She is now a patient at a public hospital maintained by one of the real parties in interest, the County of Los Angeles. Other parties are physicians, nurses and the medical and support staff employed by the County of Los Angeles. Petitioner's physical handicaps of palsy and quadriplegia have progressed to the point where she is completely bedridden. Except for a few fingers of one hand and some slight head and facial movements, she is immobile. She is physically helpless and wholly unable to care for herself. She is totally dependent upon others for all of her needs. These include feeding, washing, cleaning, toileting, turning, and helping her with elimination and other bodily functions. She cannot stand or sit upright in bed or in a wheelchair. She lies flat in bed and must do so the rest of her life. She suffers also from degenerative and severely crippling arthritis. She is in continual pain. Another tube permanently attached to her chest automatically injects her with periodic doses of morphine which relieves some, but not all of her physical pain and discomfort.

She is intelligent, very mentally competent. She earned a college degree. She was married but her husband has left her. She suffered a miscarriage. She lived with her parents until her father told her that they could no longer care for her. She has stayed intermittently with friends and at public facilities. A search for a permanent place to live where she might receive the constant care which she needs has been unsuccessful. She is without financial means to support herself and, therefore, must accept public assistance for medical and other care.

She has on several occasions expressed the desire to die. In 1983 she sought the right to be cared for in a public hospital in Riverside County while she intentionally "starved herself to death." A court in that county denied her judicial assistance to accomplish that goal. She later abandoned an appeal from

that ruling. Thereafter, friends took her to several different facilities, both public and private, arriving finally at her present location. Efforts by the staff of real party in interest County of Los Angeles and its social workers to find her an apartment of her own with publicly paid live-in help or regular visiting nurses to care for her, or some other suitable facility, have proved fruitless.

Petitioner must be spoon fed in order to eat. Her present medical and dietary staff have determined that she is not consuming a sufficient amount of nutrients. Petitioner stops eating when she feels she cannot orally swallow more, without nausea and vomiting. As she cannot now retain solids, she is fed soft liquid-like food. Because of her previously announced resolve to starve herself, the medical staff feared her weight loss might reach a life-threatening level. Her weight since admission to real parties' facility seems to hover between 65 and 70 pounds. Accordingly, they inserted the subject tube against her will and contrary to her express written instructions.

Petitioner's counsel argue that her weight loss was not such as to be life threatening and therefore the tube is unnecessary. However, the trial court found to the contrary as a matter of fact, a finding which we must accept. Nonetheless, the point is immaterial, for, as we will explain, a patient has the right to refuse any medical treatment or medical service, even when such treatment is labeled "furnishing nourishment and hydration." This right exists even if its exercise creates a "life threatening condition." . . .

The right to refuse medical treatment is basic and fundamental. It is recognized as a part of the right of privacy protected by both the state and federal constitutions. Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion. . . .

[A]ddressing one part of the problem, California passed the "Natural Death Act," Health and Safety Code section 7185 et seq. Although addressed to terminally ill patients, the significance of this legislation is its expression as state policy "that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care. . . ." Section 7188 provides the method whereby an adult person may execute a directive for the withholding or withdrawal of life-sustaining

procedures. Recognition of the right of other persons who may not be terminally ill and may wish to give other forms of direction concerning their medical care is expressed in section 7193: "Nothing in this chapter shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this chapter are cumulative."

Moreover, as the Bartling decision holds, there is no practical or logical reason to limit the exercise of this right to "terminal" patients. The right to refuse treatment does not need the sanction or approval by any legislative act, directing how and when it shall be exercised. . . .

A recent Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded in part: "The voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken, just as such choices provide the basis for other decisions about medical treatment. Health care institutions and professionals should try to enhance patients' abilities to make decisions on their own behalf and to promote understanding of the available treatment options. . . . Health care professionals serve patients best by maintaining a presumption in favor of sustaining life, while recognizing that competent patients are entitled to choose to forego any treatments, including those that sustain life."

On December 11, 1985, the Los Angeles County Bar Association, and on January 6, 1986, the Los Angeles County Medical Association recognized as general principles for decision making the conclusions as expressly stated in the cases of Barber and Bartling and endorsed the conclusion of the Presidential Commission cited above.

The American Hospital Association (AHA) Policy and Statement of Patients' Choices of Treatment Options, approved by the American Hospital Association in February of 1985, discusses the value of a collaborative relationship between the patient and the physician and states in pertinent part: "Whenever possible, however, the authority to determine the course of treatment, if any, should rest with the patient" and "the right to choose treatment

includes the right to refuse a specific treatment or all treatment. . . .”

Again, this statement reflects the fact that the controlling decision belongs to a competent, informed patient. It also contains a discussion of how that consent should be documented, and the desirability of a cooperative effort. Of course, none of the problems of incapacity due to age, unconsciousness, mental disease or disability mentioned in the policy statement affect the case before us.

Significant also is the statement adopted on March 15, 1986, by the Council on Ethical and Judicial Affairs of the American Medical Association. It is entitled “Withholding or Withdrawing Life Prolonging Medical Treatment.” In pertinent part, it declares: “The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail. Life prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.”

We do not believe that all of the foregoing case law and statements of policy and statutory recognition are mere lip service to a fictitious right. As noted in Bartling, “We do not doubt the sincerity of [the hospital and medical personnel’s] moral and ethical beliefs, or their sincere belief in the position they have taken in this case. However, if the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient’s hospital and doctors. . . . The right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right which must not be abridged.”

It is indisputable that petitioner is mentally competent. She is not comatose. She is quite intelligent, alert, and understands the risks involved. . . .

At bench the trial court concluded that with sufficient feeding petitioner could live an additional 15 to 20 years; therefore, the preservation of petitioner’s

life for that period outweighed her right to decide. In so holding the trial court mistakenly attached undue importance to the amount of time possibly available to petitioner, and failed to give equal weight and consideration for the quality of that life; an equal, if not more significant, consideration.

All decisions permitting cessation of medical treatment or life-support procedures to some degree hastened the arrival of death. In part, at least, this was permitted because the quality of life during the time remaining in those cases had been terribly diminished. In Elizabeth Bouvia’s view, the quality of her life has been diminished to the point of hopelessness, uselessness, unenjoyability and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She cannot be faulted for so concluding. If her right to choose may not be exercised because there remains to her, in the opinion of a court, a physician or some committee, a certain arbitrary number of years, months, or days, her right will have lost its value and meaning.

Who shall say what the minimum amount of available life must be? Does it matter if it be 15 to 20 years, 15 to 20 months, or 15 to 20 days, if such life has been physically destroyed and its quality, dignity and purpose gone? As in all matters lines must be drawn at some point, somewhere, but that decision must ultimately belong to the one whose life is in issue.

Here Elizabeth Bouvia’s decision to forego medical treatment or life-support through a mechanical means belongs to her. It is not a medical decision for her physicians to make. Neither is it a legal question whose soundness is to be resolved by lawyers or judges. It is not a conditional right subject to approval by ethics committees or courts of law. It is a moral and philosophical decision that, being a competent adult, is hers alone.

Adapting the language of *Satz v. Perlmutter*, “It is all very convenient to insist on continuing [Elizabeth Bouvia’s] life so that there can be no question of foul play, no resulting civil liability and no possible trespass on medical ethics. However, it is quite another matter to do so at the patient’s sole expense and against [her] competent will, thus inflicting never ending physical torture on [her] body

until the inevitable, but artificially suspended, moment of death. Such a course of conduct invades the patient's constitutional right of privacy, removes [her] freedom of choice and invades [her] right to self-determine."

Here, if force fed, petitioner faces 15 to 20 years of a painful existence, endurable only by the constant administration of morphine. Her condition is irreversible. There is no cure for her palsy or arthritis. Petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years. Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through physical acts of others. Her mind and spirit may be free to take great flights but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness. We do not believe it is the policy of this state that all and every life must be preserved against the will of the sufferer. It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure, for "15 to 20 years." We cannot conceive it to be the policy of this state to inflict such an ordeal upon anyone.

It is, therefore, immaterial that the removal of the nasogastric tube will hasten or cause Bouvia's eventual death. Being competent she has the right to live out the remainder of her natural life in dignity and peace. It is precisely the aim and purpose of the many decisions upholding the withdrawal of life-support systems to accord and provide as large a measure of dignity, respect and comfort as possible to every patient for the remainder of his days, whatever be their number. This goal is not to hasten death, though its earlier arrival may be an expected and understood likelihood.

Real parties assert that what petitioner really wants is to "commit suicide" by starvation at their facility. The trial court in its statement of decision said: "It is fairly clear from the evidence and the court cannot close its eyes to the fact that [petitioner] during her stay in defendant hospital, and for some time prior thereto, has formed an intent to die. She has voiced this desire to a member of the staff of defendant hospital. She claims, however, she

does not wish to commit suicide. On the evidence, this is but a semantic distinction. The reasonable inference to be drawn from the evidence is that [petitioner] in defendant facility has purposefully engaged in a selective rejection of medical treatment and nutritional intake to accomplish her objective and accept only treatment which gives her some degree of comfort pending her demise. Stated another way, [petitioner's] refusal of medical treatment and nutritional intake is motivated not by a bona fide exercise of her right of privacy but by a desire to terminate her life. . . . Here [petitioner] wishes to pursue her objective to die by the use of public facilities with staff standing by to furnish her medical treatment to which she consents and to refrain from that which she refuses."

Overlooking the fact that a desire to terminate one's life is probably the ultimate exercise of one's right to privacy, we find no substantial evidence to support the court's conclusion. Even if petitioner had the specific intent to commit suicide in 1983, while at Riverside, she did not carry out that plan. Then she apparently had the ability, without artificial aids, to consume sufficient nutrients to sustain herself; now she does not. That is to say, the trial court here made the following express finding, "Plaintiff, when she chooses, can orally ingest food by masticating 'finger food' though additional nutritional intake is required intravenously and by nasogastric tube. . . ." As a consequence of her changed condition, it is clear she has now merely resigned herself to accept an earlier death, if necessary, rather than live by feedings forced upon her by means of a nasogastric tube. Her decision to allow nature to take its course is not equivalent to an election to commit suicide with real parties aiding and abetting therein.

Moreover, the trial court seriously erred by basing its decision on the "motives" behind Elizabeth Bouvia's decision to exercise her rights. If a right exists, it matters not what "motivates" its exercise. We find nothing in the law to suggest the right to refuse medical treatment may be exercised only if the patient's motives meet someone else's approval. It certainly is not illegal or immoral to prefer a natural, albeit sooner, death than a drugged life attached to a mechanical device.

## Fundamental Elements of the Patient-Physician Relationship

AMA COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

In this section of its medical code of ethics, the AMA declares that the patient-physician relationship is a collaborative alliance in which both parties have responsibilities. Physicians should serve as their patients' advocates and respect their rights, including the right to accept or refuse recommended treatment, to receive complete information about treatments and their alternatives, and to have their confidentiality protected.

From ancient times, physicians have recognized that the health and well-being of patients depends upon a collaborative effort between physician and patient. Patients share with physicians the responsibility for their own health care. The patient-physician relationship is of greatest benefit to patients when they bring medical problems to the attention of their physicians in a timely fashion, provide information about their medical condition to the best of their ability, and work with their physicians in a mutually respectful alliance. Physicians can best contribute to this alliance by serving as their patients' advocate and by fostering these rights:

1. The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action. Patients are also entitled to obtain copies or summaries of their medical records, to have their questions answered, to be advised of potential conflicts of interest that their physicians might have, and to receive independent professional opinions.
2. The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment.
3. The patient has the right to courtesy, respect, dignity, responsiveness, and timely attention to his or her needs.
4. The patient has the right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by law or by the need to protect the welfare of the individual or the public interest.
5. The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.
6. The patient has a basic right to have available adequate health care. Physicians, along with the rest of society, should continue to work toward this goal. Fulfillment of this right is dependent on society providing resources so that no patient is deprived of necessary care because of an inability to pay for the care. Physicians should continue their traditional assumption of a part of the responsibility for the medical care of those who cannot afford essential health care. Physicians should advocate for patients in dealing with third parties when appropriate.

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## Advocacy or Subservience for the Sake of Patients?

HELGA KUHSE

Kuhse asks whether nurses should be patient advocates who are ready when necessary to question physician authority, or be skilled and caring professionals who must always defer to physicians on important medical decisions. Contrary to Lisa Newton's view, she favors the former, arguing that the nurse's subservience to physicians is not necessary for managing serious medical problems and issues and that requiring nurses to be subservient would probably harm patients.

The view that doctors were gods whose commands must always be obeyed was beginning to be seriously questioned in the 1960s and 1970s. There had always been courageous nurses who had occasionally challenged orders, but it is almost as if nurses needed a new metaphor to capture their new understanding of their role before they could finally attempt to free themselves from the shackles of the past. This new focus was provided by the metaphor of the nurse as patient advocate. Whereas the old metaphors had focused attention on such virtues as submissiveness and unquestioning obedience and loyalty to those in command, the new metaphor of patient advocate highlighted the virtues of assertiveness and courage, and marked a revolutionary shift in the self-perception of nurses and their role. The nurse's first loyalty, the metaphor suggested, is owed not to the doctor but to the patient. In thus focusing on the nurse's responsibilities to patients, that is, on the *recipients* rather than the *providers* of medical care, the metaphor of the nurse as patient advocate made it possible for nurses to see themselves as *professionals*. No longer were they, as the old metaphors had suggested, the loyal handmaidens of medical men: they were professionals whose primary responsibility—like that of all professionals—was to their clients or patients....

### Nursing—a Naturally Subservient Profession?

... Our first question must be this: *should* nurses reject their traditional largely subservient role and act as patient advocates? ...

From Caring: Nurses, Women and Ethics (New York: Wiley-Blackwell, 1997), 35–36, 41–53, 58–60.

... I shall, without argument, assume that a profession such as medicine or nursing does not exist for the sole or even primary purpose of benefiting its members. This view is widely shared and is implicit in most if not all professional codes; it is also regarded as one of the necessary conditions for an organization to claim professional status. For the purposes of our discussion, then, I shall assume that both nursing and medicine are professions which are, or ought to be, aiming at the welfare of others, where those others are patients or clients.

This raises the question of the relationship between medicine and nursing, and between doctors and nurses. Might it not be the case that the subordinate role of nurses has its basis not in objectionable sexism but rather in a natural hierarchy between the professions, a hierarchy that serves patients best?

Robert Baker is among those who have pointed out that we cannot simply assume that the nurse's subservient role has a sexist basis. He does not deny that sexism exists or that the subservient nursing role has traditionally been seen as a feminine one; but, he writes,

it is not at all clear whether the role of the nurse is seen as dependent because it is filled by females, who are held to be incapable of independent action by a male-dominated, sexist society... or whether females have been channelled into nursing because the profession, *by its very nature*, requires its members to play a dependent and subservient role (i.e., the traditional female role in a sexist society).

In other words, the facts that almost all nurses are women, that the traditional nurse's role has been a

subservient one and that most societies were and are male-dominated and sexist, cannot lead us to the conclusion that the nurse's role necessarily rests on objectionable sexism. The nurse's role may, 'by its very nature', be a subservient one. But is nursing 'by its very nature' subservient to medicine—is it a naturally subservient profession?

There is clearly something odd about speaking of the 'natural subservience' of nursing to medicine, or for that matter of 'the natural subservience' of any profession in relation to another. To speak of 'natural subservience' suggests that the subservient or dominant character of the relevant profession is somehow naturally given and in that sense fixed and largely unchangeable. But is this view correct? As we have seen above, nursing has developed in a very particular social and historical context, in response to the then prevailing goals and purposes of medicine on the one hand and the social roles of women and men on the other. Would this not make it more appropriate to view the character of the two health-care professions, and the tasks and privileges that attach to them, as a historically contingent accident or social construct, rather than as a compelling natural necessity?

It seems to me the answer must be 'yes'. There are no natural professional hierarchies that exist independently of human societies, and we should reject the idea that professions have fixed natures and instead view them as changing and changeable social institutions. When looking at professions in this way we may, of course, still want to think of them as having particular characteristics by which they can be defined ('social natures', if you like), but we would now view these characteristics as socially constructed, in much the same way as the institution itself is a social and historical construct.

How, then, might one go about capturing the 'social nature' or characteristics of a profession? One might do this in one of two ways: either by focusing on the functions or roles performed by members of the profession or by focusing on the profession's philosophical presuppositions or goals.

#### **Function or Role**

What is the function or role of a nurse? What is a nurse? The clear and neat boundaries and distinctions

presupposed by our everyday language and by the terms we use rarely accord with the real world. We often speak of 'the role' or 'the function' of the nurse, or of 'the role' or 'the function' of the doctor. These terms are problematical because nurses and doctors working in different areas of health care perform very different functions and act in many different roles, and there is a considerable degree of overlap between the changeable and changing functions performed by members of the two professions.

The expansion of knowledge, of nursing education, and of medical science and technology has resulted in the redefinition and scope of nursing practice. Nurses now carry out a range of procedures that were formerly exclusively performed by doctors. Some nurses give injections, take blood samples, administer medication, perform diagnostic procedures, do physical examinations, respond to medical emergencies and so on.

Take diagnosis and medical treatment. The diagnosis and treatment of medical problems had always been regarded as the realm solely of doctors. But, as Tristram H. Engelhardt notes, if one looks closely at the diagnostic activities performed by nurses, it is difficult to see them as essentially different from medical diagnoses. Nursing diagnoses such as "Airway clearance, ineffective"; "Bowel elimination, alteration in: Diarrhoea"; "Cardiac output, alteration in, decrease"; "Fluid volume deficit", Engelhardt points out, all have their medical equivalents; and the diagnosis of psychological or psychiatric disturbances, such as "Coping, ineffective individual", or "Thought processes, alteration in" can be given analogues in the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association.'

Nurses are not permitted by law to perform any 'medical acts', but in practice the line between medical and nursing acts has become rather blurred and is, in any case, the result of social and historical choice. Moreover, as nurses have become more assertive and conscious of their own knowledge and expertise, there has been a broadening of the definitions of nursing practice. In 1981 the American Nursing Association thus produced a model definition of nursing practice, which included 'diagnosis

... in the promotion and maintenance of health'. By 1984, 23 US states had included [nursing] diagnoses, or similar terms, in their nursing practice acts.

To conclude, then, the fact that nurses work in very different areas of health care, where they perform very different functions, and the fact that there are considerable overlaps between contemporary nursing functions and the functions traditionally performed by doctors makes it difficult to see how it would be possible to define nursing in terms of a particular function or role performed by nurses. If we thus think of 'the nature' of nursing in terms of some specific function or role performed by all nurses, this suggests not only that nursing lacks a particular nature, but also makes it difficult to claim that nursing is 'naturally subservient' to medicine.

It is true, of course, that nurses frequently work under the direction of doctors, and that control over many of the functions performed by them is retained by the medical profession. It is also true that only doctors may, by law, perform operations, prescribe medical treatments and authorize access to certain drugs. This might lead one to the conclusion that nursing and medicine can be distinguished by the range of socially and legally sanctioned tasks and privileges that members of one but not of the other profession may lawfully engage in. Such a distinction would, of course, be possible. But it is not a distinction that allows one to infer anything about the subservient or dominant 'nature' of either one of the two professions. The distribution of socially and legally sanctioned privileges and powers between medicine and nursing is itself a historically contingent fact, and there is nothing to suggest that the current distribution of powers and privileges is either natural or that it is the one that we should, upon reflection, adopt.

For example, why should it be the doctor who decides whether a patient should be resuscitated or not? Should it not be the patient? And if not the patient, why not the nurse?

### **Philosophical Commitment**

Is it possible to distinguish the two professions by their philosophical commitment, that is, by the philosophical presuppositions that guide their respective health-care endeavours? It is, again, not easy to see how this might be done. Someone intent

on rejecting the view that nursing is naturally subservient to medicine might point out that there is no essential difference between the philosophical commitment of the two professions that would allow one to speak of one of them as being subservient to the other. Both nursing and medicine are other-directed and committed to the welfare of clients or patients; members of both professions have a similar understanding of pain and of suffering, of well-being and of health, and both accept the same scientific presuppositions. If there are differences between individual doctors and nurses, these are no more pronounced than those found between individuals from the same professions. Hence, one might conclude, nursing does not have a nature which is different from that of medicine and can therefore not be said to be naturally subservient to medicine.

Another, diametrically opposed avenue is sometimes chosen by those writing in the field to prove wrong the claim that the nurse's role is a naturally subservient one. Rather than trying to show that the nurse's role is—either functionally or in terms of its philosophical commitment—*indistinguishable* from that of doctors, this second group of nurses claims that the nursing commitment is fundamentally *different* from that of medicine. In other words, those who take this approach start with the premise that medicine and nursing have different philosophical commitments or 'natures', and then go on to deny that this will necessarily lead to the conclusion that nursing ought to be playing a subservient role to medicine.

This is generally done in one of two ways. The first involves drawing a distinction in terms of a commitment to 'care' and to 'cure'. Whereas medicine is said to be directed at 'cure', the therapeutic commitment or moral end of nursing is identified as 'care'. Medicine and doctors, it is said, often focus on treating or curing the patient's medical condition; nursing, on the other hand, is based on holistic care, where patients are treated as complex wholes. As a number of Australian nurses put it in their submission to a 1987 inquiry into professional issues in nursing:

Medical science and technology is concerned with disease diagnosis and cure. This reductionist model

of care inevitably dissects, fragments and depersonalises human beings in the process of caring. The nurse's caring role demands the preservation and integrity of the wholeness of human beings.

The second way of attempting to draw a distinction between nursing and medicine involves an appeal to two different ethics. Whereas medicine is said to be based on principles and rules (a so-called [male] ethics of justice), nursing is said to be based on relational caring (a so-called [female] ethics of care). This means, very roughly, that doctors will put ethical principles or rules before the needs or wants of individual patients, whereas nurses regard the needs or wants of individual patients as more important than adherence to abstract principles or rules.

These two views do not deny that nursing is context-dependent or that nurses perform very different functions in different health-care settings; they also acknowledge that nurses and doctors sometimes perform very similar or identical functions and act in very similar roles. None the less, those who take this view assume that nursing is different from medicine because it has a different philosophical commitment or end—that of care. 'Care'—the nurture, the physical care, and the emotional support provided by nurses to preserve the 'human face' of medicine and the dignity of the patient—cannot, the suggestion is, 'be absent if nursing is present'.

There are a number of reasons why I am pessimistic about the endeavour of distinguishing nursing from medicine and nurses from doctors in this way. We will discuss some of these at length in later chapters of this book. Here the following will suffice: it seems very difficult, in a straightforward and practical sense, to make philosophical commitments, such as the commitment to care, the defining characteristic of a profession. Such a definition would presumably include all nurses who have this commitment, but would exclude all those who do not. A registered nurse, who has all the relevant professional knowledge and expertise, who performs her nursing functions well, but—let us assume—subscribes to 'the scientific medical model' or to an 'ethics of justice' would now, presumably, no longer be a nurse. Would her

philosophical commitment make her a doctor? And would a doctor, who subscribes to 'care' now more appropriately be described as a nurse?

The problem is raised particularly poignantly in settings, such as intensive care units (ICUs), where the emphasis is on survival and 'cure'. After Robert Zussman, a sociologist, had observed doctors and nurses in two American ICUs for some time, he reached the conclusion that ICU nurses were not 'gentle carers' but technicians. Zussman does not deny that other nurses may well be differently motivated, but in the ICU, he says, they are 'mini-interns'. 'They are not patient advocates. They are not "angels of mercy". Like physicians, they have become technicians.'

For all practical purposes, attempts to define a profession in terms of its philosophical commitment simply would not work. How would one test a potential nursing candidate for it? How could one ensure continued commitment—especially in a high-technology environment such as intensive care? And why should we assume that 'care' should always have priority over either principle or cure? Are there not times when proper care demands that we attempt to 'cure' or when ethical principle ought to trump care? If the answer is 'yes', as I think it should be, then we should abandon the attempt to draw a distinction between nursing and medicine in these ways.

There is, of course, another reason as well: Even if a sound distinction in the philosophical or ethical commitments of nursing and medicine could be drawn, this would not settle the question of whether nursing is or is not a naturally subservient profession. The fact (if it is a fact) that medicine has one philosophical commitment or nature and nursing another is quite independent of the further question of whether one of the professions is, or ought to be, subservient to the other. Further argument would be needed to show that, for nothing of substance follows from establishing that one thing, or one profession, is different from another.

### **Subservience for the Sake of Life or Limb?**

What arguments could be provided to show that nurses and nursing ought to adopt a subservient role to doctors and medicine? In accordance with

our assumption that nursing is an other-directed profession, a profession that primarily aims at the good of patients, such arguments would have to show that nurses' subservience would benefit patients more than nurses' autonomy. . . .

[O]ur main focus will be hospital-based nurses. Most nurses work in hospitals, and it is part of their role to carry out the treatment plans of doctors. Here a powerful argument is sometimes put that, regardless of what is true for other nurses, it is essential that nurses who work in acute-care settings adopt a subservient role. Those who take this view do not necessarily deny that it may be quite appropriate for some nurses, in some contexts, to play an autonomous role; but, they insist, when we are talking about hospitals matters are different.

Hospitals are bureaucratic institutions and bureaucratic institutions, so a typical argument goes, rely for efficient functioning on vertical structures of command, on strict adherence to procedure and on avoidance of initiative by those who have been charged with certain tasks. While this is true of all bureaucratic institutions, strict adherence to rules and to chains of command becomes critically important when we are focusing on hospitals. In such a setting much is at stake. A patient's health, and even her life, will often depend on quick and reliable responses by members of the health-care team to the directions of the person in charge.

Let us accept that efficiency will often depend on some of the central criteria identified above. This does not, however, answer questions regarding the proper relationship between nurses and doctors. Take the notion of a bureaucratic hierarchy. A simple appeal to that notion does not tell us how the bureaucratic hierarchy should be arranged. Here it is generally assumed that it is appropriate for doctors to be in charge and appropriate for nurses to follow the doctors' orders. But why should this be so? Why is it so widely assumed that doctors should perform the role of 'captain of the ship' and nurses those of members of the crew?

#### The Argument from Expertise

The reason most commonly given for this type of arrangement is that doctors, but not nurses, have the relevant medical knowledge and expertise to

deal with the varied and often unique medical conditions that afflict patients, and the different emergencies that might arise. Just as it would not do to put crew-members with only a limited knowledge of navigation in charge of a ship traversing unpredictable and potentially dangerous waters, so it would not do to put nurses with only a limited knowledge of medicine in charge of the treatment plans of patients. Many a ship and many a patient would be lost as a result of such an arrangement. Hence, if we want ships and patients to be in good hands, it follows that those with expertise—doctors and captains—must be in charge.

Such an argument is put by Lisa H. Newton, a vocal critic of nursing's quest for autonomy. If the purpose of saving life and health is to be accomplished in an atmosphere which is often tense and urgent, then, Newton argues,

all participating activities and agents must be completely subordinated to the medical judgments of the physician. . . . [T]hose other than physicians, involved in medical procedures in a hospital context, have no right to insert their own needs, judgments, or personalities into the situation. The last thing we need at that point is another autonomous professional on the job, whether a nurse or anyone else.

There is something right and something wrong about the above kind of argument. To see this, the argument needs untangling.

#### Shared Goals, Urgency and Medical Authority

In her argument Newton implicitly assumes that the therapeutic goals of doctors are morally worthy ones, and that the ethical question of whether a doctor should, for example, prolong a patient's life or allow her to die is not in dispute. This assumption is inherent in her observation that the tasks at hand are, or ought to be 'protective of life itself'. While we know that this very question is frequently in dispute, let us, for the purpose of our initial discussion, accept and work with that assumption. We shall question it later.

There is no doubt that doctors have special medical expertise that is relevant to the achievement of various therapeutic goals, including the goal of

saving or prolonging life. Extensive medical studies and registration or licensing procedures ensure that doctors are experts in medical diagnosis and medical therapy. Their education equips them well to act quickly and decisively in complicated and unforeseen medical circumstances. As a general rule (but only as a general rule—there could be exceptions to this rule) doctors would thus be better equipped than nurses to respond to a range of medical emergencies. In emergency situations, then, where urgent action is required, it is likely that the best outcome for patients as a whole will be achieved if doctors are in charge. Moreover, since the outcome of medical measures in such contexts often depends crucially on the practical assistance of nurses, it is important that nurses will, as a general rule, quickly and unquestioningly respond to the doctor's orders.

It seems that we should accept this type of argument. During emergency procedures it is more likely that the desired outcome will be achieved if there is not only a single decision-maker, but if this single decision-maker is also the most expert medical professional in the field. This will typically be the doctor.

In addition to those cases where urgent action by a medical expert is required to achieve the desired therapeutic goal, there are also some other specialized contexts, such as the operating room, where it is appropriate for doctors to exercise and for nurses to recognize medical authority....

There is a connection, then, between the possession of particular expertise and authority. Expertise can be crucial to the achievement of goals and, provided the goals are shared, it will frequently be appropriate for people who are authorities in a particular field to also be in authority.

If we accept this argument, it follows that doctors ought, other things being equal, to be in charge in medical emergencies and in other specialized contexts that are characterized by an element of urgency. They ought to be in charge because this arrangement best ensures that the therapeutic goal will be reached.

Acceptance of this view has, however, less far-reaching consequences than might be assumed. First, even if particular therapeutic treatment goals are most likely to be achieved if a single medically trained person is in charge *during*, for example, operations or resuscitation procedures, this does not

entail that the doctor should have overall authority as far as the patient's treatment is concerned. The authority to decide on an operation or on the desirability of implementing resuscitation procedures might, for example, rest with the patient or her relatives, and the nurse could conceivably be in charge of the overall treatment plan of the patient.

Second, it does not follow that nurses must, even during emergency procedures, *blindly* follow a doctor's order. Doctors, like the rest of us, are fallible human beings and sometimes make mistakes. This means that the nurse's obligation to follow a doctor's order, even in these specialized contexts, cannot be absolute and may at times be overridden by other considerations, such as the avoidance of harm to patients.

A study conducted in 1966, when nurses were probably more likely unquestioningly to follow a doctor's order than they are now, demonstrates that unquestioning obedience to doctors is likely to have some rather undesirable consequences for patients. In the 1966 study, nurses were asked by a doctor, by telephone, to prepare medication which was obviously excessive and to give it to a patient. Twenty-one out of 22 nurses followed the doctors' orders and were ready to give the medication to the patient when the researchers intervened....

Given, then, that doctors will occasionally make mistakes and that nurses frequently have the professional knowledge to detect them, it will be best if nurses do not understand their duty to follow a doctor's order as an absolute and exceptionless one. If the doctor's order is, in the nurse's professional judgment, clearly wrong, then the nurse must bring her 'professional intelligence' into play and question it....

Does a nurse who subscribes to the general proposition or rule that there are times when it will best serve the interests of patients that she accept the authority of doctors thereby necessarily adopt a subservient or non-autonomous role? Does she abrogate her autonomy? I think not. As long as a nurse does not *surrender* her autonomy or judgment, that is, does not blindly follow every order she is given, but rather *decides*, after reflection, to adopt a general rule that it will be best to accept and act on the doctor's authority under certain circumstances,

then she is not a subservient tool in the doctor's hands. She is not, as was once proposed, simply 'an intelligent machine'. She is a moral agent who, in distinction from a mere machine, *chooses* to act in one way rather than another.

To sum up, then: the argument that nurses should—for the sake of achieving certain worthy therapeutic goals such as the saving of life—adopt a subservient role to doctors typically rests on at least two rather dubious assumptions. The first assumption is that all or most decision-making is characterized by great urgency. The second assumption is that the therapeutic goal is best achieved by nurses adopting an absolute rather than a *prima facie* rule to carry out the doctor's orders. But, as we have seen, both assumptions must be rejected, on the grounds outlined above. . . .

### **Do Patients Need Subservient Mother Surrogates?**

A different kind of argument is sometimes put to show that nurses should, for the sake of patients, adopt a subservient role to doctors. Only then, the argument asserts, will nurses be able to meet the emotional needs of patients. To examine that claim, we shall once again focus on an argument provided by Lisa H. Newton. In her defence of the traditional role of the nurse, Newton appeals to an argument based on the patient's needs. Because a patient may not be able to take care of himself, Newton points out,

his entire self-concept of an independent human being may be threatened. . . . He needs comfort, reassurance, someone to talk to. The person he really needs, who would be capable of taking care of all these problems, is obviously his mother, and the first job of the nurse is to be a mother surrogate.

But, Newton continues her argument, mothers are not only figures of considerable authority; it is also ordinarily part of the mother's role to take control of various aspects of her dependent children's lives, and to make important decisions for them. Patients are, however, not children. Their autonomy must be protected from the threatening authority of the mother surrogate. This requires, Newton asserts, that

the role of the nurse must be from the outset, as essentially as it is nurturant, unavailable for such attribution of authority. Not only must the role of the nurse not include authority; it must be incompatible with authority: essentially, a subservient role.

This non-threatening caring function, performed by the nurse, would not only permit the patient 'to be cared for like a baby', but would also allow patients to unburden themselves and to express their doubts and resentments about doctors and the treatments prescribed by them. Patients, Newton notes, may sometimes be torn between the desire to discontinue treatment (to reassert control over their lives) and a desire to continue treatment (to reap its benefits). The nurse will be there as a sympathetic listener 'but in her subordinate position . . . can do absolutely nothing to change the course of treatment,' that is, both nurse and patient are subject to what she calls the 'sapiential authority' of the physician.

The traditional subordinate role of the nurse is thus justified by the needs of patients. Patients, Newton holds, need the emotional support of a mother surrogate but, to protect the patient's autonomy and to ensure compliance with the medical treatment plan, the nurse must completely surrender her autonomy.

Should we accept this type of argument? The first point to be noted is this: Newton's claims about humiliating treatment, about strong emotional needs and about the threatened loss of the patient's self-concept as an independent human being, while undoubtedly correct in some cases, do not apply to all patients and in all circumstances. Many patients enter hospital for relatively minor treatments or observations and do not feel that their self-concept is threatened in any way by their status of patient. They do not need or want a mother surrogate. Rather, their needs are much more likely to be met by a nurse who not only provides them with professional nursing care, but who also refuses to surrender her professional intelligence and autonomy to the doctor to protect the patient from potential harm.

Then there are the patients who are seriously ill and whose self-concept may indeed be threatened by the medical treatment they are receiving or by their incapacitated state. Many of these patients will

undoubtedly benefit from the presence of a caring and sympathetic nurse, who will listen to them with warmth and understanding. But would they want the subservient nurse Newton holds in store for them? Would their emotional needs really be satisfied by talking to a self-effacing health-care professional who, afraid of either posing a threat to the patient's autonomy or the 'sapiential authority' of the doctor, would be making sympathetic clucking noises, but would not engage with the patient in any meaningful way? I doubt it very much. By refusing to engage with patients in a meaningful way, she would be signalling to them that she does not take their concerns seriously, no more seriously than a well-meaning mother would take the incoherent babbling of her sick baby. This would not only be extremely upsetting to many patients, but would also enforce their sense of powerlessness, the feeling that they have lost control over their lives—as indeed they may have....

As we noted above, Newton recognizes that a patient may wish to discontinue treatment so as to 'reassert control over his life'. Would supporting the patient in this desire—assuming that it is a reasonable one—really threaten his autonomy? And is not the nurse's refusal ever to take the patient's desire seriously tantamount to abandoning him to another authority—the authority of the doctor? While we should not ignore the possibility that a powerful mother figure might pose a threat to the patient's autonomy, why should we assume that a powerful father figure—that of the doctor—might not pose a similar or a greater threat?

Newton simply assumes that the therapeutic success of treatment presupposes that the patient defer to the 'physician's sapiential authority'. What she does not explain, however, is why the physician's ends or goals—therapeutic success or prolongation of life, for example—should count for more than, say, the judgment of the patient or the nurse. In other words, we are not told where the doctor's moral authority comes from or why we should regard his decisions as sound.

I doubt that a totally subservient nurse could even meet the basic emotional needs of patients, or that she could meet them any better than an autonomous nurse could; and a subservient and self-effacing nurse certainly could not meet the perhaps even stronger needs of patients who want to retain or regain control of their lives and make treatment decisions for themselves.

The adoption by nurses of a subservient role of the kind envisaged by Newton would most likely harm patients more than it would benefit them; it would also be an utterly demoralizing role for many contemporary nurses, even if it would be compatible with some understanding of autonomy. Nurses would be required to stand by, doing nothing, while doctors make the occasional mistake, or provide treatment to unwilling but disempowered patients. To conclude, then, I can see no good reason why nurses should adopt a subservient mother surrogate role for the sake of patients. On the contrary, there are a number of strong reasons why nurses should reject it.

# Truth-Telling and Confidentiality

A major moral issue in patient-provider relationships is how to handle the truth—specifically, whether doctors and nurses should always tell the truth to patients and whether doctors and nurses should ever reveal the truth about their patients to others. The former question is about the presumed duty of providers not to deceive patients or withhold relevant medical information from them. The latter is about confidentiality, a provider's obligation to protect a patient's privacy. In both, the issues raised are contentious and ongoing, reverberating among patients, families, and caregivers and often forcing shifts in the policies and culture of medical practice. Though the debates are complex, they usually come down to disagreements about the limits of paternalism and the proper balance between the principles of autonomy and beneficence.

## PATERNALISM AND DECEPTION

From ancient times, the principle of nonmaleficence—the duty to do no harm—has been enshrined in codes of medical ethics. But not so with the duty of truthfulness. The Hippocratic Oath does not mention an obligation of truth-telling or disclosure, and until 1980 even the professional code of the American Medical Association did not say anything about dealing honestly with patients. Many physicians have viewed the truth as something to conceal or reveal for the therapeutic good of the patient. For them, the overriding principle was beneficence (or nonmaleficence), which was best honored by delicately managing what patients knew about their own cases. The truth could be

harmful, unsettling, and depressing—so why inflict it on vulnerable patients? In a famously blunt formulation of this view, an early-twentieth-century physician declared that to be compassionate and gracious, doctors “must frequently withhold the truth from their patients, which is tantamount to telling a lie. Moreover, the physician soon learns that the art of medicine consists largely in skillfully mixing falsehood and truth.”<sup>1</sup>

Nowadays, in the age of patient autonomy and informed consent, such strong paternalistic sentiments are less common. Most physicians value truth-telling, and professional standards encourage it while counseling sensitivity in conveying vital information to patients. But the moral problem of truthfulness still presses both physicians and patients, prompting questions with which they still wrestle. Is it ever morally permissible for a physician to lie to a patient? Does a physician's duty of beneficence sometimes justify deception? Does respect for patient autonomy rule it out? If there are exceptions to a duty of truthfulness, what are they?

Consider how easily (and painfully) such questions can arise. Karen, a 30-year-old woman with two small children, is admitted to the hospital after experiencing headaches, vomiting, memory loss, and partial paralysis. Dr. Smith runs numerous tests and discovers that Karen has a malignant brain tumor. It is advanced and untreatable, leaving Karen with only weeks to live. Before the tests, she had told Dr. Smith that she was terrified of cancer because her husband died of lung cancer and her mother of breast cancer. And if she succumbed to cancer, what would happen to her children? Who would care for them?

## IN DEPTH

### DO PATIENTS WANT THE TRUTH? DO PHYSICIANS TELL IT?

- In 1961, a survey of physicians found that 90 percent of them would avoid telling patients of a diagnosis of cancer. But in a similar 1979 survey, 97 percent of physicians said that they would disclose a diagnosis of cancer.

- More recent research suggests that most physicians in Western cultures inform their cancer patients of their diagnosis, but fewer of them tell cancer patients about their prognosis.
- Several studies indicate that most cancer patients want to know the details of their disease, whether the news is good or bad.
- Surveys suggest that patients differ in the kinds of medical information they would like to have and how it is communicated to them.

From L. J. Fallowfield, V. A. Jenkins, and H. A. Beveridge, "Truth May Hurt but Deceit Hurts More: Communication in Palliative Care," *Palliative Medicine* 16 (2002): 297–303.

Dr. Smith considers carefully whether to tell Karen of the dire prognosis. He thinks about the misery that full disclosure would cause her, the days spent in terror before the end, the dark depression that would likely spoil her remaining time with her children.

He decides to shield her from the terrible facts, shrouding them in vague statements and irrelevant details. He tells her that she has a brain disease requiring neither surgery nor radiation, and he assures her that he has many drugs at his disposal for treating her symptoms. Karen is relieved to hear the news and does not question Dr. Smith's explanation. Sensing that disturbing details might lie behind his murky pronouncements, she presses him no further and tries to rouse a sense of optimism. She is eager to go home so things can get back to normal.

The next day she does go home. But after two weeks of trying to resume her normal routine, after enduring more headaches and vomiting, she collapses and dies.<sup>2</sup>

Notice that in this scenario Dr. Smith does not actually lie to Karen (that is, intentionally give her false information), but he does deliberately mislead her by withholding crucial facts and avoiding definite statements. Either way, he handles her paternalistically. Notice also that this story is about protecting a patient from a

dreadful prognosis, but such paternalism can also apply to the truth about diagnoses and treatments.

Some medical writers would agree with Dr. Smith's decision. They think there are good reasons for occasionally misleading or lying to patients. Their main argument is that truth-telling can be injurious, evoking in patients feelings of panic, hopelessness, fear, and depression—any of which can worsen the patient's condition, sap her will to live, or tempt her to suicide. Honest disclosure must be modulated to promote the patient's welfare. The physician's duty to do no harm must take precedence over the obligation of veracity.

Others reject this argument, contending that it exaggerates the harm done to patients by full disclosure (and underestimates the beneficial effects of truthfulness) and fails to recognize that misleading or lying to patients can also do damage. A common suggestion is that if patients knew the truth about their situation, they would likely live their lives very differently than if they remained ignorant. If so, not knowing the truth robs patients of informed life decisions. If they knew their prognosis was terminal, for example, they might try harder to make every remaining day meaningful, to put their financial and legal affairs in order, and to behave differently toward their family and friends.

Advocates of full disclosure (that is, honest communication of the essential facts) also insist that informed patients are better patients—that patients who know where they stand are more likely to comply with the requirements of their treatment.

Moreover, some argue that deception breeds distrust—and not just between patient and doctor:

[T]he long-term effect of lies on the family and, perhaps most importantly, on society, is incalculable. If trust is gradually corroded, if the “wells are poisoned,” progress is hard. Mistrust creates lack of communication and increased fear, and this generation has seen just such a fearful myth created around cancer.<sup>3</sup>

The impact of the truth on patients may also depend largely on how it's told. As one writer puts it, cases that seem to indicate that truth-telling is harmful to patients may instead

argue, not for no telling, but for better telling, for sensitivity and care in determining how much the patient wants to know, explaining carefully in ways the patient can understand, and providing full support and “after-care” as in other treatments.<sup>4</sup>

Another argument against full disclosure is that patients do not want to know the truth, especially if the prognosis is grim. A common claim is that even when patients say they want all the facts, they actually do not. Many writers counter this view with data from surveys suggesting that most patients really do prefer to be told the truth about their diagnosis. In light of these findings, presuming that patients do not mean what they say seems questionable at best.

None of this implies that the truth should be forced upon patients who genuinely choose not to be informed about their medical condition. As one commentator notes, autonomy can be served by offering a patient “the opportunity to learn the truth, at whatever level of detail that patient desires.”<sup>5</sup>

Many skeptics of full disclosure have argued that physicians have no duty to tell patients the

truth because patients are incapable of understanding it anyway. The practice of medicine is technically complex—so complex that even when a physician tries to explain the relevant facts to patients, they cannot grasp them. Telling patients the whole truth, the skeptics say, is impossible.

Critics of this argument say that even if communicating the whole truth is impossible, physicians still have a duty of complete honesty—an obligation to try hard to convey to patients the essential and relevant information. What's more, some argue that conveying the “whole truth and nothing but the truth” is unnecessary:

[T]he explanation of a complicated situation in ways a layperson can understand is not a challenge unique to physicians. The same problem is faced by lawyers, electricians, automobile mechanics, and computer help-line workers. In none of these fields, including medicine, is it necessary to provide the layperson with a complete explanation (the “complete truth”) of a situation. All a patient requires is an understanding adequate to appreciate the nature and seriousness of his illness and the potential benefits and risks of the available therapies. A diabetic need not know the stages of oxidative phosphorylation to grasp the importance of insulin and the role of diet in maintaining her health.<sup>6</sup>

The main argument in favor of truth-telling rests on the principle of autonomy. The gist is that we must always respect people's autonomy—their rational capacity for self-determination. Autonomous persons must be allowed to freely exercise this capacity: to decide how to live their own lives and what can and cannot be done to their own bodies. To respect their autonomy is to respect their freedom to act by their own lights, as long as their actions accord with the freedom of others. When physicians deceive a patient, they fail to respect his autonomy by constraining his ability to make informed choices. They compel him to make important decisions in a fog of distorted or missing information.

Many who insist on truth-telling and respect for autonomy admit that deceiving a patient may sometimes be necessary, but they say that any deception requires strong justification and should be a last resort. Some contend that deceiving a patient is permissible only when the deception is small and the benefits to the patient are great (as when a minor lie will save the patient's life). Most who argue in this vein believe that cases of permissible deception are rare.

### **CONFIDENTIAL TRUTHS**

Truth-telling, then, is about health professionals imparting relevant facts to patients. Confidentiality concerns patients imparting information to health professionals who promise, implicitly or explicitly, not to disclose that information to others. It is an obligation or pledge of physicians, nurses, and others to keep secret the personal health information of patients unless they consent to disclosure. Most people probably assume they have a right to confidentiality. Physicians also take seriously their duty to protect patient privacy, though they may differ on whether the duty is absolute or *prima facie*. Their respect for confidentiality goes back centuries, having been boldly expressed in a long line of medical codes from ancient Greece onward. The Hippocratic Oath has the physician swear that "whatever I see or hear, professionally or privately, which ought not to be divulged, I will keep secret and tell no one."

Arguments for confidentiality can take both consequentialist and nonconsequentialist forms. The consequentialist can argue that unless patients are able to rely on a physician to keep their secrets, they would be reluctant to reveal truthful information about themselves—information needed if the physician is to correctly diagnose their illnesses, devise effective treatments, and provide informed prognoses. Without respect for confidentiality, physicians would have a difficult time fulfilling their duty of beneficence. Worse, trust between physician and patient would break down, and trust is what makes the

practice of medicine possible. But beyond issues of trust, the consequentialist can offer other dire consequences to consider. Disclosure of confidential medical information could expose patients to discrimination from insurance companies and employers, disrupt their personal relationships, and subject them to shame or public ridicule.

The nonconsequentialist can argue from the principle of autonomy the idea that people should be allowed to exercise their capacity for self-determination. Autonomous persons, the argument goes, have a right to determine what may or may not be done to them—not just to their bodies and to their property, but to their private lives. They therefore have a right to control access to information about themselves and to limit intrusion into their personal affairs. They have, in other words, a **right to privacy**, the authority of persons to control who may possess and use information about themselves.

A related argument is that the physician-patient relationship is based in part on the physician's implicit promise to patients to preserve confidentiality and to respect their privacy. Patients' confidentiality must therefore be protected because the physician has promised to do so. Confidentiality arises from the physician's obligation to keep promises, what some call a duty of fidelity. Others see this line as another argument from autonomy because, as Kant would have it, to break a promise is to violate autonomy.

As hinted earlier, an important issue is whether the obligation to respect confidentiality is absolute (applying in all cases) or *prima facie* (allowing exceptions when other duties obtain). Some argue for absolute confidentiality, insisting that *any* breach of it undermines trust between physicians and patients and amounts to impermissible deception. But many believe that exceptions are sometimes justified when confidentiality must be weighed against other duties, such as the duty to prevent serious harm to the patient and others. The law reflects this *prima facie* view of confidentiality. It recognizes that

**LEGAL BRIEF****Confidentiality and a Duty to Warn**

In the landmark 1976 case *Tarasoff v. Regents of the University of California*, the court held that duties of patient–psychotherapist confidentiality can be overridden when “a patient poses a serious danger of violence to others.” In related cases:

- In 1983 people who were shot by John Hinckley as he tried to assassinate Ronald Reagan sued the psychiatrist who had been treating Hinckley. In *Brady v. Hopper*, a federal district court ruled that unless a patient makes a specific threat to a readily identifiable

person, the patient’s therapist cannot be held responsible for injuries inflicted on third parties by the patient.

- In *Bradley Center Inc. v. Wessner* (1982) and *Hedlund v. Superior Court of Orange County* (1983), the courts found that therapists are obligated to take reasonable steps to determine the degree of danger posed by a patient.
- In *Ewing v. Goldstein* (2004) and *Ewing v. Northridge Hospital Medical Center* (2004), the California Court of Appeal held that a therapist has a duty to warn third parties of a possible danger posed by a patient even if the threat is communicated not by the patient but by the patient’s family.

communication between physicians and patients is “privileged” and should generally be safeguarded from invasion—yet requires physicians to breach confidentiality in some cases. State law, for example, may oblige physicians to reveal information about a patient if she has a serious contagious disease, suffers from gunshot wounds, or is the apparent victim of abuse or assault (whether she is a child or an adult). Thus, physicians can find themselves pulled not only between clashing moral duties but also between moral duties and legal requirements.

These sorts of conflicts were drawn in high relief by the famous 1976 California Supreme Court case of *Tarasoff v. Regents of the University of California*. It concerned Prosenjit Poddar, a student at UC Berkeley who sought counseling from psychotherapists employed by the university hospital. He confided in them that he intended to kill another student, Tatiana Tarasoff, when she returned from a summer trip in Brazil. The psychotherapists told the police of Poddar’s intentions but warned neither Tatiana nor her parents of the threat. Judging Poddar to be rational, the police soon released him. When

Tatiana returned from Brazil, Poddar murdered her just as he said he would. Her parents sued the university for failing to warn them of the danger to Tatiana, and they won. The court recognized the importance of confidentiality but ruled that in this case the psychotherapists had a duty to breach it to warn a third party of a serious risk of harm. “We conclude,” the majority opinion said, “that the public policy favoring protection of the confidential character of patient–psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins.”

High-stakes collisions between the duties of confidentiality and preventing harm are more common than *Tarasoff* may suggest. Prime examples are cases involving patients who are HIV positive. Let’s say a physician tells her patient that he has tested positive for HIV infection, that his wife could also become infected through sexual intercourse, and that he should inform her of the risk. But he says he will not disclose his condition to anyone and demands full physician–patient confidentiality.

Or suppose this patient has no sexual partner but will be cared for at home by people who are unaware of his HIV status (and may be exposed to his body fluids). He refuses to inform them and asks his physician to tell no one. In both cases, if the physician maintains confidentiality, there is a high risk of serious harm to people, but revealing the patient's diagnosis to others destroys confidentiality. What should the physician do?

Many physicians and ethicists say that violating confidentiality in such a case is morally permissible if there is no other way to avoid the

harm to others. They assert that violations should be a last resort after exploring other alternatives, which include getting the patient to agree to notify those at risk or to cease behavior that produces the risk.

But even with such careful attention to protecting patient privacy, is complete confidentiality really feasible? According to some observers, despite the high value we put on confidentiality, it is not what it used to be. It has been eroded, they say—not by physicians and nurses, but by our computerized, bureaucratized health care systems. The number of people

### IN DEPTH TRUTH-TELLING AND CULTURAL DIVERSITY

Several studies have shown that views toward truth-telling when people are seriously ill vary dramatically by culture. Here's a partial summary of the results of one of the more recent studies:

This study of 800 elderly subjects showed that major differences exist in the way people of different ethnicities view the issue of truth-telling. One of the core differences, around which many of the themes circled, is the question of how the truth affects the terminally ill patient. On one hand, the truth can be seen as an essential tool that allows the patient to maintain a sense of personal agency and control. Seen in this light, telling the truth, however painful, is empowering. On the other hand, the truth can be seen as traumatic and demoralizing, sapping the patient of hope and the will to live. For those who hold this view, truth-telling is an act of cruelty.

In fact, many, if not most, of our subjects held both views. They differed in the relative weight given to each view. In weighing the positive benefits of the truth versus its potential to harm, the deciding factor seems to be the way

the self is understood. Are we mainly autonomous agents whose dignity and worth come from the individual choices we make with our lives, or is our most important characteristic the web of social relations in which we exist? If we hold the former view (as most of our African-American and European-American respondents did), then lack of access to the truth is almost dehumanizing since it strips us of our ability to make choices, without which we are something less than fully human. If, however, we tend to see ourselves not as individuals, but as a part of a larger social network (as was more common in the Mexican-American and Korean-American groups), then the notion of personal choice loses something of its force, and we may expect that those close to us will act on our behalf to protect and nurture us in our time of need.

Beliefs commonly held in the European-American culture about individuality, self-determination, and the importance of maintaining control too often have been treated as if they were universal ethical principles. Only by allowing diverse voices to speak, and hearing the sometimes surprising things they have to say, can we ensure that we are addressing the real concerns of the communities we serve.

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who need to know the intimate details of a patient's records—physicians, nurses, medical technicians, students, consultants, secretaries, financial officers, data managers, insurance auditors, administrators, and more—has grown beyond all expectation. And in a digitized, networked world, the opportunities for improper

or unethical access to the records have multiplied at every step. Critics contend that the traditional ideal of complete confidentiality is no longer possible, if it ever was. So they suggest that we give up the traditional notion and try to salvage the features of confidentiality that matter to us most.

#### CLASSIC CASE FILE

### Carlos R.

For many who are HIV positive, their anguish only deepens if others know about their condition. They demand medical confidentiality, and physicians are obliged to comply—but the “duty to warn” others of the risk of infection haunts both physicians and patients. Typically those thought to need warning are sexual partners and spouses, but sometimes caregivers—whether professionals or family members—are the ones of concern. This case is of the latter kind. It recounts the events that lead up to the question at issue—whether the physician’s weightier duty is confidentiality or warning—then provides the opposing views of two commentators.

Twenty-one-year-old Carlos R. entered the hospital for treatment of gunshot wounds received in gang violence. During his stay, he confided to the attending physician that he was HIV positive, and testing proved him correct. Eventually he recovered well enough to leave the hospital to have his wounds cared for at home. The attending physician advised Carlos to have daily visits from a nurse to tend to his wounds. But Carlos was uninsured, and Medicaid would not pay for the home nursing visits because his 22-year-old sister Consuela was willing and able to care for him. For 10 years since their mother died, Consuela had assumed the role of mother for both Carlos and their younger sister.

Carlos was willing to let Consuela be his nurse, but he was adamant that she not be told about his HIV status. She was unaware of his homosexual

activity, and so too was his father. More than anything else he feared that his father would learn the truth . . .

The choice for Carlos’s physician, then, was between preserving confidentiality and breaching it to warn Consuela of the risks involved in caring for an HIV-positive patient.

One commentator on this case argues against violating confidentiality. He contends that for a physician to have a duty to warn, there must be (1) “an imminent threat of serious and irreversible harm,” (2) no other way to avert that threat except by breaching confidentiality, and (3) a situation in which the harm done by the breach is on a par with the harm avoided by the breach. In his view, none of these conditions are fully met in this case. He does not believe that the risk of Consuela becoming infected with HIV is very great—and certainly not “imminent.” He also thinks that there are alternatives to breaching confidentiality—the main one being instructing Consuela in safe wound care. Moreover, he insists that the risks to Consuela from not telling her about Carlos’s HIV status are far outweighed by the awful disruption of family relations that breaching confidentiality would cause.

The second commentator argues for violating confidentiality to warn Consuela. She maintains that Consuela has a right to information whether or not there is an appreciable risk to her. One reason is that if Consuela is not being told the

truth, she is being deceived. Most people in Consuela's situation would want to know the facts and would probably assume that Carlos was not HIV positive because no one said so. Furthermore, in getting Consuela to provide nursing care, "the health care system is using her to avoid providing a service it would otherwise be responsible for." If so, then the system has an obligation to give her

the information she needs to decide whether to accept the responsibility.

In the end, the physician should require the patient to choose: "Carlos can decide to accept Consuela's generosity—in return for which he must tell her he is HIV-infected (or ask the doctor to tell her)—or he can decide not to tell her and do without her nursing care."<sup>7</sup>

### APPLYING MAJOR THEORIES

In Kantian ethics, the morality of truth-telling and confidentiality seems unambiguous. Physicians who adopt the means-end formulation of the categorical imperative, for example, seem committed to an absolute duty of preserving both. In the Kantian view, treating people merely as a means to an end is impermissible, a violation of the principle of autonomy. Lying to patients and breaching confidentiality (by breaking a promise to respect privacy) are clear instances of such violations. For a strict Kantian, these prohibitions would have no exceptions; there would be no allowances made for extraordinary circumstances. Arguments that truth-telling could be injurious to patients and must therefore be done with an eye to medical consequences would carry no weight. Likewise, there would be no place for the notion that confidentiality may be set aside if there is a conflicting "duty to warn."

For an act-utilitarian, the morality of truth-telling and confidentiality must be judged case by case, the right action being the one that maximizes the good for all concerned. In each instance, physicians must decide carefully what to disclose to a patient, calculating the impact that any disclosure would have on the patient, her family, and everyone else involved. For each decision about confidentiality, physicians must weigh the effect of the choice on the patient, the

physician-patient relationship, third parties who may be harmed by maintaining confidentiality, and themselves (who may have to contend with legal consequences).

Rule-utilitarianism tries to regulate actions by rules that, if generally followed, would result in the best consequences, everyone considered. A rule-utilitarian might argue that the greatest amount of good is produced by a rule stating that a physician should, with care and sensitivity, tell patients the truth about their condition. This rule would presumably not only be beneficial to patients but also help foster trust in patients for their physicians and for medicine generally. A similar case could be made for a rule mandating strict adherence to the principle of confidentiality. But a rule-utilitarian could also reason that the best rules are those that require less than full disclosure to patients and less than absolute confidentiality—that is, rules with some exceptions built in. For example, the best confidentiality rule might demand full respect for a patient's privacy—except when maintaining confidentiality could put someone's life in danger.

Virtue ethics also has something to say about veracity and confidentiality. Many who favor this moral outlook might contend that if a physician cultivates the virtues of honesty and fidelity, he will be more likely to communicate truthfully with patients, to keep his promises to them, and to maintain their confidences. Moreover, if he

possesses the virtue of compassion, he will be sensitive to the effect that blunt truthfulness could have on patients and will adapt his truth-telling accordingly. He will also be able to empathize with patients and understand why confidentiality matters so much to them.

#### **KEY TERMS**

confidentiality  
right to privacy

#### **SUMMARY**

Some medical writers contend that there are good reasons for misleading or lying to patients, claiming that truth-telling can evoke in patients feelings of panic, hopelessness, and depression that can worsen the patient's condition or state of mind. Honest disclosure must be modulated to promote the patient's welfare. Others reject this argument, saying that it exaggerates the harm done to patients by full disclosure and does not recognize that misleading or lying to patients can also do damage. They maintain that informed patients are better patients and that deception breeds distrust. In these debates we often hear that patients do not want to know the truth, but scientific surveys suggest that most patients do want accurate information about their diagnosis. The main argument for truth-telling rests on the principle of autonomy, the idea that people should be allowed to exercise freely their rational capacity for self-determination.

Confidentiality concerns patients imparting information to health professionals who promise, implicitly or explicitly, not to disclose that information to others. Consequentialist arguments for confidentiality say that without it, physicians would be hard pressed to obtain information from patients that could help in treatment, and trust between physician and patient would break down. Moreover, disclosure of confidential medical information could expose patients to discrimination, disrupt their personal relationships, and subject them to shame or public ridicule. Non-consequentialist arguments appeal to the principle of autonomy, contending that autonomous

persons have a right to determine what may or may not be done to their bodies as well as to their private lives. They have a right to privacy, the authority of persons to control who may possess and use information about themselves.

A major issue is whether the obligation to respect confidentiality is absolute or *prima facie*. Some argue for absolute confidentiality, insisting that any breach of it undermines trust between physicians and patients and amounts to impermissible deception. But many believe that exceptions are sometimes justified when confidentiality must be weighed against other duties, such as the duty to prevent serious harm to the patient and others.

## **Cases for Evaluation**

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### **CASE I**

#### **Disclosing Information About the Risk of Inherited Disease**

Mrs. Durham was diagnosed with an invasive epithelial ovarian cancer and, in conjunction with conversations about her treatment, was offered genetic testing for the BRCA1 and BRCA2 mutations. It was revealed that she carried a harmful BRCA1 mutation that is known to increase the lifetime risk of breast and ovarian cancer significantly. Once the results came back, her oncologist brought up the option of a prophylactic mastectomy and advised her to inform her living relatives of the results of the test.

Mrs. Durham's primary care physician, Dr. Bartlett, expected she would do so, too. At her first appointment after the diagnosis, Dr. Bartlett asked Mrs. Durham how she was holding up and how her sister, Mrs. Weir—her only living family member and also one of Dr. Bartlett's patients—had taken the news.

"Oh. Well, I haven't told her."

"Are you going to?" asked Dr. Bartlett.

Mrs. Durham responded, "You know we haven't spoken in quite some time, and I can't imagine making this the topic of our first conversation."

"Yes, I know . . . but I think this is important information that may affect her health."

Mrs. Durham sighed. "We're estranged, for one thing, and for another, I want to keep my cancer private. I don't want people knowing I'm sick and pitying me."

Dr. Bartlett felt pulled in two directions—his obligation to respect Mrs. Durham's wishes and protect her privacy conflicted with his obligation to promote Mrs. Weir's health. BRCA1 mutations are not "reportable" illnesses like HIV and tuberculosis, so he was not compelled by law to break Mrs. Durham's confidentiality. Dr. Bartlett considered how he might be able to encourage Mrs. Durham's sister to be tested for the BRCA mutations while preserving Mrs. Durham's confidentiality.\*

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*Does Mrs. Durham have a moral obligation to inform her sister of the results of the test? Why or why not? For Dr. Bartlett, what moral principles are in conflict? If Mrs. Durham refuses to inform her sister, should Dr. Bartlett tell her? What should Dr. Bartlett do if he can't subtly ask Mrs. Weir to be tested (that is, if he can't ask her without revealing the real reason for his request)?*

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\*AMA Journal of Ethics 17, no. 9 (September 2015): 819–825.

## CASE 2

### HIV and a Researcher's Duty to Warn

John, a licensed psychologist, is Principal Investigator for the "Assist" Project. His project is designed to identify behavioral trends among HIV+ adults in the New York City area. Participants were recruited from HIV/AIDS support groups, HIV/AIDS advocacy and service organizations, and through publicity in local bars, clinics and media outlets. John uses several measures to identify patterns among these individuals. He looks at help-seeking behaviors, physical and emotional symptoms, nutrition and diet habits, sexual behavior and knowledge of HIV/AIDS.

John uses an individual interview format as the method for the study. Each participant is asked to sign an informed consent form, which guarantees that all information revealed during the interviews will be kept confidential. The consent form describes the study and informs participants of the risks involved, which John identifies as minimal. Each participant is paid \$50 for each interview. Participants in the study are also provided free psychological counseling and medical care. Participants are interviewed three times over a two-year period.

In accordance with the research protocol, John asks a participant during one of the initial interviews about her current sexual practices. The participant tells John that she is having unprotected sex with her boyfriend. She states that her boyfriend does not know about her HIV status and that she has no plans to reveal her condition. Later during the interview she mentions the name of her boyfriend. John notes the information and continues with the interview.

Upon going back to his office, John becomes anxious about what he was told by the participant. He ponders what he should do. John thinks about his moral responsibility from a relational perspective, assessing the ethical problem from the standpoint of his responsibility to preserve the scientific integrity of the project, the participants' confidentiality and the boyfriend's welfare.\*

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*What moral principles seem to be in conflict in this scenario? How would you resolve the conflict? Suppose John's only options are either to maintain confidentiality or to violate it by revealing the subject's HIV status to her boyfriend (the subject refuses to notify him voluntarily). What should John do, and on what grounds could either action be justified? Suppose that state law prohibits researchers from revealing a subject's HIV status. Would this fact change your judgment? Should any such legal fact change your judgment?*

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\*Brian Schrag, ed. (Association for Practical and Professional Ethics), "Graduate Research Ethics: Cases and Commentaries—Volume 3, 1999," Online Ethics Center for Engineering, March 27, 2006, [www.onlineethics.org/CMS/research/res-cases/gradresv3.aspx](http://www.onlineethics.org/CMS/research/res-cases/gradresv3.aspx).

**CASE 3****Emergency Department Dilemma**

A 25-year-old young man is dropped off by a friend at the emergency department (ED) and states that he was in a motor vehicle accident 30 min before arriving. He says that his car was extensively damaged but that he was able to get out of the car and walk around at the scene. There was no loss of consciousness. He states that the police were at the scene investigating. He does not volunteer whether the police questioned him personally or why the police let him leave. Except for bumps and bruises, he is not significantly injured enough to justify a radiograph or computed tomography scan of his head. However, I detect the odor of ethanol on his breath, and so I order a blood ethanol to evaluate his capacity further. It is my opinion that if he is legally impaired, then he cannot leave the ED unless someone picks him up and assumes responsibility for him. He does not refuse the test and his blood ethanol level is 0.17 mg/dl, indicating that he is legally impaired.

Emergency physicians know that people who think they might be legally impaired have a strong incentive to leave the scene of accidents to avoid detection by investigating police. This patient's story about being involved in a multicar crash severe enough to cause significant property damage, and then the investigating police allowing him to leave the scene without checking him for potential ethanol intoxication does not ring true.\*

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*Should the physician maintain doctor-patient confidentiality? Should he tell the police that his impaired patient probably broke the law and may have hurt others? What moral principles are relevant to deciding what to do? How much weight would you give to them? Should regard for public safety and the law ever outweigh doctor-patient confidentiality? Explain.*

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\*“Ethics Roundtable Debate: Is a Physician-Patient Confidentiality Relationship Subservient to the Greater Good?” ccforum.com, April 25, 2005, <http://ccforum.com/content/9/3/233>.

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**NOTES**

1. Joseph Collins, “Should Doctors Tell the Truth?,” *Harper’s Monthly Magazine* 155 (1927): 320–26.
2. This scenario was inspired by one discussed in Susan Cullen and Margaret Klein, “Respect for Patients, Physicians, and the Truth,” in Ronald Munson, *Intervention and Reflection* (Belmont, CA: Wadsworth/Thomson Learning, 2004), 157–58.
3. Roger Higgs, “On Telling Patients the Truth,” in *Moral Dilemmas in Modern Medicine*, ed. Michael Lockwood (New York: Oxford University Press, 1985), 187–91, 193–202.
4. Ibid., 201.
5. Benjamin Freedman, “Offering the Truth: One Ethical Approach to the Uninformed Cancer Patient,” *Archives of Internal Medicine* 153 (March 8, 1993), 572–76.
6. Cullen and Klein, “Respect for Patients,” 161.
7. Leonard Fleck and Marcia Angell (commentators), “Please Don’t Tell: A Case About HIV and Confidentiality,” *Hastings Center Report* 21 (Nov.–Dec. 1991): 39–40.

**READINGS****On Telling Patients the Truth**

MACK LIPKIN

Lipkin urges a decidedly paternalistic attitude toward truth-telling. He argues that because the stress of being sick can distort patients' thinking and because they lack understanding of medical concepts, it is usually impossible to convey to patients the full medical truth. Many times, telling the whole truth can do more harm than good. Moreover, many patients prefer not to know the full details about their condition. "Often enough," Lipkin says, "the ethics of the situation, the true moral responsibility, may demand that the naked facts not be revealed." The critical question is not whether deception occurs, but whether the deception is meant to benefit the patient or the physician.

Should a doctor always tell his patients the truth? In recent years there has been an extraordinary increase in public discussion of the ethical problems involved in this question. But little has been heard from physicians themselves. I believe that gaps in understanding the complex interactions between doctors and patients have led many laymen astray in this debate.

It is easy to make an attractive case for always telling patients the truth. But as L. J. Henderson, the great Harvard physiologist-philosopher of decades ago, commented:

To speak of telling the truth, the whole truth and nothing but the truth to a patient is absurd. Like absurdity in mathematics, it is absurd simply because it is impossible. . . . The notion that the truth, the whole truth, and nothing but the truth can be conveyed to the patient is a good specimen of that class of fallacies called by Whitehead "the fallacy of misplaced concreteness." It results from neglecting factors that cannot be excluded from the concrete situation and that are of an order of magnitude and relevancy that make it imperative to consider them. Of course, another fallacy is also often involved, the belief that diagnosis and prognosis are more certain than they are. But that is another question.

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From *Newsweek*, June 4, 1979, p. 13. Reprinted with permission.

Words, especially medical terms, inevitably carry different implications for different people. When these words are said in the presence of anxiety-laden illness, there is a strong tendency to hear selectively and with emphases not intended by the doctor. Thus, what the doctor means to convey is obscured.

Indeed, thoughtful physicians know that transmittal of accurate information to patients is often impossible. Patients rarely know how the body functions in health and disease, but instead have inaccurate ideas of what is going on; this hampers the attempts to "tell the truth."

Take cancer, for example. Patients seldom know that while some cancers are rapidly fatal, others never amount to much; some have a cure rate of 99 percent, others less than 1 percent; a cancer may grow rapidly for months and then stop growing for years; may remain localized for years or spread all over the body almost from the beginning; some can be arrested for long periods of time, others not. Thus, one patient thinks of cancer as curable, the next thinks it means certain death.

How many patients understand that "heart trouble" may refer to literally hundreds of different abnormalities ranging in severity from the trivial to the instantly fatal? How many know that the term "arthritis" may refer to dozens of different types of joint involvement? "Arthritis" may raise a vision of

the appalling disease that made Aunt Eulalee a helpless invalid until her death years later; the next patient remembers Grandpa grumbling about the damned arthritis as he got up from his chair. Unfortunately but understandably, most people's ideas about the implications of medical terms are based on what they have heard about a few cases.

The news of serious illness drives some patients to irrational and destructive behavior; others handle it sensibly. A distinguished philosopher forestalled my telling him about his cancer by saying, "I want to know the truth. The only thing I couldn't take and wouldn't want to know about is cancer." For two years he had watched his mother die slowly of a painful form of cancer. Several of my physician patients have indicated they would not want to know if they had a fatal illness.

Most patients should be told "the truth" to the extent that they can comprehend it. Indeed, most doctors, like most other people, are uncomfortable with lies. Good physicians, aware that some may be badly damaged by being told more than they want or need to know, can usually ascertain the patient's preference and needs.

Discussions about lying often center about the use of placebos. In medical usage, a "placebo" is a treatment that has no specific physical or chemical action on the condition being treated, but is given to affect symptoms by a psychologic mechanism, rather than a purely physical one. Ethicists believe that placebos necessarily involve a partial or complete deception by the doctor, since the patient is allowed to believe that the treatment has a specific effect. They seem unaware that placebos, far from being inert (except in the rigid pharmacological sense), are among the most powerful agents known to medicine.

Placebos are a form of suggestion, which is a direct or indirect presentation of an idea, followed by an uncritical, i.e., not thought-out, acceptance. Those who have studied suggestion or looked at medical history know its almost unbelievable

potency; it is involved to a greater or lesser extent in the treatment of every conscious patient. It can induce or remove almost any kind of feeling or thought. It can strengthen the weak or paralyze the strong; transform sleeping, feeding, or sexual patterns; remove or induce a vast array of symptoms; mimic or abolish the effect of very powerful drugs. It can alter the function of most organs. It can cause illness or a great sense of well-being. It can kill. In fact, doctors often add a measure of suggestion when they prescribe even potent medications for those who also need psychologic support. Like all potent agents, its proper use requires judgment based on experience and skill.

Communication between physician and the apprehensive and often confused patient is delicate and uncertain. Honesty should be evaluated not only in terms of a slavish devotion to language often misinterpreted by the patient, but also in terms of intent. *The crucial question is whether the deception was intended to benefit the patient or the doctor.*

Physicians, like most people, hope to see good results and are disappointed when patients do poorly. Their reputations and their livelihood depend on doing effective work; purely selfish reasons would dictate they do their best for their patients. Most important, all good physicians have a deep sense of responsibility toward those who have entrusted their welfare to them.

As I have explained, it is usually a practical impossibility to tell patients "the whole truth." Moreover, often enough, the ethics of the situation, the true moral responsibility, may demand that the naked facts not be revealed. The now popular complaint that doctors are too authoritarian is misguided more often than not. Some patients who insist on exercising their right to know may be doing themselves a disservice.

Judgment is often difficult and uncertain. Simplistic assertions about telling the truth may not be helpful to patients or physicians in times of trouble.

## Is It Ever OK to Lie to Patients?

SHELLY K. SCHWARTZ

In this essay, Shelly Schwartz explores the issue of truth-telling as it relates to physicians' responsibilities, discussing legal, moral, and emotional aspects.

### Here's What You Need to Know About the Legal and Ethical Ramifications of Withholding Information from Patients

If there's one thing sacred in the doctor-patient relationship, it's trust. Open and honest dialogue on both sides of the exam table is by all accounts critical to effective care. Patients have to be truthful to ensure diagnostic accuracy and an appropriate treatment plan, while doctors need to provide full disclosure about their patient's health—the good and the bad—to help patients make informed decisions. Indeed, patient autonomy is the cornerstone of modern medicine and patient-centered care.

That patients are entitled to the truth, then, is a given, but just how much doctors are obligated to reveal is in fact a matter of much debate—particularly as it relates to the sick and dying. Physicians are often forced to balance compassion with the patient's right to know. There are patients, for example, who are too emotionally frail to be told about the progressive symptoms of their disease. There are accident victims who are alert enough to learn of a loved one's death—but whose relatives ask that the news be delivered later by a family member. There are elderly patients with dementia who would be mercilessly forced to relive the loss of a spouse on a daily basis. There are adult children who demand that you spare their elderly parent from a grim diagnosis. And there are patients whose cultural beliefs differ greatly on the topic of medical disclosure. Such scenarios beg the question: Is it ever appropriate to spin the truth or withhold information from a patient? Is it ever OK to lie?

"There are rarely cut and dry ethical issues because you've got competing interests," says Nancy

Berlinger, a research scholar who specializes in end-of-life healthcare ethics at The Hastings Center, an independent bioethics research institute in Garrison, New York. "It's very complex. No one in medicine gets up in the morning and says, 'I'm going to lie to people today.' It's more about saying, 'How do I balance my obligation to be truthful with my desire to be compassionate and how does that work, really, in practice?'"

### The Law

Informed consent wasn't always the mantra. Thirty years ago, cancer patients in the United States were frequently misled about the extent of their illness. "I remember being in medical school years ago and being distinctly told that when a person has lung cancer, never tell them they have lung cancer," says Peter Dixon, a former oncologist and current primary-care doctor with a geriatric group in Essex, Connecticut. "We were told to give them a dose of morphine and wash our hands of it. Things have certainly changed." Today, doctors are expected to treat patients as partners, delivering a complete picture of their prognosis and treatment options so patients can take an active role in their own healthcare.

Aside from the ethical mandate of truth telling in the modern age of medicine, physicians in most states are also legally obligated to disclose all relevant health information to patients. At least one exception, however, exists. Earlier this year, the Oklahoma legislature passed a law that prevents women who give birth to a disabled child from suing a doctor who misled them or outright lied about the health of their baby while they were pregnant—including cases where the fetus had a fatal anomaly that would not allow it to live outside the womb. Bill sponsors say the law is designed to

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From Shelly K. Schwartz, *Physicians Practice*, October 21, 2010, 1–3 (October 28, 2015).

prevent lawsuits by women who wish, later on, that their doctor had counseled them to abort. But opponents say it protects physicians who mislead pregnant women on purpose, to prevent them from having an abortion.

Sean F. X. Dugan, a medical malpractice defense trial lawyer and senior partner with Martin Clearwater & Bell LLP in New York, says he's also starting to see some "cracks in the citadel" over which parties physicians are obligated to be truthful to. "The law clearly indicates that the physician's fiduciary obligation runs to her patient—period," says Dugan. "But over my 30 years in practice, I've seen that iron-bound rule start to crack." In recent years, he notes, several lawsuits have been passed up through the courts in which a physician informed the spouse of a patient who was diagnosed with a life-threatening sexually transmitted disease. "Once, that would have been summarily dismissed, but now we as a society are beginning to dip our toe in the water," says Dugan. "Some courts are now beginning to say that maybe, under those circumstances, the doctor should go beyond the physician-patient relationship, and that they have a duty to disclose information to another party if they know someone is in danger." Where to draw that line is the trick. Consider patients with a contagious and deadly disease who live with someone they are not married to, or with young kids.

### A Case for Compassion?

While outright lying to patients is rare, many physicians (particularly oncologists) say that at some point in their career they have failed to answer questions directly, given incomplete information about the burden or benefit of treatment, and otherwise avoided "imminent death" discussions with patients suffering from an advanced disease, says Thomas J. Smith, professor of internal medicine, hematology/oncology at Virginia Commonwealth University and cofounder of the Thomas Palliative Care Unit at VCU Massey Cancer Center in Richmond, Virginia. Just 37 percent of terminally ill patients, he notes, have explicit conversations with their doctors about the fact that they are going to die from their disease.

The most common argument against obligatory truth telling is the impact it may have on a patient's physical or emotional state. Healthcare providers in other parts of the world, like central Asia and the former Soviet Union, still censor information from cancer patients on the grounds that it causes depression and an earlier death. "None of that is true," says Smith, whose study earlier this year found that giving honest information to patients with terminal cancer did not rob them of hope. "Most patients, certainly in the Western world, want to know what they have, what their options are, and what's going to happen to them."

Above all else, Smith notes, patients want assurances that their doctors and nurses won't abandon them when their treatment options run dry. "When there's nothing left to be done to make the cancer go away, there are still lots of things to be done to help that person adapt to their new reality and maximize the time they have left," he says, noting the benefits of knowing the gravity of their condition far outweigh [the benefits of] sparing patients from any anxiety. Disclosure enables patients to plan—to create a will and living will, make their wishes known to family members, pass along what they've learned to loved ones, name a durable power of medical attorney, decide where they want to spend the rest of their life, and make spiritual and family member amends. "You get the chance to do what some people call a life review," says Smith.

Indeed, most studies over the last decade found that patients who were told candidly they are going to die lived just as long, had better medical care, spent less time in the hospital, and had fewer "bad deaths"—those whose lives ended in the ICU, ER, or with CPR—than those who were not. A 2008 study of 332 terminally ill patients and their caregivers by researchers at the Dana-Farber Cancer Institute also found that patients who had end-of-life discussions were not more depressed, worried, or sad than those who did not. Instead they were far more likely to accept their illness and preferred comfort care over aggressive life-extending therapies, which often create upsetting side effects and hamper communication with loved ones. Interestingly, these results of full disclosure also had a

“cascading effect” on the patients’ loved one’s ability to cope with their loss. Individuals whose loved ones died in an ICU were more likely to develop a major depressive disorder than those whose loved ones did not receive such intensive care.

### **What’s Your Motive?**

Another reason doctors give for creating a less painful truth is that a full discussion takes too much time, the same reason doctors cite for their reluctance to initiate DNR discussions, says Smith. “It does take more time to say, ‘Let’s talk about your illness and how you’re coping with it,’ than it does to say, ‘Well, the next chemo we’re going to try is XYZ,’ because if you start talking about the fact that treatment has a marginal if any benefit and that person is going to die sooner rather than later it takes a lot longer,” he says. “A good doctor will sit and listen to the answers and that takes time.”

And then, of course, there’s the simple fact that it’s tough. “The real reason doctors avoid having these discussions is that it’s just really hard to look another person in the eye and tell them that there’s nothing more that can be done to make them live longer or give them a miraculous chance of a cure,” says Smith. “Anyone who says, ‘Oh, that’s just part of your job,’ probably hasn’t done it very much.”

### **It’s All in the Delivery**

Dixon says an important part of delivering difficult truths to your patients is learning how to read your patients’ personalities. While all are entitled to the truth about their condition, some are satisfied with a broad picture of their illness and the options available. Some need a greater degree of detail and others need it all in small doses. Patients facing death also differ significantly in the type of medical care they wish to pursue. Some, particularly younger patients, will seek more aggressive treatment options, while others (primarily the elderly) just want your support with as little medical intervention as possible. “If you sense that you’re going too fast, or that it seems too scary, you can say, ‘Look, sometimes we talk awfully fast. Do you want to stop here and come back next week and talk more about this? We don’t need to do it all right away.’”

Remember, too, that honesty and an emphasis on the positive are not mutually exclusive. “You need to focus on what’s important about their condition, but there is an art to presenting things to people in different ways,” says Dixon. “You can give bad news but put a positive spin on it. When patients come to me with a spot on their liver from an X-ray, their primary-care doctor has already told them they have cancer. When they see me, I can say, well, 98 percent of your liver looks great.”

When faced with family members who wish to shield their aging parents or grandparents from a poor prognosis, Dixon says he simply levels with them. “I don’t think that’s fair to the person who is sick,” he says. “I express my opinion, that I’m not comfortable with hiding things. You don’t have to go into explicit detail [about their fragile state] and you can be more general, but I tell them to put themselves in the patient’s shoes and think about what they would want.”

Though doctors in private practice rarely encounter such scenarios, physicians who work in a hospital setting may also be asked by the friends or family of an [auto] accident victim to delay information about another passenger’s death until a parent can break the news. In those cases, says Berlinger, it’s a judgment call. “It would have to be clear how long we’re talking about—an hour or four days, because if it was several days that might be tantamount to deception,” she says, noting this is a case where a hospital ethics consult can assist. “It’s about the information, but it’s also about providing support to a person who is getting bad news. It’s a very stressful situation and they need to feel continuity of care—that someone, like a nurse, their doctor, a chaplain, or a family member, is sticking with them and attending to their emotional needs.”

Whatever your motivation for being less than truthful with patients, Berlinger says, there is really never good cause to keep patients in the dark. “If a doctor is considering withholding information, the first thing they have to ask themselves is why would I do this—given my obligation to disclose information to my patients and their right to information about their own health?” she says.

For most patients, full disclosure about their condition takes fear off the table. “One of the problems is that physicians don’t level with people and discuss openly what happens next and what to expect—what you’re going to feel like,” says Dixon. “When people are prepared they’re not afraid anymore.”

### In Summary

Treating patients is a complex business. Sometimes you have to have tough conversations with patients about their diagnoses. Is it ever appropriate to spin the truth or withhold information from a patient? Consider the following:

- In most states physicians are legally obligated to disclose all relevant health information to patients.
- Is it more compassionate to patients to withhold upsetting details about life-threatening diseases or to give them the comfort of knowing the truth and making their own decisions about the end of their lives?
- Physicians should examine their motive for withholding information: Is it compassion, fear of the time it takes to have more involved discussions, avoidance because it’s hard to deliver such news, or something else?

## Why Privacy Is Important

JAMES RACHELS

Why should we care so much about privacy? Rachels asks. He notes that we have a sense of privacy that cannot be explained fully by our fear of being embarrassed or our concerns about being disadvantaged in some material way. He argues that “privacy is necessary if we are to maintain the variety of social relationships with other people that we want to have, and that is why it is important to us.” To manage the relationships that we have with people, we must have “control over who has access to us.”

Privacy is one of those familiar values that seem unproblematic until we start thinking about them, and then puzzles appear at every turn. The first puzzle is why, exactly, privacy is important. According to Justice Brandeis, it is “the right most valued by civilized men.”<sup>1</sup> But why should we care so much about it? At first it may appear that no unitary explanation is possible, because people have so many interests that may be harmed by invasions of their privacy:

1. Privacy is sometimes necessary to protect people’s interests in competitive situations. For example, it obviously would be a disadvantage to Bobby Fischer if he could not analyze the adjourned position in a chess game

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in private, without his opponent learning his results.

2. In other cases someone may want to keep some aspect of his life or behavior private simply because it would be embarrassing for other people to know about it. There is a splendid example of this in John Barth’s novel *End of the Road*. The narrator of the story, Jake Horner, is with Joe Morgan’s wife, Rennie, and they are approaching the Morgan house where Joe is at home alone:

“Want to eavesdrop?” I whispered impulsively to Rennie. “Come on, it’s great! See the animals in their natural habitat.”

Rennie looked shocked. “What for?” “You mean you never spy on people when they’re alone? It’s wonderful! Come on, be a sneak! It’s the most unfair thing you can do to a person.”

"You disgust me, Jake!" Rennie hissed. "He's just reading. You don't know Joe at all, do you?" "What does that mean?"

"Real people aren't any different when they're alone. No masks. What you see of them is authentic."

... Quite reluctantly, she came over to the window and peeped in beside me.

It is indeed the grossest of injustices to observe a person who believes himself to be alone. Joe Morgan, back from his Boy Scout meeting, had evidently intended to do some reading, for there were books lying open on the writing table and on the floor beside the bookcase. But Joe wasn't reading. He was standing in the exact center of the bare room, fully dressed, smartly executing military commands. About *face!* Right *dress!* 'Tenshun! Parade rest! He saluted briskly, his cheeks blown out and his tongue extended, and then proceeded to cavort about the room—spinning, pirouetting, bowing, leaping, kicking. I watched entranced by his performance, for I cannot say that in my strangest moments (and a bachelor has strange ones) I have surpassed him. Rennie trembled from head to foot.<sup>2</sup>

The scene continues even more embarrassingly.

3. There are several reasons medical records should be kept private, having to do with the consequences to individuals of facts about them becoming public knowledge. The president of the American Medical Association warned, "The average patient doesn't realize the importance of the confidentiality of medical records. Passing out information on venereal disease can wreck a marriage. Revealing a pattern of alcoholism or drug abuse can result in a man's losing his job or make it impossible for him to obtain insurance protection."<sup>3</sup>
4. When people apply for credit (or for large amounts of insurance or for jobs of certain types), they are often investigated, and the result is a fat file of information about them. There is something to be said in favor of such investigations, for business people surely do have the right to know whether credit applicants are financially reliable. The trouble is that all sorts of other information can find its

way into such files—information about the applicant's sex life, his political views, and so on. Clearly, it is unfair for one's application for credit to be influenced by such irrelevant matters.

These examples illustrate the variety of interests that may be protected by guaranteeing people's privacy, and it would be easy to give further examples of the same general sort. However, I do not think that examining such cases will provide a complete understanding of the importance of privacy, for two reasons.

First, these cases all involve relatively unusual sorts of situations, in which someone has something to hide or in which information about a person might provide someone with a reason for mistreating him in some way. Thus, reflection on these cases gives us little help in understanding the value that privacy has in *normal* or *ordinary* situations. By this I mean situations in which there is nothing embarrassing or shameful or unpopular in what we are doing and nothing ominous or threatening connected with its possible disclosure. For example, even married couples whose sex lives are normal (whatever that is), and so who have nothing to be ashamed of, by even the most conventional standards, and certainly nothing to be blackmailed about, do not want their bedrooms bugged. We need an account of the value that privacy has for us not only in the few special cases but in the many common and remarkable cases as well.

Second, even those invasions of privacy that do result in embarrassment or in some specific harm are objectionable on other grounds. A woman may rightly be upset if her credit rating is adversely affected by a report about her sexual behavior, because the use of such information is unfair; however, she may also object to the report simply because she feels—as most of us would—that her sex life is *nobody else's business*. This is an extremely important point. We have a sense of privacy that is violated in such affairs, and this sense of privacy cannot adequately be explained merely in terms of our fear of being embarrassed or disadvantaged in one of the obvious ways. An adequate account of privacy should help us to understand what makes

something “someone’s business” and why intrusions into things that are “none of your business” are, as such, offensive.

These considerations suggest that there is something important about privacy that we will miss if we confine our attention to examples such as (1)–(4). In what follows I will try to bring out what this something is.

### Social Relationships and Appropriate Behavior

I will give an account of the value of privacy based on the idea that there is a close connection between our ability to control who has access to us and to information about us and our ability to create and maintain different sorts of social relationships with different people. According to this account, privacy is necessary if we are to maintain the variety of social relationships with other people that we want to have, and that is why it is important to us. By a “social relationship” I do not mean anything unusual or technical; I mean the sort of thing that we usually have in mind when we say of two people that they are friends or that they are husband and wife or that one is the other’s employer.

We may begin by noticing that there are fairly definite *patterns of behavior* associated with these relationships. Our relationships with other people determine, in large part, how we act toward them and how they behave toward us. Moreover, there are different patterns of behavior associated with different sorts of relationships. Thus a man may be playful and affectionate with his children (although sometimes firm), businesslike with his employees, and respectful and polite with his mother-in-law. And to his close friends he may show a side of his personality that others never see—perhaps he is secretly a poet, and rather shy about it, and shows his verse only to his closest friends.

It is sometimes suggested that there is something deceitful or hypocritical about such variations in behavior. It is suggested that underneath all the role-playing there is the “real” person and that the various “masks” that we wear are some sort of phony disguise that we use to conceal our “true” selves. I take it that this is what is behind Rennie’s remark, in the passage from Barth: “Real people

aren’t any different when they’re alone. No masks. What you see of them is authentic.” According to this way of looking at things, the fact that we observe different standards of conduct with different people is merely a sign of dishonesty. Thus the cold-hearted businessman who reads poetry to his friends is “really” a gentle, poetic soul whose businesslike demeanor in front of his employees is only a false front; and the man who curses and swears when talking to his friends, but who would never use such language around his mother-in-law, is just putting on an act for her.

This is wrong. Of course the man who does not swear in front of his mother-in-law may be just putting on an act so that, for example, she will not disinherit him, when otherwise he would curse freely in front of her without caring what she thinks. But it may be that his conception of how he ought to behave with his mother-in-law is simply different from his conception of how he may behave with his friends. (Or it may not be appropriate for him to swear around *her* because “she is not that sort of person.”) Similarly, the businessman may be putting up a false front for his employees, perhaps because he dislikes his work and has to make a continual, disagreeable effort to maintain the role. But on the other hand he may be, quite comfortably and naturally, a businessman with a certain conception of how it is appropriate for a businessman to behave; and this conception is compatible with his also being a husband, a father, and a friend, with different conceptions of how it is appropriate to behave with his wife, his children, and his friends. There need be nothing dishonest or hypocritical in any of this, and neither side of his personality need be the “real” him, any more than any of the others.

It is not merely accidental that we vary our behavior with different people according to the different social relationships that we have with them. Rather, the different patterns of behavior are (partly) what define the different relationships; they are an important part of what makes the different relationships what they are. The relation of friendship, for example, involves bonds of affection and special obligations, such as the duty of loyalty, that friends owe to one another; but it is also an

important part of what it means to have a friend that I welcome her company, confide in her, tell her things about myself, and show her sides of my personality that I would not tell or show to just anyone.<sup>4</sup> Suppose I believe someone is my close friend, and then I discover that she is worried about her job and is afraid of being fired. But while she has discussed this situation with several other people, she has not mentioned it at all to me. And then I learn that she writes poetry and that this is an important part of her life; but while she has shown her poems to other people, she has not shown them to me. Moreover, I learn that she behaves with her other friends in a much more informal way than she behaves with me, that she makes a point of seeing them socially much more than she sees me, and so on. In the absence of some special explanation of her behavior, I would have to conclude that we are not as close as I had thought.

The same general point can be made about other sorts of human relationships: employer to employee, minister to congregant, doctor to patient, husband to wife, parent to child, and so on. In each case, the sort of relationship that people have to one another involves a conception of how it is appropriate for them to behave with each other and, what is more, a conception of the kind and degree of knowledge concerning one another that it is appropriate for them to have. Of course such relationships are not structured in exactly the same way for everyone. Some parents are casual and easygoing with their children, while others are more formal and reserved. Some doctors want to be friends with at least some of their patients; others are businesslike with all. Moreover, the requirements of social roles may vary from community to community—the role of wife may not require exactly the same sort of behavior in rural Alabama that it does in New York or New Guinea. And the requirements of social roles may change; the women's movement, for example, has made a tremendous impact on our understanding of the husband-wife relationship. The examples that I have been giving are drawn, loosely speaking, from contemporary American society, but this is mainly a matter of convenience. The important point is that however one conceives one's relations with other people, there is inseparable from that

conception an idea of how it is appropriate to behave with and around them and what information about oneself it is appropriate for them to have.

### **Privacy and Personal Relationships**

All of this has to do with the way that a crucial part of our lives—our relations with other people—is organized, and as such, its importance to us can hardly be exaggerated. Therefore, we have good reason to object to anything that interferes with these relationships and makes it difficult or impossible for us to maintain them in the way that we want. That is why the loss of privacy is so disturbing. Our ability to control who has access to us and to information about us allows us to maintain the variety of relationships with other people that we want to have.

Consider what happens when close friends are joined by a casual acquaintance. The character of the group changes; one of the changes is that conversation about intimate matters is now out of order. Suppose these friends could never be alone; suppose there were always third parties (let us say casual acquaintances or strangers) intruding. Then they could do either of two things. They could carry on as close friends do, sharing confidences, freely expressing their feelings about things, and so on. But this would mean violating their sense of how it is appropriate to behave around casual acquaintances or strangers. Or they could avoid doing or saying anything that they think inappropriate to do or say around the third party. But this would mean that they could no longer behave with one another in the way that friends do and, further, that, eventually, they would no longer *be* close friends.

Again, consider the differences between the way that a husband and wife behave when they are alone and the way they behave in the company of third parties. Alone, they may be affectionate, sexually intimate, have their fights and quarrels, and so on; but with others, a more "public" face is in order. If they could never be alone together, they would either have to abandon the relationship that they would otherwise have as husband and wife or else behave in front of others in ways they now deem inappropriate.<sup>5</sup>

These considerations suggest that we need to separate our associations, at least to some extent, if we are to maintain a system of different relationships with different people. Separation allows us to behave with certain people in the way that is appropriate to the sort of relationship we have with them, without at the same time violating our sense of how it is appropriate to behave with, and in the presence of, others with whom we have different kinds of relationships. Thus if we are to be able to control the relationships that we have with other people, we must have control over who has access to us.

We now have an explanation of the value of privacy in ordinary situations in which we have nothing to hide. The explanation is that even in the most common and unremarkable circumstances, we regulate our behavior according to the kinds of relationships we have with the people around us. If we cannot control who has access to us, sometimes including and sometimes excluding various people, then we cannot control the patterns of behavior we need to adopt (this is one reason that privacy is an aspect of liberty) or the kinds of relations with other people that we will have.

What about our feeling that certain facts about us are “nobody else’s business”? Here, too, it is useful to consider the nature of our relationships. If someone is our doctor, then it literally is her business to keep track of our health; if someone is our employer, then it literally is his business to know what salary we are paid; our financial dealings literally are the business of the people who extend us credit; and so on. In general, a fact about ourselves is someone’s business if there is a specific relationship between us that entitles him to know. We are often free to choose whether or not to enter into such relationships, and those who want to maintain as much privacy as possible will enter them only reluctantly. What we cannot do is accept such a social role with respect to another person and then expect to retain the same degree of privacy relative to him or her that we had before. Thus, if we are asked how much money we have in the bank, we cannot say “It’s none of your business” to our banker, prospective creditors, or our spouses. But, at the risk of

being boorish, we could say that to others with whom we have no such relationship.

### **Thomson’s View**

In an important essay,<sup>6</sup> Judith Jarvis Thomson suggests that the key to understanding the right to privacy is to realize that there is nothing special about it. She suggests, “as a simplifying hypothesis, that the right to privacy is itself a cluster of rights, and that it is not a distinct cluster of rights but itself intersects with the cluster of rights which the right over the person consists of, and also with the cluster of rights which owning property consists of.” This is an appealing idea because these other rights seem less puzzling than the right to privacy. Therefore, if the simplifying hypothesis is correct, the right to privacy may be much easier to understand.

Thomson explains that “the right over the person” consists of such “un-grand” rights as the right not to have various parts of one’s body looked at, the right not to have one’s elbow painted green, and so on. She understands these rights as analogous to property rights. The idea is that our bodies are ours and so we have the same rights with respect to them that we have with respect to our other possessions.

Is this plausible? Is a woman’s right to prevent a Peeping Tom from looking at her breasts no different from her right to control who drives her car or who uses her fountain pen? These seem importantly different because the kind of interest we have in controlling who looks at what parts of our bodies is different from the interest we have in our cars or pens. For most of us, physical intimacy is a part of special sorts of personal relationships. Exposing one’s knee or one’s face to someone does not count for us as physical intimacy, but exposing a breast, and allowing it to be seen and touched, does. Of course the details are to some extent a matter of social convention; it is easy to understand that for a Victorian woman an exposed knee could be a sign of intimacy. She would be right to be distressed at learning that she had left a knee uncovered and that someone was staring at it. By dissociating the body from ideas of physical intimacy and the complex of

personal relationships of which such intimacies are a part, we can make this “right over the body” seem to be an ungrand kind of property right; but that dissociation separates this right from the matters that make privacy important.

Thomson suggests the following case as a possible source of trouble for the simplifying hypothesis:

Some acquaintances of yours indulge in some very personal gossip about you. Let us imagine that all of the information they share was arrived at without violation of any right of yours, and that none of the participants violates a confidence in telling what he tells. Do they violate a right of yours in sharing the information? If they do, there is trouble for the simplifying hypothesis, for it seems to me there is no right not identical with, or included in, the right to privacy cluster which they could be thought to violate.<sup>7</sup>

But, she adds, this case does not really cause trouble, because the gossips “don’t violate any right of yours. It seems to me we simply do not have rights against others that they shall not gossip about us.”

This is, as Thomson says, a debatable case, but if our account of why privacy is important is correct, we have at least some reason to think that your right to privacy can be violated in such a case. Let us fill in some details. Suppose you are recently divorced, and the reason your marriage failed is that you became impotent shortly after the wedding. You have shared your troubles with your closest friend, but this is not the sort of thing you want everyone to know. Not only would it be humiliating for everyone to know, it is none of their business. It is the sort of intimate fact about you that is not appropriate for strangers or casual acquaintances to know. But now the gossips have obtained the information. Perhaps one of them innocently overheard your conversation with a friend; it was not his fault, so he did not violate your privacy in the hearing, but then you did not know he was within earshot. And now the gossips are spreading it around to everyone who knows you and to some who do not. Are they violating your right to privacy? Surely they are. If so, it is not surprising, for the interest

involved in this case is just the sort of interest that the right to privacy typically protects. Since the right that is violated in this case is not also a property right or a right over the person, the simplifying hypothesis fails. But this should not be surprising, either, for if the right to privacy has a different point than these other rights, we should not expect it always to overlap with them. And even if it did always overlap, we could still regard the right to privacy as a distinctive sort of right in virtue of the special kind of interest it protects.

#### NOTES

1. *Olmstead v United States*, 277 US 438,478 (1928).
2. John Barth, *End of the Road* (New York: Avon, 1960), 57–58.
3. Dr. Malcolm Todd, quoted in the *Miami Herald*, 26 October 1973, sec. A, p. 18.
4. This is similar to Charles Fried’s view of the relation between friendship and privacy in his illuminating book *An Anatomy of Values* (Cambridge: Harvard University Press, 1970).
5. This is from a television program guide in the *Miami Herald*, 21 October 1973, p. 17:

“I think it was one of the most awkward scenes I’ve ever done,” said actress Brenda Benet after doing a romantic scene with her husband, Bill Bixby, in his new NBC-TV series, “The Magician.”

“It was even hard to kiss him,” she continued. “It’s the same old mouth, but it was terrible. I was so abnormally shy; I guess because I don’t think it’s anybody’s business. The scene would have been easier had I done it with a total stranger because that would be real acting. With Bill, it was like being on exhibition.”

On the view presented here, it is not “abnormal shyness” or shyness of any type that is behind such feelings. Rather, it is a sense of what is appropriate with and around people with whom one has various sorts of personal relationships. Kissing *another actor* in front of the camera crew, the director, and so on, is one thing; but kissing *one’s husband* in front of all these people is quite another thing. What made Ms. Benet’s position confusing was that her husband was another actor, and the behavior that was permitted by one relationship was discouraged by the other.

6. Judith Jarvis Thomson, “The Right to Privacy,” *Philosophy and Public Affairs* 4 (1975): 295–314.
7. Thomson, “Right to Privacy,” 311–12.

## Confidentiality in Medicine—A Decrepit Concept

MARK SIEGLER

Sieglar points out that in this age of high-technology health care, the traditional ideal of patient–physician confidentiality does not exist in practice. Modern health care involves teams of specialists—medical, financial, governmental, social, and more—and they all require access to, and dissemination of, a great deal of confidential information about patients. These developments seem to be in response to people's demand for better and more comprehensive care. But they also are changing our traditional concept of medical confidentiality. Confidentiality is important because it shows respect for the patient's individuality and privacy and nurtures the bond of trust between patient and doctor.

Medical confidentiality, as it has traditionally been understood by patients and doctors, no longer exists. This ancient medical principle, which has been included in every physician's oath and code of ethics since Hippocratic times, has become old, worn-out, and useless; it is a decrepit concept. Efforts to preserve it appear doomed to failure and often give rise to more problems than solutions. Psychiatrists have tacitly acknowledged the impossibility of ensuring the confidentiality of medical records by choosing to establish a separate, more secret record. The following case illustrates how the confidentiality principle is compromised systematically in the course of routine medical care.

A patient of mine with mild chronic obstructive pulmonary disease was transferred from the surgical intensive-care unit to a surgical nursing floor two days after an elective cholecystectomy. On the day of transfer, the patient saw a respiratory therapist writing in his medical chart (the therapist was recording the results of an arterial blood gas analysis) and became concerned about the confidentiality of his hospital records. The patient threatened to leave the hospital prematurely unless I could guarantee that the confidentiality of his hospital record would be respected.

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The patient's complaint prompted me to enumerate the number of persons who had both access to his hospital record and a reason to examine it. I was amazed to learn that at least 25 and possibly as many as 100 health professionals and administrative personnel at our university hospital had access to the patient's record and that all of them had a legitimate need, indeed a professional responsibility, to open and use that chart. These persons included 6 attending physicians (the primary physician, the surgeon, the pulmonary consultant, and others); 12 house officers (medical, surgical, intensive-care unit, and "covering" house staff); 20 nursing personnel (on three shifts); 6 respiratory therapists; 3 nutritionists; 2 clinical pharmacists; 15 students (from medicine, nursing, respiratory therapy, and clinical pharmacy); 4 unit secretaries; 4 hospital financial officers; and 4 chart reviewers (utilization review, quality assurance review, tissue review, and insurance auditor). It is of interest that this patient's problem was straightforward, and he therefore did not require many other technical and support services that the modern hospital provides. For example, he did not need multiple consultants and fellows, such specialized procedures as dialysis, or social workers, chaplains, physical therapists, occupational therapists, and the like.

Upon completing my survey I reported to the patient that I estimated that at least 75 health professionals and hospital personnel had access to his

medical record. I suggested to the patient that these people were all involved in providing or supporting his health-care services. They were, I assured him, working for him. Despite my reassurances the patient was obviously distressed and retorted, "I always believed that medical confidentiality was part of a doctor's code of ethics. Perhaps you should tell me just what you people mean by 'confidentiality'!"

### **Two Aspects of Medical Confidentiality**

#### **Confidentiality and Third-Party Interests**

Previous discussions of medical confidentiality usually have focused on the tension between a physician's responsibility to keep information divulged by patients secret and a physician's legal and moral duty, on occasion, to reveal such confidences to third parties, such as families, employers, public health authorities, or police authorities. In all these instances, the central question relates to the stringency of the physician's obligation to maintain patient confidentiality when the health, well-being, and safety of identifiable others or of society in general would be threatened by a failure to reveal information about the patient. The tension in such cases is between the good of the patient and the good of others.

#### **Confidentiality and the Patient's Interest**

As the example above illustrates, further challenges to confidentiality arise because the patient's personal interest in maintaining confidentiality comes into conflict with his personal interest in receiving the best possible health care. Modern high-technology health care is available principally in hospitals (often, teaching hospitals), requires many trained and specialized workers (a "healthcare team"), and is very costly. The existence of such teams means that information that previously had been held in confidence by an individual physician will now necessarily be disseminated to many members of the team. Furthermore, since healthcare teams are expensive and few patients can afford to pay such costs directly, it becomes essential to grant access to the patient's medical record to persons who are responsible for obtaining third-party payment.

These persons include chart reviewers, financial officers, insurance auditors, and quality-of-care assessors. Finally, as medicine expands from a narrow, disease-based model to a model that encompasses psychological, social, and economic problems, not only will the size of the health-care team and medical costs increase, but more sensitive information (such as one's personal habits and financial condition) will now be included in the medical record and will no longer be confidential.

The point I wish to establish is that hospital medicine, the rise of health-care teams, the existence of third-party insurance programs, and the expanding limits of medicine all appear to be responses to the wishes of people for better and more comprehensive medical care. But each of these developments necessarily modifies our traditional understanding of medical confidentiality.

#### **The Role of Confidentiality in Medicine**

Confidentiality serves a dual purpose in medicine. In the first place, it acknowledges respect for the patient's sense of individuality and privacy. The patient's most personal physical and psychological secrets are kept confidential in order to decrease a sense of shame and vulnerability. Secondly, confidentiality is important in improving the patient's health care—a basic goal of medicine. The promise of confidentiality permits people to trust (i.e., have confidence) that information revealed to a physician in the course of a medical encounter will not be disseminated further. In this way patients are encouraged to communicate honestly and forthrightly with their doctors. This bond of trust between patient and doctor is vitally important both in the diagnostic process (which relies on an accurate history) and subsequently in the treatment phase, which often depends as much on the patient's trust in the physician as it does on medications and surgery. These two important functions of confidentiality are as important now as they were in the past. They will not be supplanted entirely either by improvements in medical technology or by recent changes in relations between some patients and doctors toward a rights-based, consumerist model.

## Possible Solutions to the Confidentiality Problem

First of all, in all nonbureaucratic, noninstitutional medical encounters—that is, in the millions of doctor-patient encounters that take place in physicians' offices, where more privacy can be preserved—meticulous care should be taken to guarantee that patients' medical and personal information will be kept confidential.

Secondly, in such settings as hospitals or large-scale group practices, where many persons have opportunities to examine the medical record, we should aim to provide access only to those who have "a need to know." This could be accomplished through such administrative changes as dividing the entire record into several sections—for example, a medical and financial section—and permitting only health professionals access to the medical information.

The approach favored by many psychiatrists—that of keeping a psychiatric record separate from the general medical record—is an understandable strategy but one that is not entirely satisfactory and that should not be generalized. The keeping of separate psychiatric records implies that psychiatry and medicine are different undertakings and thus drives deeper the wedge between them and between physical and psychological illness. Furthermore, it is often vitally important for internists or surgeons to know that a patient is being seen by a psychiatrist or is taking a particular medication. When separate records are kept, this information may not be available. Finally, if generalized, the practice of keeping a separate psychiatric record could lead to the unacceptable consequence of having a separate record for each type of medical problem.

Patients should be informed about what is meant by "medical confidentiality." We should establish the distinction between information about the patient that generally will be kept confidential regardless of the interest of third parties and information that will be exchanged among members of the health-care team in order to provide care for the patient. Patients should be made aware of the large number of persons in the modern hospital who require access to the medical record in order to serve the patient's medical and financial interests.

Finally, at some point most patients should have an opportunity to review their medical record and to make informed choices about whether their entire record is to be available to everyone or whether certain portions of the record are privileged and should be accessible only to their principal physician or to others designated explicitly by the patient. This approach would rely on traditional informed-consent procedural standards and might permit the patient to balance the personal value of medical confidentiality against the personal value of high-technology, team health care. There is no reason that the same procedure should not be used with psychiatric records instead of the arbitrary system now employed, in which everything related to psychiatry is kept secret.

## Afterthought: Confidentiality and Indiscretion

There is one additional aspect of confidentiality that is rarely included in discussions of the subject. I am referring here to the wanton, often inadvertent, but avoidable exchanges of confidential information that occur frequently in hospital rooms, elevators, cafeterias, doctors' offices, and at cocktail parties. Of course, as more people have access to medical information about the patient the potential for this irresponsible abuse of confidentiality increases geometrically.

Such mundane breaches of confidentiality are probably of greater concern to most patients than the broader issue of whether their medical records may be entered into a computerized data bank or whether a respiratory therapist is reviewing the results of an arterial blood gas determination. Somehow, privacy is violated and a sense of shame is heightened when intimate secrets are revealed to people one knows or is close to—friends, neighbors, acquaintances, or hospital roommates—rather than when they are disclosed to an anonymous bureaucrat sitting at a computer terminal in a distant city or to a health professional who is acting in an official capacity.

I suspect that the principles of medical confidentiality, particularly those reflected in most medical codes of ethics, were designed principally to prevent just this sort of embarrassing personal

indiscretion rather than to maintain (for social, political, or economic reasons) the absolute secrecy of doctor-patient communications. In this regard, it is worth noting that Percival's Code of Medical Ethics (1803) includes the following admonition: "Patients should be interrogated concerning their complaint in a tone of voice which cannot be overheard" [Leake, C. D., ed., *Percival's Medical Ethics*. Baltimore: Williams and Wilkins, 1927]. We in the medical profession frequently neglect these simple courtesies.

## Conclusion

The principle of medical confidentiality described in medical codes of ethics and still believed in by patients no longer exists. In this respect, it is a decrepit concept. Rather than perpetuate the myth of confidentiality and invest energy vainly to preserve it, the public and the profession would be better served if they devoted their attention to determining which aspects of the original principle of confidentiality are worth retaining. Efforts could then be directed to salvaging those.

## **Tarasoff v. Regents of the University of California**

SUPREME COURT OF CALIFORNIA

In this 1976 case, the court held that the professional duties of confidentiality can be overridden when a patient poses a serious danger to others. It concluded that "the public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins."

On October 27, 1969, Prosenjit Poddar killed Tatiana Tarasoff. Plaintiffs, Tatiana's parents, allege that two months earlier Poddar confided his intention to kill Tatiana to Dr. Lawrence Moore, a psychologist employed by the Cowell Memorial Hospital at the University of California at Berkeley. They allege that on Moore's request, the campus police briefly detained Poddar, but released him when he appeared rational. They further claim that Dr. Harvey Powelson, Moore's superior, then directed that no further action be taken to detain Poddar. No one warned plaintiffs of Tatiana's peril....

Plaintiffs' complaints predicate liability on two grounds: defendants' failure to warn plaintiffs of the impending danger and their failure to bring about Poddar's confinement pursuant to the Lanterman-Petris-Short Act. Defendants, in turn, assert that they owed no duty of reasonable care to Tatiana and that they are immune from suit under the California Tort Claims Act of 1963.

We shall explain that defendant therapists cannot escape liability merely because Tatiana herself was not their patient. When a therapist determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to use reasonable care to protect the intended victim against such danger. The discharge of this duty may require the therapist to take one or more of various steps, depending upon the nature of the case. Thus it may call for him to warn the intended victim or others likely to apprise the victim of the danger, to notify the police, or to take whatever other steps are reasonably necessary under the circumstances....

### **Plaintiffs' Complaints**

Plaintiffs, Tatiana's mother and father, filed separate but virtually identical second amended complaints. The issue before us on this appeal is whether those complaints now state, or can be amended to state, causes of action against defendants.

We therefore begin by setting forth the pertinent allegations of the complaints.

Plaintiffs' first cause of action, entitled "Failure to Detain a Dangerous Patient," alleges that on August 20, 1969, Poddar was a voluntary outpatient receiving therapy at Cowell Memorial Hospital. Poddar informed Moore, his therapist, that he was going to kill an unnamed girl, readily identifiable as Tatiana, when she returned home from spending the summer in Brazil. Moore, with the concurrence of Dr. Gold, who had initially examined Poddar, and Dr. Yandell, assistant to the director of the department of psychiatry, decided that Poddar should be committed for observation in a mental hospital. Moore orally notified Officers Atkinson and Teel of the campus police that he would request commitment. He then sent a letter to Police Chief William Beall requesting the assistance of the police department in securing Poddar's confinement.

Officers Atkinson, Brownrigg, and Halloran took Poddar into custody, but, satisfied that Poddar was rational, released him on his promise to stay away from Tatiana. Powelson, director of the department of psychiatry at Cowell Memorial Hospital, then asked the police to return Moore's letter, directed that all copies of the letter and notes that Moore had taken as therapist be destroyed, and "ordered no action to place Prosenjit Poddar in 72-hour treatment and evaluation facility."

Plaintiffs' second cause of action, entitled "Failure to Warn on a Dangerous Patient," incorporates the allegations of the first cause of action, but adds the assertion that defendants negligently permitted Poddar to be released from police custody without "notifying the parents of Tatiana Tarasoff that their daughter was in grave danger from Prosenjit Poddar." Poddar persuaded Tatiana's brother to share an apartment with him near Tatiana's residence; shortly after her return from Brazil, Poddar went to her residence and killed her.

Plaintiffs' third cause of action, entitled "Abandonment of a Dangerous Patient," seeks \$10,000 punitive damages against defendant Powelson. Incorporating the crucial allegations of the first cause of action, plaintiffs charge that Powelson "did the things herein alleged with intent to abandon a

dangerous patient, and said acts were done maliciously and oppressively."

Plaintiffs' fourth cause of action, for "Breach of Primary Duty to Patient and the Public," states essentially the same allegations as the first cause of action, but seeks to characterize defendants' conduct as a breach of duty to safeguard their patient and the public. Since such conclusory labels add nothing to the factual allegations of the complaint, the first and fourth causes of action are legally indistinguishable....

... We direct our, attention . . . to the issue of whether Plaintiffs' second cause of action can be amended to state a basis for recovery.

### **Plaintiffs Can State a Cause of Action Against Defendant Therapists for Negligent Failure to Protect Tatiana**

The second cause of action can be amended to allege that Tatiana's death proximately resulted from defendants' negligent failure to warn Tatiana or others likely to apprise her of her danger. Plaintiffs contend that as amended, such allegations of negligence and proximate causation, with resulting damages, establish a cause of action. Defendants, however, contend that in the circumstances of the present case they owed no duty of care to Tatiana or her parents and that, in the absence of such duty, they were free to act in careless disregard of Tatiana's life and safety.

In analyzing this issue, we bear in mind that legal duties are not discoverable facts of nature, but merely conclusory expressions that, in cases of a particular type, liability should be imposed for damage done. "The assertion that liability must . . . be denied because defendant bears no 'duty' to plaintiff 'begs the essential question—whether the plaintiff's interests are entitled to legal protection against the defendant's conduct. . . [Duty] is not sacrosanct in itself, but only an expression of the sum total of those considerations of policy which lead the law to say that the particular plaintiff is entitled to protection.'"

In the landmark case of *Rowland v. Christian* (1968), Justice Peters recognized that liability should be imposed "for an injury occasioned to another by his want of ordinary care or skill" as expressed in

section 1714 of the Civil Code. Thus, Justice Peters, quoting from *Heaven v. Pender* (1883) stated: "Whenever one person is by circumstances placed in such a position with regard to another . . . that if he did not use ordinary care and skill in his own conduct . . . he would cause danger of injury to the person or property of the other, a duty arises to use ordinary care and skill to avoid such danger."

We depart from "this fundamental principle" only upon the "balancing of a number of considerations"; major ones "are the foreseeability of harm to the plaintiff, the degree of certainty that the plaintiff suffered injury, the closeness of the connection between the defendant's conduct and the injury suffered, the moral blame attached to the defendant's conduct, the policy of preventing future harm, the extent of the burden to the defendant and consequences to the community of imposing a duty to exercise care with resulting liability for breach, and the availability, cost and prevalence of insurance for the risk involved."

The most important of these considerations in establishing duty is foreseeability. As a general principle, a "defendant owes a duty of care to all persons who are foreseeably endangered by his conduct, with respect to all risks which make the conduct unreasonably dangerous." As we shall explain, however, when the avoidance of foreseeable harm requires a defendant to control the conduct of another person, or to warn of such conduct, the common law has traditionally imposed liability only if the defendant bears some special relationship to the dangerous person or to the potential victim. Since the relationship between a therapist and his patient satisfies this requirement, we need not here decide whether foreseeability alone is sufficient to create a duty to exercise reasonable care to protect a potential victim of another's conduct.

Although, as we have stated above, under the common law, as a general rule, one person owed no duty to control the conduct of another nor to warn those endangered by such conduct, the courts have carved out an exception to this rule in cases in which the defendant stands in some special relationship to either the person whose conduct needs to be controlled or in a relationship to the foreseeable victim of that conduct. Applying this exception

to the present case, we note that a relationship of defendant therapists to either Tatiana or Poddar will suffice to establish a duty of care; as explained in section 315 of the Restatement Second of Torts, a duty of care may arise from either "(a) a special relation . . . between the actor and the third person which imposes a duty upon the actor to control the third person's conduct, or (b) a special relation . . . between the actor and the other which gives to the other a right of protection."

Although Plaintiffs' pleadings assert no special relation between Tatiana and defendant therapists, they establish as between Poddar and defendant therapists the special relation that arises between a patient and his doctor or psychotherapist. Such a relationship may support affirmative duties for the benefit of third persons. Thus, for example, a hospital must exercise reasonable care to control the behavior of a patient which may endanger other persons. A doctor must also warn a patient if the patient's condition or medication renders certain conduct, such as driving a car, dangerous to others.

Although the California decisions that recognize this duty have involved cases in which the defendant stood in a special relationship *both* to the victim and to the person whose conduct created the danger, we do not think that the duty should logically be constricted to such situations. Decisions of other jurisdictions hold that the single relationship of a doctor to his patient is sufficient to support the duty to exercise reasonable care to protect others against dangers emanating from the patient's illness. The courts hold that a doctor is liable to persons infected by his patient if he negligently fails to diagnose a contagious disease, or having diagnosed the illness, fails to warn members of the patient's family.

Since it involved a dangerous mental patient, the decision in *Merchants Nat. Bank & Trust Co. of Fargo v. United States* (1967) comes closer to the issue. The Veterans Administration arranged for the patient to work on a local farm, but did not inform the farmer of the man's background. The farmer consequently permitted the patient to come and go freely during non-working hours; the patient borrowed a car, drove to his wife's residence and killed her. Notwithstanding the lack of any

"special relationship" between the Veterans Administration and the wife, the court found the Veterans Administration liable for the wrongful death of the wife.

In their summary of the relevant rulings Fleming and Maximov conclude that the "case law should dispel any notion that to impose on the therapists a duty to take precautions for the safety of persons threatened by a patient, where due care so requires, is in any way opposed to contemporary ground rules on the duty relationship. On the contrary, there now seems to be sufficient authority to support the conclusion that by entering into a doctor-patient relationship the therapist becomes sufficiently involved to assume some responsibility for the safety, not only of the patient himself, but also of any third person whom the doctor knows to be threatened by the patient." [Fleming & Maximov, *The Patient or His Victim: The Therapist's Dilemma* (1974) 62 Cal. L. Rev. 1025, 1030.]

Defendants contend, however, that imposition of a duty to exercise reasonable care to protect third persons is unworkable because therapists cannot accurately predict whether or not a patient will resort to violence. In support of this argument amicus representing the American Psychiatric Association and other professional societies cites numerous articles which indicate that therapists, in the present state of the art, are unable reliably to predict violent acts; their forecasts, amicus claims, tend consistently to overpredict violence, and indeed are more often wrong than right. Since predictions of violence are often erroneous, amicus concludes, the courts should not render rulings that predicate the liability of therapists upon the validity of such predictions.

The role of the psychiatrist, who is indeed a practitioner of medicine, and that of the psychologist who performs an allied function, are like that of the physician who must conform to the standards of the profession and who must often make diagnoses and predictions based upon such evaluations. Thus the judgment of the therapist in diagnosing emotional disorders and in predicting whether a patient presents a serious danger of violence is comparable to the judgment which doctors and professionals must regularly render under accepted rules of responsibility.

We recognize the difficulty that a therapist encounters in attempting to forecast whether a patient presents a serious danger of violence. Obviously we do not require that the therapist, in making the determination, render a perfect performance; the therapist need only exercise "that reasonable degree of skill, knowledge, and care ordinarily possessed and exercised by members of [that professional specialty] under similar circumstances." Within the broad range of reasonable practice and treatment in which professional opinion and judgment may differ, the therapist is free to exercise his or her own best judgment without liability; proof, aided by hindsight, that he or she judged wrongly is insufficient to establish negligence.

In the instant case, however, the pleadings do not raise any question as to failure of defendant therapists to predict that Poddar presented a serious danger of violence. On the contrary, the present complaints allege that defendant therapists did in fact predict that Poddar would kill, but were negligent in failing to warn.

Amicus contends, however, that even when a therapist does in fact predict that a patient poses a serious danger of violence to others, the therapist should be absolved of any responsibility for failing to act to protect the potential victim. In our view, however, once a therapist does in fact determine, or under applicable professional standards reasonably should have determined, that a patient poses a serious danger of violence to others, he bears a duty to exercise reasonable care to protect the foreseeable victim of that danger. While the discharge of this duty of due care will necessarily vary with the facts of each case, in each instance the adequacy of the therapist's conduct must be measured against the traditional negligence standard of the rendition of reasonable care under the circumstances. As explained in Fleming and Maximov, *The Patient or His Victim: The Therapist's Dilemma* (1974), ". . . the ultimate question of resolving the tension between the conflicting interests of patient and potential victim is one of social policy, not professional expertise. . . . In sum, the therapist owes a legal duty not only to his patient, but also to his patient's would-be victim and is subject in both respects to scrutiny by judge and jury. . . ."

The risk that unnecessary warnings may be given is a reasonable price to pay for the lives of possible victims that may be saved. We would hesitate to hold that the therapist who is aware that his patient expects to attempt to assassinate the President of the United States would not be obligated to warn the authorities because the therapist cannot predict with accuracy that his patient will commit the crime.

Defendants further argue that free and open communication is essential to psychotherapy; that "unless a patient . . . is assured that . . . information [revealed by him] can and will be held in utmost confidence, he will be reluctant to make the full disclosure upon which diagnosis and treatment . . . depends." The giving of a warning, defendants contend, constitutes a breach of trust which entails the revelation of confidential communications.

We recognize the public interest in supporting effective treatment of mental illness and in protecting the rights of patients to privacy and the consequent public importance of safeguarding the confidential character of psychotherapeutic communication. Against this interest, however, we must weigh the public interest in safety from violent assault. The Legislature has undertaken the difficult task of balancing the countervailing concerns. In Evidence Code section 1014, it established a broad rule of privilege to protect confidential communications between patient and psychotherapist. In Evidence Code section 1024, the Legislature created a specific and limited exception to the psychotherapist-patient privilege: "There is no privilege . . . if the psychotherapist has reasonable cause to believe that the patient is in such mental or emotional condition as to be dangerous to himself or to the person or property of another and that disclosure of the communication is necessary to prevent the threatened danger."

We realize that the open and confidential character of psychotherapeutic dialogue encourages patients to express threats of violence, few of which are ever executed. Certainly a therapist should not

be encouraged routinely to reveal such threats; such disclosures could seriously disrupt the patient's relationship with his therapist and with the persons threatened. To the contrary, the therapist's obligations to his patient require that he not disclose a confidence unless such disclosure is necessary to avert danger to others, and even then that he do so discreetly, and in a fashion that would preserve the privacy of his patient to the fullest extent compatible with the prevention of the threatened danger.

The revelation of a communication under the above circumstances is not a breach of trust or a violation of professional ethics; as stated in the Principles of Medical Ethics of the American Medical Association (1957), section 9: "A physician may not reveal the confidence entrusted to him in the course of medical attendance . . . unless *he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community.*" (Emphasis added.) We conclude that the public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins.

Our current crowded and computerized society compels the interdependence of its members. In this risk-infested society we can hardly tolerate the further exposure to danger that would result from a concealed knowledge of the therapist that his patient was lethal. If the exercise of reasonable care to protect the threatened victim requires the therapist to warn the endangered party or those who can reasonably be expected to notify him, we see no sufficient societal interest that would protect and justify concealment. The containment of such risks lies in the public interest. For the foregoing reasons, we find that Plaintiffs' complaints can be amended to state a cause of action against defendants Moore, Powelson, Gold, and Yandell and against the Regents as their employer, for breach of a duty to exercise reasonable care to protect Tatiana. . . .

# Informed Consent

Most who have thought carefully about the issue believe that there is more to the ethics of provider–patient relationships than just a regard for truthfulness and confidentiality. A larger, more complex notion often guides such interactions: **informed consent**. At the simplest level, the term refers to the action of an autonomous, informed person agreeing to submit to medical treatment or experimentation. The idea arises from the intuition that patients, as autonomous persons, should have the ultimate say in what is done to their bodies, that they ought not to be treated without their voluntary, informed agreement. Informed consent, then, is thought to be an ethical ideal in which physicians are obligated to tell patients about possible medical interventions and to respect their choices regarding them. It is also a legal requirement, compelling health care providers to disclose information about interventions to patients and obtain their permission before proceeding. (Requirements of informed consent also apply to researchers and research subjects, as discussed in Chapter 6.) The ethical ideal has often proved difficult to define precisely, to apply in real-life cases, and to embody effectively in laws and policies. But among most health care professionals and many of the patients they serve, there is little doubt about its importance and influence.

## AUTONOMY AND CONSENT

Philosophers and other thinkers have justified informed consent through appeals to the principles of autonomy and beneficence. The principle of autonomy tells us that we should respect people’s capacity for self-determination. To

accept this standard is to reject strong medical paternalism, in which physicians or nurses decide unilaterally what is best for patients. Honoring the principle means letting patients voluntarily choose—even when their choices conflict with medical advice. The principle of beneficence urges physicians and nurses to promote patient welfare, and this goal is thought to be consistent with respecting patient autonomy. Thus, bioethicists argue that informed consent promotes the good for patients because knowledgeable, autonomous patients who choose for themselves will advance their own best interests as they themselves conceive them. They will likely avoid unacceptable risks, protect themselves from abuses, and comply with the demands of their chosen treatment.

The ethical underpinnings of informed consent may be old and revered, but the concept as we know it today is young. Throughout most of medical history, devoted physicians practiced the healing arts while paying little attention to notions of patient self-determination and full disclosure. Beginning in the early twentieth century, judicial rulings began to challenge that approach bit by bit. The 1914 case *Schloendorff v. Society of New York Hospital* made it clear that “every human being of adult years and sound mind has a right to determine what shall be done with his own body,” but there was no suggestion that any consent had to be informed.<sup>1</sup> Simple consent was sufficient. Not until 1957 in the California court case *Salgo v. Leland Stanford Junior University Board of Trustees* was the physician’s disclosure of information firmly tied to the patient’s consent. In a ruling that concocted the term “informed consent,” the court

held that “a physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.”<sup>2</sup> In the 1960s other cases went further by identifying the basic features of informed consent: the patient’s voluntary consent informed by physicians who have a duty to disclose information about the patient’s illness, the proposed treatment, its risks and benefits, and treatment alternatives (including no treatment at all).

These rulings still left many unanswered questions about the legal doctrine, most conspicuous among them being how to judge the adequacy of the physician’s disclosure. The prevailing view in the early rulings was that disclosure is adequate if it meets the customary standards of medical practice. Information given to patients is sufficient if the medical profession considers it sufficient. But in the 1970s, courts began to insist that the adequacy of disclosure should be judged by what patients themselves find relevant to their situation. The most influential ruling of this kind came in 1972 in the U.S. Court of Appeals case *Canterbury v. Spence*. “The scope of the physician’s communication to the patient, then,” says Judge Robinson, “must be measured by the patient’s need, and that need is the information material to the decision.”<sup>3</sup>

Despite such judicial clarifications (and the enactment of countless statutes and institutional policies), much about informed consent remains unsettled—and unsettling. For one thing, many critics see huge discrepancies between the ethical ideal of informed consent and the laws or rules meant to implement it. They know, for example, that too often a patient can sign a form disclosing treatment risks and thereby, according to local law and institutional policy, grant her informed consent. But she may be neither informed nor autonomous and may not intend to consent to anything. Laws and policies may require physicians merely to warn patients of the risks of treatment, a thin

imitation of bona fide informed consent. Some observers also decry the gap between theory and everyday medical practice, contending that physicians view informed consent as a bureaucratic or legalistic burden instead of a way to promote patient self-determination and well-being. As one critic put it, “The idea of physicians making decisions *for*, rather than *with*, patients, is still deeply embedded in the ideology of medical professionalism.”<sup>4</sup>

## CONDITIONS OF INFORMED CONSENT

Theorists break down informed consent into components believed to be necessary to the concept. Typically, they maintain that an informed consent exists if and only if (1) the patient is *competent* to decide, (2) she gets an adequate *disclosure* of information, (3) she *understands* the information, (4) she decides about the treatment *voluntarily*, and (5) she *consents* to the treatment.<sup>5</sup> This analysis seems straightforward enough, but complications (and controversy) ensue when we try to specify precisely what these conditions entail and to apply them to real-life cases.

As it pertains to informed consent, **competence** is very roughly the ability to render decisions about medical interventions. Individuals who are incompetent in this sense cannot give their informed consent, in which case the burden of decision-making falls to a surrogate (often a court-appointed guardian or a proxy selected through the patient’s advance directive). Most of the time, however, people are presumed to be competent unless there are good reasons to think otherwise. Patients are often judged incompetent in cases of intellectual disability, dementia, psychosis, alcoholism, and minority (being underage). But they may also be thought incompetent in less clear-cut situations—when they are overwhelmed by fear or pain, for instance. In addition, they are sometimes considered incompetent because they lack only one or two particular mental capacities—for example, the ability to communicate a decision, to

understand the implications of a choice, to provide reasons, to explain decision-making, or to understand disclosed information. Still, incompetence is not necessarily total, or global; it may be specific to particular aspects of life. A woman who has been legally declared incompetent to handle her personal finances may be fully competent to give her informed consent. A man who has been involuntarily institutionalized for mental illness may still be able to make decisions regarding his medical treatment.

Sometimes a court will formally determine someone to be incompetent. But in most cases, the judicial system never gets involved, and the task of making informal determinations of incompetence goes to physicians (often in consultation with the patient's family).

To give their informed consent, competent patients must receive an adequate disclosure of information from physicians—but what is an adequate disclosure? What kind and amount of information are sufficient? The ethical doctrine of informed consent says that disclosure is adequate if it allows patients to weigh intelligently the risks and benefits of available choices. But how to achieve this ideal in practice is not obvious. Early court decisions suggested that physicians should be the arbiters of adequate disclosure (the physician-based standard); later rulings insisted that adequate disclosure is whatever satisfies the information needs of a hypothetically reasonable person (the patient-based standard); and others called for a subjective standard in which disclosure is supposed to be based on the information needs of a particular patient. But a purely physician-based standard for disclosure would ignore the patient's needs for information relevant to her own personal decisions. The kind of disclosure suitable for a hypothetically reasonable person would probably be very difficult to determine—and might, like the physician-based standard, impose disclosure criteria that have little to do with the information requirements of a particular patient. And an entirely subjective standard naively assumes that patients can always decide

for themselves what facts they do and do not need to evaluate treatment options. Some courts have combined these standards, but no configuration of requirements has been entirely true to the spirit of informed consent.

Despite these difficulties, courts and legislatures have generally mandated the disclosure of several pieces of important information:

1. The nature of the procedure (for example, whether it is a test or treatment, whether it is invasive, and how long it will take to perform)
2. The risks of the procedure (what kind of risks are involved, their seriousness, their probability of occurring, and when they might happen)
3. The alternatives to the proposed procedure—including the option of no treatment (includes information on the options' nature, risks, and benefits)
4. The expected benefits of the proposed treatment—including their extent and their likelihood of being achieved

Physicians are not obligated to provide disclosure in all situations; the duty of physicians to obtain informed consent has exceptions. Disclosure is often dispensed with in emergencies when stopping to obtain consent could seriously harm the patient. As suggested earlier, informed consent is not required when a patient is incompetent. Neither is it obligatory in cases of waiver, the patient's voluntary and deliberate giving up of the right to informed consent. It is an exercise in autonomous choice—the choice not to choose or decide. Authority to decide medical issues is turned over to the physician or surrogates. A much more controversial exception is **therapeutic privilege**, the withholding of relevant information from a patient when the physician believes disclosure would likely do harm. The idea behind it is that some patients are so distraught, depressed, or weak that disclosure could make their condition worse. Laws regarding therapeutic privilege vary on when invoking it is justified, with some allowing it only when

## IN DEPTH

### DECISION-MAKING CAPACITY

How can you tell if a patient is competent to make important decisions about her health? This question is not as easy to answer as you might think, and it is often controversial among medical providers. Here is one example of some carefully crafted guidelines.

Assessing for “decision-making capacity” involves determining whether or not a patient or subject is psychologically or legally capable of adequate decision-making. Illness or medications may impair the ability of patients to make decisions about their health—they may be unable to make decisions at all or may make choices that are not in their best interests and may result in serious harm. It is important to remember that this capacity relates to the specific medical decision at hand and does not imply a global ability to make any or all decisions about health care or other matters. Only a court can deem a patient incapable of making global health care decisions. If that is the case, the patient is deemed to lack “competence” and a surrogate is appointed for the patient. Rarely do we need to involve the court or deem someone to lack competence. Instead, we more commonly refer to decision-making capacity as it relates to individual medical decisions.

#### HOW IS DECISION-MAKING CAPACITY RELEVANT TO MEDICINE?

In order for a patient to make autonomous decisions or to give informed consent to medical treatments or research participation, an individual must have decision-making capacity. The principle of autonomy requires that a physician respect the authority of a patient to make decisions, even when the decisions appear to be unwise. However, beneficence requires that a physician act in the patient’s best interest. . . . [S]ometimes tension exists between the principles of autonomy and beneficence, and it can be difficult to determine the best course of action. However, it is important to

recognize that autonomy is only possible when the patient possesses the ability to make relevant health decisions. If individuals lack decision-making capability, they may make decisions that are contrary to their best interests and thus need to be protected from harm. If decision-making capacity is intact, the physician generally should respect the patient’s choices. If it is impaired, other arrangements can be made for making health decisions on behalf of the patient.

#### WHAT ARE THE STANDARDS FOR ASSESSING DECISION-MAKING CAPACITY?

The standards for assessing decision-making capacity are somewhat subjective. However, the patient can generally be considered to possess decision-making capacity if:

- The patient makes and communicates a choice regarding medical treatment/course of action.
- The patient appreciates the following information regarding medical care:
  - medical diagnosis and prognosis
  - nature of the recommended care
  - alternative courses of care
  - risks, benefits, and consequences of each alternative.
- The patient makes decisions that are consistent with his/her values and goals.
- The decision is not the result of delusions.
- The patient uses logical reasoning to make a decision.

#### WHO DECIDES WHETHER A PATIENT HAS DECISION-MAKING CAPACITY?

In medicine, the attending physician is often the one who determines whether a patient is able to make decisions regarding his/her medical care. Sometimes the courts may be involved, but usually this is too time-consuming and unnecessary. Psychiatrists may be consulted, as they have extensive training in dealing with mentally impaired patients and in talking with patients; however, the attending physician is ultimately responsible for determining whether the patient has decision-making capacity.

(continued)

## HOW DO YOU DETERMINE WHETHER A PATIENT HAS DECISION-MAKING CAPACITY?

- Does the patient understand disclosed information?
  - “Tell me what you believe is wrong with your health now.”
  - “What will the angiography do for you?”
- Does the patient appreciate the consequences of his/her choices?
  - “What do you believe will happen if you do not have the angiography?”
  - “I’ve described the probable benefits and risks. How do you think your daily activities would be affected if these benefits and risks were to occur?”
- Does the patient use reasoning to make a choice?
  - “Tell me how you reached your decision.”
  - “Help me understand how you decided to refuse the angiogram.”
  - “Tell me what makes angiography seem worse than the alternatives.”
- Talk to the patient’s family and friends.
  - This will help to determine whether the patient’s choices are consistent with the patient’s values and beliefs. These individuals can also help clarify whether the patient’s mental status has changed over time.
- Mental status examinations.
  - These tests may be used to evaluate whether the patient is oriented to person, place, and time, attention span, memory function, ability to perform simple calculations, and language skills. However, it is important to remember that these tests do not specifically assess the patient’s understanding of the proposed interventions. Individuals with abnormal mental status may be competent to make decisions regarding their health care.
- Enhance the ability of the patient to make decisions.
  - Treating underlying medical or psychiatric illnesses may improve the patient’s

decision-making capacity. Presenting information slowly, in simple language, more than once, and in digestible bits may help patients comprehend the details of their medical conditions and proposed interventions. Having family members present during presentation of information may reduce patient anxiety, help to focus on important points, and correct misunderstandings.

## SPECIAL SITUATIONS

- Mental illness: Some psychiatric disorders, particularly schizophrenia and depression, can affect a patient’s ability to appreciate the relevance of information to his/her situation or to have a rational perspective on treatments. Patients may be involuntarily committed if they pose a danger to self or others. . . . However, involuntary commitment does not give physicians the right to administer treatments without the patient’s consent.
- Religious beliefs: Patients may make medical decisions on the basis of religious beliefs; this is commonly accepted as a valid reason for refusal of medical treatment. However, it is important to establish that the patient held the same religious beliefs before the treatment and that he/she is not experiencing delusions. In addition, physicians may seek court orders to override parents’ refusal of treatment for their children on religious grounds.

## HOW ARE DECISIONS MADE FOR PATIENTS WHO LACK DECISION-MAKING CAPACITY?

Once a physician determines that a patient lacks decision-making capacity, the medical community looks to *advance directives* and *surrogate decision-making* to help make medical decisions for the patient.

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From Steven Pantilat, “Decision-Making Capacity,” *Missing Link*, <http://missinglink.ucsf.edu/lm/ethics/index.htm>, the Regents, University of California, 2008.

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## IN DEPTH

### TWO VIEWS OF INFORMED CONSENT

While agreeing on the value of informed consent, theorists have differed on its core meaning. For example, some define informed consent as “autonomous authorization,” and others seem to equate it with “shared decision-making.” Consider these contrasting views:

[The President's] Commission . . . believes that “shared decisionmaking” is the appropriate ideal for patient-professional relationships that a sound doctrine of informed consent should support. . . . [The doctor–patient interaction] should, at a minimum, provide the patient with a basis for effective participation in sound decisionmaking. . . . It will usually consist of discussions between professional and patient that bring the knowledge, concerns, and perspective of each to the process of seeking agreement on a course of treatment. Simply put, this means that the physician or other health professional invites the patient to participate in a dialogue in which the professional seeks to help the patient understand the medical situation and available

courses of action, and the patient conveys his or her concerns and wishes. This does not involve a mechanical recitation of abstruse medical information, but should include disclosures that give the patient an understanding of his or her condition and an appreciation of its consequences.<sup>6</sup>

The idea of informed consent suggests that a patient or subject does more than express agreement with, acquiesce in, yield to, or comply with an arrangement or a proposal. He or she actively *authorizes* the proposal in the act of consent. John may *assent* to a treatment plan without authorizing it. The assent may be a mere submission to the doctor's authoritative order, in which case John does not call on his own authority in order to give permission, and thus does not authorize the plan. Instead, he acts like a child who submits, yields, or assents to the school principal's spanking and in no way gives permission for or authorizes the spanking. . . . There is of course an historical relationship in clinical medicine between medical decisionmaking and informed consent. The emergence of the legal doctrine of informed consent was instrumental in drawing attention to issues of decisionmaking as well as authority in the doctor-patient relationship. Nevertheless, it is a confusion to treat informed consent and shared decisionmaking as anything like synonymous.<sup>7</sup>

disclosure would be extremely dangerous for the patient or when it would seriously diminish the patient's autonomy. Others permit physicians far more leeway in deciding when to claim the privilege.

Critics worry that too many physicians use therapeutic privilege when they should in fact tell patients the facts and that overuse of it can undo informed consent. In any case, informed consent seems to imply that physicians should not use therapeutic privilege merely to avoid giving patients unpleasant news or to prevent them from rejecting a treatment.

It seems obvious that there can be no informed consent unless patients understand the information disclosed to them (although the law is equivocal on this point). But it is less clear what such understanding amounts to. At a minimum, informed consent seems to require that patients be able to take in the relevant information and assess it well enough to appreciate the consequences of their choices. They need not completely fathom all the information given, but they should comprehend what is most relevant to their decision. And their refusal to submit to a recommended treatment

**LEGAL BRIEF**

## **Important Informed Consent Cases**

- *Schloendorff v. Society of New York Hospital* (1914)—Justice Cardozo underscored the value of patient self-determination and voluntary consent, declaring that “every human being of adult years and sound mind has a right to determine what shall be done with his body.”
- *Salgo v. Leland Stanford Jr. University Board of Trustees* (1957)—The California Supreme Court found that physicians “have the duty to disclose any facts which are necessary to form the basis of an intelligent consent by the patient to proposed treatment.”
- *Natanson v. Kline* (1960) and *Mitchell v. Robinson* (1960)—These decisions further specified the information to be conveyed to patients, insisting that the risks involved in a medical procedure should be disclosed.
- *Cobb v. Grant* (1972)—The California Supreme Court held that disclosure must consist of “all

information relevant to a meaningful decisional process.”

- *Canterbury v. Spence* (1972)—The U.S. Court of Appeals ruled that the adequacy of disclosure by a physician should not be judged by what the medical profession thinks is appropriate but by what information the patient finds relevant to his or her decision.
- *Catalano v. Moreland* (2002)—The Supreme Court of New York held that the adequacy of informed consent cannot be ascertained by merely applying a hospital’s bylaws. The court declared, “Thus . . . the reasonableness of defendant’s conduct will be measured, not against the Hospital bylaws, but rather against what would have been disclosed by a reasonable medical practitioner.”
- *Shinal v. Toms* (2017)—The Pennsylvania Supreme Court ruled, in a 4–3 decision, that informed-consent information that surgeons must provide to their patients about surgical procedures must be delivered to patients in person, not through a nurse or other intermediary.

should not be taken as evidence of a lack of understanding.

Of course, impediments to sufficient understanding abound. It can be deficient if physicians overload the patient with information or frame it in misleading ways (by playing up minimal benefits while playing down significant risks, for instance). The patient’s ability to process or appreciate information can be shattered by fear, denial, wishful thinking, magical thinking, and false beliefs. But these problems do not show that acquiring an understanding sufficient for informed consent is impossible—only that it can be difficult and that physicians cannot assume that mere disclosure is enough.

The consent of an informed, competent, understanding patient cannot be legitimate unless

it is given voluntarily—that is, freely, without undue (autonomy-robbing) pressure from others. Coercion and manipulation are the most obvious examples of such pressure. Some philosophers have plausibly defined coercion as the intentional use of “a credible and severe threat of harm or force to control another.”<sup>8</sup> We might therefore judge a patient to be coerced if her doctor threatens to abandon her unless she submits to treatment, or if he plays on her fear of disability to get her to be more cooperative. Manipulation refers to many noncoercive ways of controlling someone’s actions—for example, giving false or misleading information or withholding relevant facts. The use of therapeutic privilege to control a patient’s decisions is, of course, manipulative—and corrosive to

informed consent. But note that these forms of undue pressure can come not just from health care providers but also from the patient's family and friends.

Everyday life is filled with social influences on our actions, beliefs, and reasoning. But these pressures are typically not so powerful that they overwhelm our autonomy. Likewise, physicians can influence patients through reasoning, emotional appeals, and authority—yet these pressures are not necessarily undue. In any given case, the line may be difficult to draw between pressures that render consent involuntary and those that do not.

In the ethical ideal, consent is more than assent—more than the patient's giving into the physician's wishes or doing what is expected. As several theorists have insisted, it is a kind of authorization to proceed with a course of action. When a patient authorizes her physician to treat her, she does not merely say yes, but autonomously, knowledgeably decides and *assumes responsibility* for the decision.<sup>9</sup> Actual practice, however, usually falls far short of the ideal, with form-signing and acquiescence substituting for free, informed authorization.

### APPLYING MAJOR THEORIES

In what light would the major moral theories have us view informed consent? To ask a more precise question, would they require physicians to obtain informed consent before treating patients? Utilitarianism wants us to judge actions involving informed consent by the overall good they would produce, everyone considered. For an act-utilitarian, this standard must be applied to each individual case, and whether a physician should try to obtain informed consent depends on the benefits generated for all concerned (patient, medical providers, family, and others). There is both good and bad to weigh. Providing relevant information to the patient and seeking her authorization for treatment might reduce her anxiety and depression, increase her compliance and

cooperation, enhance her satisfaction with treatment, or encourage her to be actively involved in her own care. But the process might also frighten or confuse her, force her to make decisions that she would rather leave to the physician, prompt her to choose a treatment judged by her physician not to be in her best interests, or take up too much of the physician's time. Forgoing the process altogether might also exact a toll in patient confusion, anxiety, and depression, and there would be the possibility of an erosion of trust between doctor and patient and, in the worst scenarios of mistrust, lawsuits.

So by act-utilitarian lights, in some instances a physician may be obliged to obtain informed consent, but in others she may be justified in ignoring it, even invoking therapeutic privilege. On this view, though informed consent may be frequently used, it is not a moral requirement.

A rule-utilitarian might conclude that the best overall consequences would be achieved if physicians consistently followed a rule requiring informed consent (except in a few extraordinary circumstances). In some cases, adhering to the rule might have worse results than ignoring it, but overall it would produce the greatest good for patients, physicians, nurses, and the medical profession.

The requirement of informed consent can be derived directly from Kantian ethics. As autonomous beings, people are entitled to respect, to be treated as ends in themselves, never merely as a means to an end. They therefore cannot be subjected to medical treatment just because physicians believe it is in their best interests. They must voluntarily consent to be treated, and for the choice to be fully autonomous, they must be informed truthfully about what is involved. To lie to them, withhold relevant information from them, coerce them, or manipulate them is to treat them merely as a means.

From a strictly Kantian viewpoint, therapeutic privilege is never permissible, but waiver is allowed because it represents an autonomous choice not to choose. Some theorists make an

exception to these restrictions if the therapeutic privilege or other manipulative tactic is used to help restore or enhance a person's autonomy.

Rawls's contract theory calls for equal liberties for all, a demand that seems to support the doctrine of informed consent. Treating people

without their informed authorization would be a violation of such liberties, and manipulation and coercion to obtain consent would be impermissible. This would be the case even if treating a few patients without informed consent would somehow benefit all of society.

#### CLASSIC CASE FILE

### Jerry Canterbury

How much are physicians obligated to disclose to patients, and by what standard should the adequacy of the disclosure be judged? In 1972 some answers came in the turning-point case *Canterbury v. Spence*.

Nineteen-year-old Jerry Canterbury entered the hospital for tests to determine the cause of the excruciating pain he felt between his shoulder blades. He had been in pain for months, and the prescription medications he had been taking weren't helping. Dr. William Spence ordered a myelogram, an x-ray of the spinal column taken after the column is injected with a traceable dye. After seeing the test results, Dr. Spence told Canterbury that the problem was probably a ruptured disk, and he recommended surgery on the spinal column to correct the problem. Canterbury consented to the procedure.

After the operation, he seemed to be recovering normally, but then he fell in the hospital and became paralyzed from the waist down. He learned later that paralysis was a possible risk of the kind of surgery he had undergone, but Dr. Spence had not mentioned it. Eventually he regained some muscle control but, even years later, needed crutches to walk and suffered from paralysis of the bowels and urinary incontinence.

Canterbury sued Dr. Spence for failure to tell him before the surgery of the risk of paralysis, and the court found in his favor, marking out some tenets of informed consent along the way. The court strongly affirmed the doctrine and the rationale upon which it rests:

True consent to what happens to one's self is the informed exercise of a choice, and that

entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. The average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment with which to reach an intelligent decision. From these almost axiomatic considerations springs the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible. . . . And it is evident that it is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient's edification.<sup>10</sup>

In a departure from most other rulings on informed consent, the court declared that the standard for judging whether a physician's disclosure is acceptable should not be the customary practices of physicians but the patient's requirements for pertinent information. In many situations, the court said, no relevant customary practice may exist, and—more importantly—to let the professional customs of physicians decide is to undermine the patient's right of self-determination. The rights and needs of patients set the bar:

In our view, the patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and

that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked.<sup>11</sup>

The court characterized the test as what a reasonable person would likely need to know to make an informed decision about a proposed treatment.

Nevertheless, the judges recognized that the physician's invoking of therapeutic privilege (withholding information) is sometimes reasonable and proper. But they rejected "the paternalistic notion

that the physician may remain silent simply because divulgence might prompt the patient to forgo therapy the physician feels the patient really needs."<sup>12</sup> Dr. Spence had cited this very notion in his defense.

Some have accused the court of being unclear on the issues of therapeutic privilege and the customary-practice standard of disclosure. But whether or not that's true, *Canterbury v. Spence* helped delineate essential features of the doctrine of informed consent that are now widely accepted. After *Canterbury*, there seemed no going back to the old ideas about disclosure.

### KEY TERMS

competence  
informed consent  
therapeutic privilege  
waiver

### SUMMARY

Informed consent refers to the action of an autonomous, informed person agreeing to submit to medical treatment or experimentation. It is a powerful notion that thinkers have justified by appealing to the principles of autonomy and beneficence. Court decisions have helped to establish the doctrine in law and society, most notably the case of *Canterbury v. Spence*, which asserted that the adequacy of disclosure by physicians should be judged by what patients think is relevant to their situations.

Theorists maintain that an informed consent exists if and only if (1) the patient is competent to decide, (2) she gets an adequate disclosure of information, (3) she understands the information, (4) she decides about the treatment voluntarily, and (5) she consents to the treatment. Competence is the ability to render decisions about medical interventions. Incompetent patients cannot give their informed consent and must rely on

surrogates. What constitutes an adequate disclosure of information to patients is controversial, but the courts have generally ruled that disclosure must include information about the nature of the procedure, its risks, its alternatives (including no treatment), and its expected benefits.

Informed consent is not obligatory in cases of waiver, the patient's voluntary and deliberate giving up of the right to informed consent. It is an exercise in autonomous choice; authority to decide medical issues is turned over to the physician or surrogates. A controversial exception to informed consent is therapeutic privilege, the withholding of relevant information from a patient when the physician believes disclosure would likely do harm. Laws regarding therapeutic privilege vary on when invoking it is justified, with some allowing it only when disclosure would be extremely dangerous for the patient or when it would seriously diminish the patient's autonomy. Others permit physicians far more leeway in deciding when to claim the privilege.

An act-utilitarian would judge whether a physician should try to obtain informed consent according to the benefits generated for all concerned. A rule-utilitarian might conclude that the best overall consequences would be achieved

if physicians consistently followed a rule requiring informed consent. In Kantian ethics, informed consent is an absolute requirement, and therapeutic privilege is never permissible. Rawls's contract theory seems to support the doctrine of informed consent. Treating people without their informed authorization would be a violation of basic liberties.

## Cases for Evaluation

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### CASE I

#### Informed Consent or Not?

A 64-year-old woman with multiple sclerosis (MS) is hospitalized. The team feels she may need to be placed on a feeding tube soon to assure adequate nourishment. They ask the patient about this in the morning and she agrees. However, in the evening (before the tube has been placed), the patient becomes disoriented and seems confused about her decision to have the feeding tube placed. She tells the team she doesn't want it in. They revisit the question in the morning, when the patient is again lucid. Unable to recall her state of mind from the previous evening, the patient again agrees to the procedure.\*

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*Explain your answers: Has the woman given her informed consent? Should she be judged competent? Should her final agreement to the procedure be sufficient to establish informed consent, or should her earlier waffling and confusion also be taken into account?*

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\*“Informed Consent,” *Ethics in Medicine* (University of Washington School of Medicine), <http://depts.washington.edu/bioethx/topics/consent.html>.

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### CASE 2

#### Informed Consent and Organ Transplants

(AP)—A woman in her 30s who is one of the four organ transplant patients [who became] infected with HIV and hepatitis [because of the transplant]

was not told that the infected donor was high risk, and had previously rejected another donor “because of his lifestyle,” her attorney said.

Attorney Thomas Demetrio filed a petition Thursday in Cook County Circuit Court on behalf of the woman, asking officials to keep a hospital and an organ procurement center from destroying or altering any records involving the donation.

“She’s really a mess right now,” Demetrio said of the Chicago-area woman. “She’s still in shock.”

The patient, identified in court documents as Jane Doe, received a kidney transplant at the University of Chicago Medical Center on Jan. 9, Demetrio said.

Gift of Hope Organ & Tissue Donor Network in Elmhurst and the University of Chicago both knew the kidney donor was high-risk and did not inform the patient, Demetrio said.

University of Chicago spokesman John Easton responded in an e-mail: “We believe we follow guidelines, and of course with the patient’s consent we will provide necessary records and documents, as is consistent with our open process.”

Gift of Hope did not immediately respond to requests for comment.

The woman had been told the donor was a healthy young man, her attorney said. But on Tuesday, hospital officials disclosed to the woman that he was actually high-risk, a 38-year-old gay man, Demetrio said. CDC guidelines say that gay men who are sexually active should not be used as organ donors unless the patient is in imminent danger of death.

The woman was told she had HIV and hepatitis on Nov. 1, he said.

“The (organ) procurement group knew, the hospital knew, but the most important person did not know,” he said. “The people that dedicate their lives to these transplant surgeries, they’re just great people, but they need to bring the patient into the mix and let them make an informed decision.”

U.S. Centers for Disease Control and Prevention guidelines were violated twice, the attorney said. One violation was not informing the woman about the donor’s status and then not testing her afterward for HIV until just recently, after HIV and hepatitis were found during tests on another patient who was being evaluated for a second transplant....

She's been started on an HIV drug regimen "and unfortunately one of the side effects is it's not good for the kidneys," Demetrio said. She's not hospitalized.

Dr. Dan Berger, medical director of a large HIV-AIDS clinic in Chicago, said U.S. doctors have had several years of experience treating HIV-infected patients who went on to get transplant organs. Such patients need an HIV specialist and a transplant specialist to monitor their medications, which include anti-rejection drugs for the transplant and antiretrovirals for HIV, he said.

The four patients infected by the high-risk donor's organs have extra medical concerns, Berger said.

"When a patient first becomes infected with HIV there's a huge spike in viral load and (at the same time) severe immune compromise," he said. "The fact that they also are on immune-suppressive medications (after transplant) may put them at extreme risk for opportunistic infection."\*

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*If Jane Doe had not become infected with HIV and hepatitis after her transplant, would the failure of the donor network and the university to fully inform her about the donor have been morally wrong? If so, why? Would her consenting to the transplant have been permissible if she had known that the donor was high risk? Should a patient have the right to consent to and undergo risky treatments? Explain.*

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\*The Associated Press, "Atty: Woman Wasn't Told Donor Was a Risk," November 16, 2007.

### CASE 3

#### Adolescent Informed Consent

In mid-summer, a 14-year-old youth was brought to the pediatric emergency department by his mother for evaluation for altered mental status. The mother returned from work to find her son acting strangely. She had last seen him the previous evening, and there were no problems or complaints at that time. Earlier in the week the child had sustained several mosquito bites. The child was now at times

lethargic and at other times agitated. There were two episodes of vomiting. There was no history of fever trauma, medications, or known ingestions. The medical history was negative. The social history was significant for a high-achieving honor student who came from a very financially successful household. Physical examination revealed a drowsy and disoriented athletic male. The vital signs were temperature of 37.8° Celsius, heart rate of 107 beats per minute, respiratory rate of 20 per minute, and blood pressure of 123/87 mm Hg. The general physical examination was unremarkable. The neurologic examination revealed a disoriented teenager with ataxia, brisk reflexes throughout, reactive pupils, and intact cranial nerves II through XII. A bedside glucose test and pulse oximetry were both normal. Given the ongoing epidemic of West Nile virus at the time of presentation, the mother was convinced that the child had contracted the insect-borne disease because of the combination of mosquito bites and altered mental status. The mother was absolutely insistent that a spinal tap (lumbar puncture) be performed immediately, to evaluate for the possibility of West Nile virus.

The patient's pediatrician was also concerned and requested a full and thorough evaluation. An intravenous line was started and routine blood evaluations were ordered. The patient seemed at times to be more lucid, but at other times was again disoriented. When interviewed alone, he denied having West Nile virus, but he agreed to tell the physician why he believed this to be the case, but only if his parents were not told. The physician explained that all information given by the patient would be kept in strict confidence. Because of the assurance of confidentiality, the patient disclosed that he had bought a large amount of dextromethorphan on the Internet and had taken it with his friends after school.

Dextromethorphan ingestion, even in large quantities, generally does not require anything but supportive care. The mother, not knowing about the ingestion of this drug, continued to be insistent that further tests be performed, including a spinal tap.\*

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*Who, if anyone, in this scenario should be allowed to give informed consent to treatment (or no treatment)? Why? Should the physician regard the*

14-year-old as a mature minor? What actions should the physician take if she regarded him as a mature minor? What actions would the physician likely take if she decided to set aside the issue of informed consent and act only in the patient's best interests?

\*Reza Keshavarz, "Adolescents, Informed Consent and Confidentiality: A Case Study," *The Mount Sinai Journal of Medicine* 72, no. 4 (July 4, 2005): 232–35.

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## READINGS

### The Concept of Informed Consent

RUTH R. FADEN AND TOM L. BEAUCHAMP

Faden and Beauchamp distinguish two common views of informed consent and argue that only one of them reflects the true meaning of the concept. Real informed consent involves more than a patient's merely agreeing to, or acquiescing in, some suggested course of action. An informed consent is a patient's autonomous action that authorizes a course of action. The other common meaning of the term is defined legally or institutionally and does not refer to autonomous authorization. Faden and Beauchamp also believe that the tendency to equate informed consent with shared decision-making is confused. Decision-making, which has been linked historically to informed consent, is not enough.

What is an informed consent? Answering this question is complicated because there are two common, entrenched, and starkly different meanings of “informed consent.” That is, the term is analyzable in two profoundly different ways—not because of mere subtle differences of connotation that appear in different contexts, but because two different *conceptions* of informed consent have emerged from its history and are still at work, however unnoticed, in literature on the subject.

In one sense, which we label *sense<sub>1</sub>*, “informed consent” is analyzable as a particular kind of action by individual patients and subjects: an autonomous authorization. In the second sense, *sense<sub>2</sub>*, informed consent is analyzable in terms of the web of cultural and policy rules and requirements of consent that collectively form the social practice of informed consent in institutional contexts where *groups* of patients and subjects must be treated in accordance with rules, policies, and standard practices. Here, informed consents are not always *autonomous* acts, nor are they always in any meaningful respect *authorizations*.

### **Sense<sub>1</sub>: Informed Consent as Autonomous Authorization**

The idea of an informed consent suggests that a patient or subject does more than express agreement with, acquiesce in, yield to, or comply with an arrangement or a proposal. He or she actively *authorizes* the proposal in the act of consent. John may *assent* to a treatment plan without authorizing it. The assent may be a mere submission to the doctor’s authoritative order, in which case John does not call on his own authority in order to give permission, and thus does not authorize the plan. Instead, he acts like a child who submits, yields, or assents to the school principal’s spanking and in no way gives permission for or authorizes the spanking. Just as the child merely submits to an authority in a system where the lines of authority are quite clear, so often do patients.

Accordingly, an informed consent in *sense<sub>1</sub>* should be defined as follows: An informed consent

is an autonomous action by a subject or a patient that authorizes a professional either to involve the subject in research or to initiate a medical plan for the patient (or both). We can whittle down this definition by saying that an informed consent in *sense<sub>1</sub>* is given if a patient or subject with (1) substantial understanding and (2) in substantial absence of control by others (3) intentionally (4) authorizes a professional (to do intervention I).

All substantially autonomous acts satisfy conditions 1–3; but it does not follow from that analysis alone that all such acts satisfy 4. The fourth condition is what distinguishes informed consent as one *kind* of autonomous action. (Note also that the definition restricts the kinds of authorization to medical and research contexts.) A person whose act satisfies conditions 1–3 but who refuses an intervention gives an *informed refusal*.

### **The Problem of Shared Decisionmaking**

This analysis of informed consent in *sense<sub>1</sub>* is deliberately silent on the question of how the authorizer and agent(s) being authorized *arrive at an agreement* about the performance of “I.” Recent commentators on informed consent in clinical medicine, notably Jay Katz and the President’s Commission, have tended to equate the idea of informed consent with a model of “shared decisionmaking” between doctor and patient. The President’s Commission titles the first chapter of its report on informed consent in the patient-practitioner relationship “Informed Consent as Active, Shared Decision Making,” while in Katz’s work “the idea of informed consent” and “mutual decisionmaking” are treated as virtually synonymous terms.<sup>1</sup>

There is of course an historical relationship in clinical medicine between medical decisionmaking and informed consent. The emergence of the legal doctrine of informed consent was instrumental in drawing attention to issues of decisionmaking as well as authority in the doctor-patient relationship. Nevertheless, it is a confusion to treat informed consent and shared decisionmaking as anything like *synonymous*. For one thing, informed consent is not restricted to clinical medicine. It is a term that applies equally to biomedical and behavioral research contexts where a model of shared decisionmaking is frequently inappropriate. Even in

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From *A History and Theory of Informed Consent* by Ruth R. Faden and Tom L. Beauchamp, pp. 276–86. Copyright © 1986 Oxford University Press, reprinted with permission.

clinical contexts, the social and psychological dynamics involved in selecting medical interventions should be distinguished from the patient's *authorization*.

We endorse Katz's view that effective communication between professional and patient or subject is often instrumental in obtaining informed consents (*sense<sub>1</sub>*), but we resist his conviction that the idea of informed consent entails that the patient and physician "share decisionmaking," or "reason together," or reach a consensus about what is in the patient's best interest. This is a manipulation of the concept from a too singular and defined moral perspective on the practice of medicine that is in effect a moral program for changing the practice. Although the patient and physician *may* reach a decision together, they need not. It is the essence of informed consent in *sense<sub>1</sub>* only that the patient or subject *authorizes autonomously*; it is a matter of indifference where or how the proposal being authorized originates.

For example, one might advocate a model of shared decisionmaking for the doctor-patient relationship without simultaneously advocating that every medical procedure requires the consent of patients. Even relationships characterized by an ample slice of shared decisionmaking, mutual trust, and respect would and should permit many decisions about routine and low-risk aspects of the patient's medical treatment to remain the exclusive province of the physician, and thus some decisions are likely always to remain subject exclusively to the physician's authorization. Moreover, in the uncommon situation, a patient could autonomously authorize the physician to make *all* decisions about medical treatment, thus giving his or her informed consent to an arrangement that scarcely resembles the sharing of decisionmaking between doctor and patient.

### Authorization

In authorizing, one both assumes responsibility for what one has authorized and transfers to another one's authority to implement it. There is no informed consent unless one *understands* these features of the act and *intends* to perform that act. That is, one must understand that one is assuming responsibility and warranting another to proceed.

To say that one assumes responsibility does not quite locate the essence of the matter, however, because a *transfer* of responsibility as well as of authority also occurs. The crucial element in an authorization is that the person who authorizes uses whatever right, power, or control he or she possesses in the situation to endow another with the right to act. In so doing, the authorizer assumes some responsibility for the actions taken by the other person. Here one could either authorize *broadly* so that a person can act in accordance with general guidelines, or *narrowly* so as to authorize only a particular, carefully circumscribed procedure.

### **Sense<sub>2</sub>: Informed-Consent as Effective Consent**

By contrast to *sense<sub>1</sub>*, *sense<sub>2</sub>*, or *effective consent*, is a policy-oriented sense whose conditions are not derivable solely from analyses of autonomy and authorization, or even from broad notions of respect for autonomy. "Informed consent" in this second sense does not refer to *autonomous* authorization, but to a legally or institutionally *effective* (sometimes misleadingly called *valid*) authorization from a patient or a subject. Such an authorization is "effective" because it has been obtained through procedures that satisfy the rules and requirements defining a specific institutional practice in health care or in research.

The social and legal practice of requiring professionals to obtain informed consent emerged in institutional contexts, where conformity to operative rules was and still is the sole necessary and sufficient condition of informed consent. Any consent is an informed consent in *sense<sub>2</sub>* if it satisfies whatever operative rules apply to the practice of informed consent. *Sense<sub>2</sub>* requirements for informed consent typically do not focus on the autonomy of the act of giving consent (as *sense<sub>1</sub>* does), but rather on regulating the behavior of the *consent-seeker* and on establishing *procedures and rules* for the context of consent. Such requirements of professional behavior and procedure are obviously more readily monitored and enforced by institutions.

However, because formal institutional rules such as federal regulations and hospital policies

govern whether an act of authorizing is effective, a patient or subject can autonomously authorize an intervention, and so give an informed consent in sense<sub>1</sub>, and yet *not effectively authorize* that intervention in sense<sub>2</sub>.

Consider the following example. Carol and Martie are nineteen-year-old, identical twins attending the same university. Martie was born with multiple birth defects, and has only one kidney. When both sisters are involved in an automobile accident, Carol is not badly hurt, but her sister is seriously injured. It is quickly determined that Martie desperately needs a kidney transplant. After detailed discussions with the transplant team and with friends, Carol consents to be the donor. There is no question that Carol's authorization of the transplant surgery is substantially autonomous. She is well informed and has long anticipated being in just such a circumstance. She has had ample opportunity over the years to consider what she would do were she faced with such a decision. Unfortunately, Carol's parents, who were in Nepal at the time of the accident, do not approve of her decision. Furious that they were not consulted, they decide to sue the transplant team and the hospital for having performed an unauthorized surgery on their minor daughter. (In this state the legal age to consent to surgical procedures is twenty-one.)

According to our analysis, Carol gave her informed consent in sense<sub>1</sub> to the surgery, but she did not give her informed consent in sense<sub>2</sub>. That is, she autonomously authorized the transplant and thereby gave an informed consent in sense<sub>1</sub> but did not give a consent that was effective under the operative legal and institutional policy, which in this case required that the person consenting be a legally authorized agent. Examples of other policies that can define sense<sub>2</sub> informed consent (but not sense<sub>1</sub>) include rules that consent be witnessed by an auditor or that there be a one-day waiting period between solicitation of consent and implementation of the intervention in order for the person's authorization to be effective. Such rules can and do vary, both within the United States by jurisdiction and institution, and across the countries of the world.

Medical and research codes, as well as case law and federal regulations, have developed models of informed consent that are delineated entirely in a sense<sub>2</sub> format, although they have sometimes attempted to justify the rules by appeal to something like sense<sub>1</sub>. For example, disclosure conditions for informed consent are central to the history of "informed consent" in sense<sub>2</sub>, because disclosure has traditionally been a *necessary* condition of effective informed consent (and sometimes a *sufficient* condition!). The legal doctrine of informed consent is primarily a law of disclosure; satisfaction of disclosure rules virtually consumes "informed consent" in law. This should come as no surprise, because the legal system needs a generally applicable informed consent mechanism by which injury and responsibility can be readily and fairly assessed in court. These disclosure requirements in the legal and regulatory contexts are not conditions of "informed consent" in sense<sub>1</sub>; indeed disclosure may be entirely irrelevant to giving an informed consent in sense<sub>1</sub>. If a person has an adequate *understanding* of relevant information without benefit of a disclosure, then it makes no difference whether someone *discloses* that information.

Other sense<sub>2</sub> rules besides those of disclosure have been enforced. These include rules requiring evidence of adequate comprehension of information and the aforementioned rules requiring the presence of auditor witnesses and mandatory waiting periods. Sense<sub>2</sub> informed consent requirements generally take the form of rules focusing on disclosure, comprehension, the minimization of potentially controlling influences, and competence. These requirements express the present-day mainstream conception in the federal government of the United States. They are also typical of international documents and state regulations, which all reflect a sense<sub>2</sub> orientation.

### The Relationship Between Sense<sub>1</sub> and Sense<sub>2</sub>

A sense<sub>1</sub> "informed consent" can fail to be an informed consent in sense<sub>2</sub> by a lack of conformity to applicable rules and requirements. Similarly, an informed consent in sense<sub>2</sub> may not be an informed consent in sense<sub>1</sub>. The rules and requirements that

determine sense<sub>2</sub>, consents need not result in autonomous authorizations at all in order to qualify as informed consents.

Such peculiarities in informed consent law have led Jay Katz to argue that the legal doctrine of “informed consent” bears a “name” that “promises much more than its construction in case law has delivered.” He has argued insightfully that the courts have, in effect, imposed a mere duty to warn on physicians, an obligation confined to risk disclosures and statements of proposed interventions. He maintains that “This judicially imposed obligation must be distinguished from the *idea* of informed consent, namely, that patients have a decisive role to play in the medical decisionmaking process. The idea of informed consent, though alluded to also in case law, cannot be implemented, as courts have attempted, by only expanding the disclosure requirements.” By their actions and declarations, Katz believes, the courts have made informed consent a “cruel hoax” and have allowed “the idea of informed consent . . . to wither on the vine.”<sup>2</sup>

The most plausible interpretation of Katz’s contentions is through the sense<sub>1</sub>/sense<sub>2</sub> distinction. If a physician obtains a consent under the courts’ criteria, then an informed consent (sense<sub>2</sub>) has been obtained. But it does not follow that the courts are using the *right* standards, or *sufficiently rigorous* standards in light of a stricter autonomy-based model—or “idea” as Katz puts it—of informed consent (sense<sub>1</sub>).<sup>3</sup> If Katz is correct that the courts have made a mockery of informed consent and of its moral justification in respect for autonomy, then of course his criticisms are thoroughly justified. At the same time, it should be recognized that people can proffer legally or institutionally effective authorizations under prevailing rules even if they fall far short of the standards implicit in sense<sub>1</sub>.

Despite the differences between sense<sub>1</sub> and sense<sub>2</sub>, a definition of informed consent need not fall into one or the other class of definitions. It may conform to both. Many definitions of informed consent in policy contexts reflect at least a strong and definite reliance on informed consent in sense<sub>1</sub>. Although the conditions of sense<sub>1</sub> are not logically necessary conditions for sense<sub>2</sub>, we take it as morally axiomatic that they *ought* to serve—and in fact

have served—as the benchmark or model against which the moral adequacy of a definition framed for sense<sub>2</sub> purposes is to be evaluated. This position is, roughly speaking, Katz’s position.

A defense of the moral viewpoint that policies governing informed consent in sense<sub>2</sub> should be formulated to conform to the standards of informed consent in sense<sub>1</sub> is not hard to express. The goal of informed consent in medical care and in research—that is, the purpose behind the obligation to obtain informed consent—is to enable potential subjects and patients to make autonomous decisions about whether to grant or refuse authorization for medical and research interventions. Accordingly, embedded in the reason for having the social institution of informed consent is the idea that institutional requirements for informed consent in sense<sub>2</sub> should be intended to maximize the likelihood that the conditions of informed consent in sense<sub>1</sub> will be satisfied.

A major problem at the policy level, where rules and requirements must be developed and applied in the aggregate, is the following: The obligations imposed to enable patients and subjects to make authorization decisions must be evaluated not only in terms of the demands of a set of abstract conditions of “true” or sense<sub>1</sub> informed consent, but also in terms of the impact of imposing such obligations or requirements on various institutions with their concrete concerns and priorities. One must take account of what is fair and reasonable to require of health care professionals and researchers, the effect of alternative consent requirements on efficiency and effectiveness in the delivery of health care and the advancement of science, and—particularly in medical care—the effect of requirements on the welfare of patients. Also relevant are considerations peculiar to the particular social context, such as proof, precedent, or liability theory in case law, or regulatory authority and due process in the development of federal regulations and IRB consent policies.

Moreover, at the sense<sub>2</sub> level, one must resolve not only which requirements will define effective consent; one must also settle on the rules stipulating the conditions under which effective consents must be obtained. In some cases, hard decisions must be made about whether requirements of

informed consent (in sense<sub>2</sub>) should be imposed at all, even though informed consent (in sense<sub>1</sub>) could realistically and meaningfully be obtained in the circumstances and could serve as a model for institutional rules. For example, should there be any consent requirements in the cases of minimal risk medical procedures and research activities?

This need to balance is not a problem for informed consent in sense<sub>2</sub>, which is not policy oriented. Thus, it is possible to have a *morally acceptable* set of requirements for informed consent in sense<sub>2</sub> that deviates considerably from the conditions of informed consent in sense<sub>1</sub>. However, the burden of moral proof rests with those who defend such deviations since the primary moral justification of the

obligation to obtain informed consent is respect for autonomous action.

#### NOTES

1. President's Commission, *Making Health Care Decisions*, Vol. 1, 15 and Jay Katz, *The Silent World of Doctor and Patient* (New York: The Free Press, 1984), 87 and "The Regulation of Human Research—Reflections and Proposals," *Clinical Research* 21 (1973): 758–91. Katz does not provide a sustained analysis of joint or shared decisionmaking, and it is unclear precisely how he would relate this notion to informed consent.
2. Jay Katz, "Disclosure and Consent," in A. Milunsky and G. Annas, eds., *Genetics and the Law II* (New York: Plenum Press, 1980), 122, 128.
3. We have already noted that Katz's "idea" of informed consent—as the active involvement of patients in the medical decisionmaking process—is different from our sense<sub>1</sub>.

## Informed Consent—Must It Remain a Fairy Tale?

JAY KATZ

The ideal of informed consent with its presumptions of autonomy and joint decision-making is yet to be fully realized in practice, says Katz. The concept has been legally recognized, but genuine patient self-determination is still not the norm. Physicians acknowledge it but are likely to see it as a perfunctory fulfillment of legal requirements or as an enumeration of risks. The goal of joint decision-making between physicians and patients is still unfulfilled. Physicians must come to see that they have a "duty to respect patients as persons so that care will encompass allowing patients to live their lives in their own self-willed ways."

### I. The Pre-History of Informed Consent in Medicine

The idea that, prior to any medical intervention, physicians must seek their patients' informed consent was introduced into American law in a brief paragraph in a 1957 state court decision,<sup>1</sup> and then elaborated on in a lengthier opinion in 1960.<sup>2</sup> The emerging legal idea that physicians were from now on obligated to share decisionmaking authority with their patients shocked the medical community, for it constituted a radical break with the

silence that had been the hallmark of physician-patient interactions throughout the ages. Thirty-five years are perhaps not long enough for either law or medicine to resolve the tension between legal theory and medical practice, particularly since judges were reluctant to face up to implications of their novel doctrine, preferring instead to remain quite deferential to the practices of the medical profession.

Viewed from the perspective of medical history, the doctrine of informed consent, if taken seriously, constitutes a revolutionary break with customary practice. Thus, I must review, albeit all too briefly, the history of doctor-patient communication. Only then can one appreciate how unprepared the

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medical profession was to heed these new legal commands. But there is more: Physicians could not easily reject what law had begun to impose on them, because they recognized intuitively that the radical transformation of medicine since the age of medical science made it possible, indeed imperative, for a doctrine of informed consent to emerge. Yet, bowing to the doctrine did not mean accepting it. Indeed, physicians could not accept it because, for reasons I shall soon explore, the nature of informed consent has remained in the words of Churchill, “an enigma wrapped in a mystery.”

Throughout the ages physicians believed that they should make treatment decisions for their patients. This conviction inheres in the Hippocratic Oath: “I swear by Apollo and Aesculapius [that] I will follow that system of regimen which according to *my* ability and judgment *I* consider for the benefit of *my* patients. . . .”<sup>3</sup> The patient is not mentioned as a person whose ability and judgment deserve consideration. Indeed, in one of the few references to disclosure in the Hippocratic Corpus, physicians are admonished “to [conceal] most things from the patient while attending to him; [to] give necessary orders with cheerfulness and serenity, . . . revealing nothing of the patient’s future or present condition.”<sup>4</sup> When twenty-five centuries later, in 1847, the American Medical Association promulgated its first Code of Ethics, it equally admonished patients that their “obedience . . . to the prescriptions of [their] physician should be prompt and implicit. [They] should never permit [their] own crude opinions . . . to influence [their] attention to [their physicians].”<sup>5</sup>

The gulf separating doctors from patients seemed unbridgeable both medically and socially. Thus, whenever the Code did not refer to physicians and patients as such, the former were addressed as “gentlemen” and the latter as “fellow creatures.” To be sure, caring for patients’ medical needs and “abstain[ing] from whatever is deleterious and mischievous”<sup>6</sup> was deeply imbedded in the ethos of Hippocratic medicine. The idea that patients were also “autonomous” human beings, entitled to being partners in decision-making, was, until recently, rarely given recognition in the lexicon of medical ethics. The notion that human beings possess

individual human rights, deserving of respect, of course, is of recent origin. Yet it antedates the twentieth century and therefore could have had an impact on the nature and quality of the physician-patient relationship.

It did not. Instead, the conviction that physicians should decide what is best for their patients, and, therefore, that the authority and power to do so should remain vested in them, continued to have a deep hold on the practices of the medical profession. For example, in the early 1950s the influential Harvard sociologist Talcott Parsons, who echoed physicians’ views, stated that the physician is a technically competent person whose competence and specific judgments and measures cannot be competently judged by the layman and that the latter must take doctors’ judgments and measures on “authority.” The necessity for such authority was supported by three claims:

*First, physicians’ esoteric knowledge, acquired in the course of arduous training and practical experience, cannot be comprehended by patients.* While it is true that this knowledge, in its totality, is difficult to learn, understand and master, it does not necessarily follow that physicians cannot translate their esoteric knowledge into language that comports with patients’ experiences and life goals (i.e., into language that speaks to quality of future life, expressed in words of risks, benefits, alternatives and uncertainties). Perhaps patients can understand this, but physicians have had too little training and experience with, or even more importantly, a commitment to, communicating their “esoteric knowledge” to patients in plain language to permit a conclusive answer as to what patients may comprehend.

*Second, patients, because of their anxieties over being ill and consequent regression to childlike thinking, are incapable of making decisions on their own behalf.* We do not know whether the childlike behavior often displayed by patients is triggered by pain, fear, and illness, or by physicians’ authoritarian insistence that good patients comply with doctors’ orders, or by doctors’ unwillingness to share information with patients. Without providing such information, patients are groping in the dark and their stumbling attempts to ask questions, if made

at all, makes them appear more incapable of understanding than they truly are.

We know all too little about the relative contributions which being ill, being kept ignorant, or being considered incompetent make to these regressive manifestations. Thus, physicians' unexamined convictions easily become self-fulfilling prophesies. For example, Eric Cassell has consistently argued that illness robs patients of autonomy and that only subsequent to the act of healing is autonomy restored.<sup>8</sup> While there is some truth to these contentions, they overlook the extent to which doctors can restore autonomy prior to the act of healing by not treating patients as children but as adults whose capacity for remaining authors of their own fate can be sustained and nourished. Cassell's views are reminiscent of Dostoyevsky's Grand Inquisitor who proclaimed that "at the most fearful moments of life," mankind is in need of "miracle, mystery and authority."<sup>9</sup> While, in this modern age, a person's capacity and right to take responsibility for his or her conduct has been given greater recognition than the Grand Inquisitor was inclined to grant, it still does not extend to patients. In the context of illness, physicians are apt to join the Grand Inquisitor at least to the extent of asserting that, while patients, they can only be comforted through subjugation to miracle, mystery and authority.

Third, *physicians' commitment to altruism is a sufficient safeguard for preventing abuses of their professional authority.* While altruism, as a general professional commitment, has served patients well in their encounters with physicians, the kind of protection it does and does not provide has not been examined in any depth. I shall have more to say about this later on. For now, let me only mention one problem: Altruism can only promise that doctors will try to place their patients' medical needs over their own personal needs. Altruism cannot promise that physicians will know, without inquiry, patients' needs. Put another way, patients and doctors do not necessarily have an identity of interest about matters of health and illness. Of course, both seek restoration of health and cure, and whenever such ends are readily attainable by only one route, their interests indeed may coincide.

In many physician-patient encounters, however, cure has many faces and the means selected affect the nature of cure in decisive ways. Thus, since quality of life is shaped decisively by available treatment options (including no treatment), the objectives of health and cure can be pursued in a variety of ways. Consider, for example, differences in value preferences between doctors and patients about longevity versus quality of remaining life. Without inquiry, one cannot presume identity of interest. As the surgeon Nuland cogently observed: "A doctor's altruism notwithstanding, his agenda and value system are not the same as those of the patient. That is the fallacy in the concept of beneficence so cherished by many physicians."<sup>10</sup>

## **II. The Age of Medical Science and Informed Consent**

During the millennia of medical history, and until the beginning of the twentieth century, physicians could not explain to their patients, or—from the perspective of hindsight—to themselves, which of their treatment recommendations were curative and which were not. To be sure, doctors, by careful bedside observation, tried their level best "to abstain from what is deleterious and mischievous," to help if they could, and to be available for comfort during the hours, days or months of suffering. Doing more curatively, however, only became possible with the advent of the age of medical science. The introduction of scientific reasoning into medicine, aided by the results of carefully conducted research, permitted doctors for the first time to discriminate more aptly between knowledge, ignorance and conjecture in their recommendations for or against treatment. Moreover, the spectacular technological advances in the diagnosis and treatment of disease, spawned by medical science, provided patients and doctors with ever-increasing therapeutic options, each having its own particular benefits and risks.

Thus, for the first time in medical history it is possible, even medically and morally imperative, to give patients a voice in medical decisionmaking. It is possible because knowledge and ignorance can be better specified; it is medically imperative because a variety of treatments are available, each of which

can bestow great benefits or inflict grievous harm; it is morally imperative because patients, depending on the lifestyle they wish to lead during and after treatment, must be given a choice.

All this seems self-evident. Yet, the physician-patient relationship—the conversations between the two parties—was not altered with the transformation of medical practice during the twentieth century. Indeed, the silence only deepened once laboratory data were inscribed in charts and not in patients' minds, once machines allowed physicians' eyes to gaze not at patients' faces but at the numbers they displayed, once x-rays and electrocardiograms began to speak for patients' suffering rather than their suffering voices.

What captured the medical imagination and found expression in the education of future physicians, was the promise that before too long the diagnosis of patients' diseases would yield objective, scientific data to the point of becoming algorithms. *Treatment*, however, required subjective data from patients and would be influenced by doctors' subjective judgments. This fact was overlooked in the quest for objectivity. Also overlooked was the possibility that greater scientific understanding of the nature of disease and its treatment facilitated better communication with patients. In that respect contemporary Hippocratic practices remained rooted in the past.

### **III. The Impact of Law**

The impetus for change in traditional patterns of communication between doctors and patients came not from medicine but from law. In a 1957 California case,<sup>11</sup> and a 1960 Kansas case,<sup>12</sup> judges were astounded and troubled by these undisputed facts: That without any disclosure of risks, new technologies had been employed which promised great benefits but also exposed patients to formidable and uncontrollable harm. In the California case, a patient suffered a permanent paralysis of his lower extremities subsequent to the injection of a dye, sodium urokan, to locate a block in the abdominal aorta. In the Kansas case, a patient suffered severe injuries from cobalt radiation, administered, instead of conventional x-ray treatment, subsequent to a mastectomy for breast cancer. In the latter case, Justice Schroeder attempted to give greater

specifications to the informed consent doctrine, first promulgated in the California decision: "To disclose and explain to the patient, in language as simple as necessary, the nature of the ailment, the nature of the proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions within the body."<sup>13</sup>

From the perspective of improved doctor-patient communication, or better, shared decision-making, the fault lines inherent in this American legal doctrine are many:

One: The common law judges who promulgated the doctrine restricted their task to articulating new and more stringent standards of liability whenever physicians withheld material information that patients should know, particularly in light of the harm that the spectacular advances in medical technology could inflict. Thus, the doctrine was limited in scope, designed to specify those minimal disclosure obligations that physicians must fulfill to escape *legal* liability for alleged non-disclosures. Moreover, it was shaped and confined by legal assumptions about the objectives of the laws of evidence and negligence, and by economic philosophies as to who should assume the financial burdens for medical injuries sustained by patients.

Even though the judges based the doctrine on "Anglo-American law[s] . . . premise of thorough-going self-determination,"<sup>14</sup> the Kansas court put it, or on "the root premise . . . fundamental in American jurisprudence that 'every human being of adult years and sound mind has a right to determine what shall be done with his own body,'"<sup>15</sup> as the Circuit Court for the District of Columbia put it in a subsequent opinion, the doctrine was grounded not in battery law (trespass), but in negligence law. The reasons are many. I shall only mention a compelling one: Battery law, based on unauthorized trespass, gives doctors only one defense—that they have made adequate disclosure. Negligence law, on the other hand, permits doctors to invoke many defenses, including "the therapeutic privilege" not to disclose when in their judgment, disclosure may prove harmful to patients' welfare.

Two recent opinions illustrate the problems identified here. First, in a rare opinion, the Supreme

Court of Pennsylvania reconfirmed its adherence to the minority view among American jurisdictions that battery, not negligence, is the appropriate cause of action whenever lack of informed consent is alleged. The court held that whenever “the patient . . . demonstrated, and the jury found, that he was not advised of . . . material facts, risks, complications and alternatives to surgery which a reasonable man would have considered significant in deciding whether to have the operation . . . the causation inquiry ends. The sole issue remaining [is] a determination of damages.”<sup>16</sup> Earlier in its opinion, the court quoted, with approval, a prior Pennsylvania decision:

[W]here a patient is mentally and physically able to consult about his condition, in the absence of an emergency, the consent of the patient is “a prerequisite to a surgical operation by his physician, and an operation without the patient’s consent is a *technical assault*.<sup>17</sup>

Second, the Court of Appeals of California, in a ground-breaking opinion, significantly reduced the scope of the therapeutic privilege by requiring that in instances of hopeless prognosis (the most common situation in which the privilege has generally been invoked) the patient be provided with such information by asking, “If not the physician’s duty to disclose a terminal illness, then whose?”<sup>18</sup> The duty to disclose prognosis had never before been identified specifically as one of the disclosure obligations in an informed consent opinion.

Thus, the appellate court’s ruling constituted an important advance. It established that patients have a right to make decisions not only about the fate of their bodies but about the fate of their lives as well. The California Supreme Court, however, reversed. In doing so, the court made too much of an issue raised by the plaintiffs that led the appellate court to hold that doctors must disclose “statistical life expectancy information.”<sup>19</sup> To be sure, disclosure of statistical information is a complex problem, but in focusing on that issue, the supreme court’s attention was diverted from a more important new disclosure obligation promulgated by the appellate court: the duty to inform patients of their dire prognosis. The supreme court did not comment on that

obligation. Indeed, it seemed to reverse the appellate court on this crucial issue by reinforcing the considerable leeway granted physicians to invoke the therapeutic privilege exception to full disclosure: “We decline to intrude further, either on the subtleties of the physician-patient relationship or in the resolution of claims that the physician’s duty of disclosure was breached, by requiring the disclosure of information that may or may not be indicated in a given treatment context.”<sup>20</sup>

Two: The doctrine of informed consent was not designed to serve as a *medical blueprint* for interactions between physicians and patients. The medical profession still faces the task of fashioning a “doctrine” that comports with its own vision of doctor-patient communication and that is responsive both to the realities of medical practices in an age of science and to the commands of law. As I said years ago,

[T]ranslating the ingredients of [the informed consent] process into legal and useful medical prescriptions that respect patients’ wishes to maintain and surrender autonomy, as well as physicians’ unending struggles with omnipotence and impotence in the light of medical uncertainty, is a difficult task [which the medical profession] has not pursued . . . in any depth.<sup>21</sup>

Thus, disclosure practices only changed to the extent of physicians disclosing more about the risks of a proposed intervention in order to escape legal liability.

Three: Underlying the legal doctrine there lurks a broader assumption which has neither been given full recognition by judges nor embraced by physicians. The underlying idea is this: That from now on patients and physicians must make decisions jointly, with patients ultimately deciding whether to accede to doctors’ recommendations. In *The Cancer Ward*, Solzhenitsyn captured, as only a novelist can, the fears that such an idea engenders. When doctor Ludmilla Afanasyevna was challenged by her patient, Oleg Kostoglotov, about physicians’ rights to make unilateral decisions on behalf of patients, Afanasyevna gave a troubled, though unequivocal, answer: “But doctors *are* entitled to the right—doctors above all. Without that right, there’d be no such thing as medicine.”<sup>22</sup>

If Afanasyevna is correct, then patients must continue to trust doctors silently. Conversation, to comport with the idea of informed consent, ultimately requires that both parties make decisions jointly and that their views and preferences be treated with respect. Trust, based on blind faith—on passive surrender to oneself or to another—must be distinguished from trust that is earned after having first acknowledged to oneself and then shared with the other what one knows and does not know about the decision to be made. If all of that had been considered by physicians, they would have appreciated that a new model of doctor-patient communication, that takes informed consent seriously required a radical break with current medical disclosure practice.

Four: The idea of joint decisionmaking is one thing, and its application in practice another. To translate theory into practice cannot be accomplished, as the Judicial Council of the American Medical Association attempted to do in one short paragraph. The Judicial Council stated that “[t]he patient should make his own determination on treatment. Informed consent is a basic *social* policy. . . .”<sup>23</sup> To translate social policy into *medical* policy is an inordinately difficult task. It requires a reassessment of the limits of medical knowledge in the light of medical uncertainty, a reassessment of professional authority to make decisions for patients in light of the consequences of such conduct for the well-being of patients, and a reassessment of the limits of patients’ capacities to assume responsibility for choice in the light of their ignorance about medical matters and their anxieties when ill. Turning now to these problems, I wish to highlight that, in the absence of such reassessments, informed consent will remain a charade, and joint decisionmaking will elude us.

#### **IV. Barriers to Joint Decisionmaking**

##### **A. Medical Uncertainty**

The longer I reflect about doctor-patient decisionmaking, the more convinced I am that in this modern age of medical science, which for the first time permits sharing with patients the uncertainties of diagnosis, treatment, and prognosis, the problem of uncertainty poses the most formidable

obstacle to disclosure and consent. By medical uncertainty I mean to convey what the physician Lewis Thomas observed so eloquently, albeit disturbingly:

The only valid piece of scientific truth about which I feel totally confident is that we are profoundly ignorant about nature. . . . It is this sudden confrontation with the depth and scope of ignorance that represents the most significant contribution of twentieth-century science to the human intellect. *We are, at last facing up to it.* In earlier times, we either pretended to understand . . . or ignored the problem, or simply made up stories to fill the gap.<sup>24</sup>

Alvan Feinstein put this in more concrete language: “Clinicians are still uncertain about the best means of treatment for even such routine problems as . . . a fractured hip, a peptic ulcer, a stroke, a myocardial infarction. . . . At a time of potent drugs and formidable surgery, the exact effects of many therapeutic procedures are dubious or shrouded in dissension.”<sup>25</sup>

Medical uncertainty constitutes a formidable obstacle to joint decisionmaking for a number of reasons: Sharing uncertainties requires physicians to be more aware of them than they commonly are. They must learn how to communicate them to patients and they must shed their embarrassment over acknowledging the true state of their own and of medicine’s art and science. Thus, sharing uncertainties requires a willingness to admit ignorance about benefits and risks; to acknowledge the existence of alternatives, each with its own known and unknown consequences; to eschew one single authoritative recommendation; to consider carefully how to present uncertainty so that patients will not be overwhelmed by the information they will receive; and to explore the crucial question of how much uncertainty physicians themselves can tolerate without compromising their effectiveness as healers.

To so conduct oneself is most difficult. For, once doctors, on the basis of their clinical experience and knowledge, conclude which treatment is best, they tend to disregard, if not reject, the view of other colleagues who treat the same condition differently. Consider the current controversy over the management of localized prostate cancer: surgery,

radiation or watchful waiting.<sup>26</sup> Some of the physicians involved in the debate are not even willing to accept that uncertainty exists, or at least they minimize its relevance to choice of treatment. Most who advocate treatment strongly prefer one type over another based on professional specialization (radiologists tend to recommend radiation; surgeons surgery).

Moreover, acknowledgment of uncertainty is undermined by the threat that it will undermine doctors' authority and sense of superiority. As Nuland put it, to feel superior to those dependent persons who are the sick, is after all a motivating factor that often influences their choice of medicine as a profession.<sup>27</sup> All of this suggests that implementation of the idea of informed consent is, to begin with, not a patient problem but a physician problem.

### B. Patient Incompetence

Earlier, I touched on physicians' convictions that illness and medicine's esoteric knowledge rob patients of the capacity to participate in decisionmaking. Yet we do not know whether this is true. The evidence is compromised by the groping, half-hearted, and misleading attempts to inform patients about uncertainty and other matters which can make doctors' communications so confusing and incomprehensible. If patients then appear stupid and ignorant this should come as no surprise; nor should patients' resigned surrender to this dilemma: "You are the doctor, you decide."

It is equally debatable, as Thomas Duffy has contended, that "[p]aternalism exists in medicine . . . to fulfill a need created by illness."<sup>28</sup> It led him to argue, echoing Cassell, that "obviously autonomy cannot function as the cornerstone of the doctor-patient relationship [since] the impact of disease on personal integrity results in the patient's loss of autonomy. . . . In the doctor-patient relationship, the medical profession should always err on the side of beneficence."<sup>29</sup> If Duffy is correct, however, then informed consent is *ab initio* fatally compromised.

### C. Patient Autonomy

Duffy's invocation of beneficence as the guiding principle is deeply rooted in the history of

Hippocratic medicine. It finds expression in the ancient maxim: *primum non nocere*, above all do no harm, with "harm" remaining undefined but in practice being defined only as physical harm. Before presenting my views on the controversy over the primacy of autonomy or beneficence, let me briefly define their meaning.

In their authoritative book *Principles of Biomedical Ethics*, Thomas Beauchamp and James Childress defined these principles:

Autonomy is a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. [Respect for individuals as autonomous agents entitles them] to such autonomous determinations without limitation on their liberty being imposed by others.<sup>30</sup>

Beneficence, on the other hand,

[r]equires not only that we treat persons autonomously and that we refrain from harming them, but also that we contribute to their welfare including their health. [Thus the principle asserts] the duty to help others further their important and legitimate interests . . . to *confer* benefits and actively to prevent and remove harms . . . [and] to *balance* possible goods against the possible harms of an action.<sup>31</sup>

Beauchamp and Childress' unequivocal and strong postulate on autonomy contrasts with the ambiguities contained in their postulate on beneficence. What do they mean by "benefits" and "harms" that allow invocation of beneficence? Do they mean only benefits and harms to patients' physical integrity, or to their dignitary integrity as choice-making individuals as well? Furthermore, what degree of discretion and license is permissible in the duty "to balance?" I have problems with balancing unless it is resorted to only as a *rare* exception to respect for autonomy. While human life is, and human interactions are, too complex to make any principle rule absolute, any exceptions must be rigorously justified.

I appreciate that mine is a radical proposal and constitutes a sharp break with Hippocratic practices. If informed consent, however, is ever to be based on the postulate of joint decisionmaking,

the obligation “to respect the autonomous choices and actions of others,”<sup>32</sup> as Childress has put it, must be honored. Otherwise, informed consent is reduced to doctors providing more information but leaving decisionmaking itself to the authority of physicians.

As one physician once told me, echoing only an all too prevalent belief (and he was a physician allegedly deeply committed to informed consent), “I must first make the judgment which treatment alternative is best for patients, and only after I have exercised that professional judgment, will I discuss the risks and benefits of *the recommended treatment*.” This story illustrates the emphasis doctors place on risk disclosures rather than alternatives. The latter, however, is more crucial to joint decisionmaking than the former. Such a view, however, again encounters the issue of disclosure of medical uncertainty inherent in any forthright discussion of treatment alternatives. Physicians remain most reluctant to acknowledge uncertainty to themselves, and even more to their patients.

## V. Respect for Autonomy

It should be evident by now that physicians must embark on a prolonged period of self-examination about how to interact with patients in new ways in an age of medical science and informed consent. Physicians must cease to complain about lawyers forcing them “to do silly things.” Whenever doctors do so, they often observe that they can easily present their disclosures in ways that lead patients to agree with what they had thought to be the best alternative in the first place. This contention is a correct assessment of what transpires in customary practices that continue to eschew joint decision-making. Therefore, as I have already suggested, informed consent in today’s world, is largely a charade which misleads patients into thinking that they are making decisions when indeed they are not.

Any meaningful change in Hippocratic decision-making practices first requires a new and revolutionary commitment to one principle: that physicians must respect patients as autonomous persons. The most crucial reason for my placing such high value on autonomy and self-determination is because doing so safeguards, as nothing else can, the

recognition by the other that the person before him or her is as much a person as he or she is. Beneficence can readily reduce persons to non-persons by “taking care of them” in all of the many not only caring, but also, non-caring meanings of this phrase.

## VI. The Current State of Physician-Patient Decisionmaking

In his recent book, entitled *How We Die*, Sherwin Nuland, a distinguished surgeon, reflects with profundity and insight on his lifelong interactions with patients. In a chapter on cancer and its treatment he speaks movingly about “death belong[ing] to the dying and to those who love them.”<sup>33</sup> Yet, that privilege is often wrested from them when,

[d]ecisions about continuation of treatment are influenced by the enthusiasm of the doctors who propose them. Commonly, the most accomplished of the specialists are also the most convinced and unyielding believers in biomedicine’s ability to over-come the challenge presented by a pathological process. . . . [W]hat is offered as objective clinical reality is often the subjectivity of a devout disciple of the philosophy that death is an implacable enemy. To such warriors, even a temporary victory justifies the laying waste of the fields in which a dying man has cultivated his life.<sup>34</sup>

Looking back at his work, he concludes that “more than a few of my victories have been Pyrrhic. The suffering was sometimes not worth the success. . . . [H]ad I been able to project myself into the place of the family and the patient, I would have been less often certain that the desperate struggle should be undertaken.”<sup>35</sup>

In his view, a surgeon,

[t]hough he be kind and considerate of the patient he treats . . . allows himself to push his kindness aside because the seduction of The Riddle [the quest for diagnosis and cure] is so strong and the failure to solve it renders him so weak. [Thus, at times he convinces] patients to undergo diagnostic or therapeutic measures at a point in illness so far beyond reason that The Riddle might better have remained unsolved.<sup>36</sup>

Speaking then about the kind of doctor he will seek out when afflicted with a major illness, Nuland does

not expect him to “understand my values, my expectations for myself . . . my philosophy of life. *That is not what he is trained for and that is not what he will be good at.*”<sup>37</sup> Doctors can impart information, but “[i]t behooves every patient to study his or her own disease and learn enough about it. [Patients] should no longer expect from so many of our doctors what they cannot give.”<sup>38</sup>

Nuland’s views, supported by a great many poignant clinical vignettes, sensitively and forthrightly describe the current state of physician-patient decisionmaking, so dominated by physicians’ judgments as to what is best. He presents many reasons for this state of affairs. One is based on doctors’ “fear of failure”:

A need to control that exceeds in magnitude what most people would find reasonable. When control is lost, he who requires it is also a bit lost and so deals badly with the consequences of his impotence. In an attempt to maintain control, a doctor, usually without being aware of it, convinces himself that he knows better than the patient what course is proper. He dispenses only as much information as he deems fit, thereby influencing a patient’s decisionmaking in ways he does not recognize as self-serving.<sup>39</sup>

I have presented Nuland’s observations at some length because they illustrate and support my contentions that joint decisionmaking between doctors and patients still eludes us. My critics had claimed earlier that work on informed consent was dated because informed consent had become an integral aspect of the practice of medicine. In the paperback edition of *The Silent World of Doctor and Patient*, I argued that they have dismissed too lightly my central arguments:

[T]hat meaningful collaboration between physicians and patients cannot become a reality until physicians have learned (1) how to treat their patients not as children but as the adults they are; (2) how to distinguish between their ideas of the best treatment and their patients’ ideas of what is best; (3) how to acknowledge to their patients (and often to themselves as well) their ignorance and uncertainties about diagnosis, treatment, and prognosis; [and to all this, I now want to add, (4) how to explain to patients the uncertainties inherent in the

state of the art and science of medicine which otherwise permits doctors on the basis of their clinical experience to leave unacknowledged that their colleagues on the basis of their clinical experience have different beliefs as to which treatment is best].<sup>40</sup>

Nuland pleads for the resurrection of the family doctor<sup>41</sup> because he believes that the specialist is inadequate to the task of shouldering the burdens of decision with his patients. About this I differ with him. I believe that physicians (and surgeons as well) *can*, and *must*, learn to converse with patients in the spirit of joint decisionmaking. Physicians can and must learn to appreciate better than they do now that the principle of respect for person speaks to the caring commitment of physicians in old and new ways: *Old* in that it highlights the ancient and venerable medical duty not to abandon patients, and *new* by requiring doctors to communicate with them and remain at their sides, not only while their bodies are racked with pain and suffering but also while their minds are beset by fear, confusion, doubt and suffering over decisions to be made; also *new* in that implementation of the principle of psychological autonomy imposes the obligations on physicians both to invite, and respond to, questions about the decisions to be made, and to do so by respecting patients’ ultimate choices, a new aspect of the duty to care.

The moral authority of physicians will not be undermined by this caring view of interacting with patients. Doctors’ authority resides in the medical knowledge they possess, in their capacity to diagnose and treat, in their ability to evaluate what can be diagnosed and what cannot, what is treatable and what is not, and what treatment alternatives to recommend, each with its own risks and benefits and each with its own prognostic implications as to cure, control, morbidity, exacerbation or even death.

The moral authority of physicians resides in knowing better than others the certainties and the uncertainties that accompany diagnosis, treatment, prognosis, health and disease, as well as the extent and the limits of their *scientific* knowledge and *scientific* ignorance. Physicians must learn to face up to and acknowledge the tragic limitations of their

own professional knowledge, their inability to impart all their insights to all patients, and their own personal incapacities—at times more pronounced than others—to devote themselves fully to the needs of their patients. They must learn not to be unduly embarrassed by their personal and professional ignorance and to trust their patients to react appropriately to such acknowledgment. From all this it follows that ultimately the moral authority of physicians resides in their capacity to sort out *with* patients the choices to be made.

It is in this spirit that duty and caring become interwoven. Bringing these strands together imposes upon physicians the duty to respect patients as persons so that care will encompass allowing patients to live their lives in their own self-willed ways. To let patients follow their own lights is not an abandonment of them. It is a professional duty that, however painful, doctors must obey.

Without fidelity to these new professional duties, true caring will elude physicians. There is much new to be learned about caring that in decades to come will constitute the kind of caring that doctors in the past have wished for but have been unable to dispense, and that patients may have always yearned for.

I do not know whether my vision of a new physician-patient relationship defies medical reality. Thus, I may be wrong and I am willing to entertain this possibility as long as my critics are willing to admit that they too may be wrong. *As a profession we have never examined and tested in a committed manner what I have proposed.* It is this fact which, in conclusion, I want to highlight. For, I believe that in this age of medical science and informed consent the category of patient is in need of a radical reconceptualization. Throughout medical history, patients have been viewed as passive, ignorant persons whose welfare was best protected by their following doctors' orders, and physicians and patients were socialized to interact with one another on that basis. Throughout this essay, I have argued that such a view of the physician-patient relationship was dictated by doctors' inability to explain to themselves what was therapeutic and what was not in the practice of medicine. The advent of the age of medical science has changed all that and for the first time in medical history doctors now

can distinguish better between knowledge, ignorance and conjecture. In turn, this permits physicians to take patients into their confidence.

Finally, my purpose in writing this essay is two-fold: (1) To argue, notwithstanding any theories of tort law and cost containment to the contrary,<sup>42</sup> that patients must ultimately be given the deciding vote in matters that effect their lives; and (2) to suggest that informed consent will remain a fairy tale as long as the idea of joint decisionmaking, based on a commitment to patient autonomy and self-determination, does not become an integral aspect of the ethos of medicine and the law of informed consent. Until then, physicians, patients and judges can only deceive themselves or be deceived about patients having a vital voice in the medical decisionmaking process. Of course, there are alternatives to joint decision-making. One that I have briefly explored elsewhere suggested that we need a number of informed (and uninformed) consent doctrines depending on the nature of the decisions to be made, with the implication that only in certain medical contexts must informed consent rise to the rigor advanced in this essay.<sup>43</sup> Another alternative is to fashion an informed consent doctrine for law and medicine that is *not* based on “[t]he root premise . . . fundamental in American jurisprudence, that ‘[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.’”<sup>44</sup> It is not a road on which I would like to travel and thus, I leave that task to others. It is important that those who disagree with me set forth their premises about who decides what; otherwise physicians and patients are condemned to interact with one another, under the rubric of what is now called “informed consent,” by deception of both self and the other.

#### NOTES

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7. Talcott Parsons, *The Social System* 464–65 (1951).

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13. *Id.* at 1106.
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33. Sherwin B. Nuland, *How We Die* 265 (1994).
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35. *Id.* at 266.
36. *Id.* at 249.
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## Transparency: Informed Consent in Primary Care

HOWARD BRODY

Brody observes that the theory and the practice of informed consent are far apart and that accepted legal standards send physicians the wrong message about what they are supposed to do. He thinks that a conversation standard of informed consent does send the right message but is probably legally unworkable. He proposes instead a “transparency standard,” which says that “disclosure is adequate when the physician’s basic thinking has been rendered transparent to the patient.”

While the patient’s right to give informed consent to medical treatment is now well-established both in U.S. law and in biomedical ethics, evidence

continues to suggest that the concept has been poorly integrated into American medical practice, and that in many instances the needs and desires of patients are not being well met by current policies.<sup>1</sup> It appears that the theory and the practice of informed consent are out of joint in some crucial

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ways. This is particularly true for primary care settings, a context typically ignored by medical ethics literature, but where the majority of doctor-patient encounters occur. Indeed, some have suggested that the concept of informed consent is virtually foreign to primary care medicine where benign paternalism appropriately reigns and where respect for patient autonomy is almost completely absent.<sup>2</sup>

It is worth asking whether current legal standards for informed consent tend to resolve the problem or to exacerbate it. I will maintain that accepted legal standards, at least in the form commonly employed by courts, send physicians the wrong message about what is expected of them. An alternative standard that would send physicians the correct message, a conversation standard, is probably unworkable legally. As an alternative, I will propose a transparency standard as a compromise that gives physicians a doable task and allows courts to review appropriately. I must begin, however, by briefly identifying some assumptions crucial to the development of this position even though space precludes complete argumentation and documentation.

### **Crucial Assumptions**

Informed consent is a meaningful ethical concept only to the extent that it can be realized and promoted within the ongoing practice of good medicine. This need not imply diminished respect for patient autonomy, for there are excellent reasons to regard respect for patient autonomy as a central feature of good medical care. Informed consent, properly understood, must be considered an essential ingredient of good patient care, and a physician who lacks the skills to inform patients appropriately and obtain proper consent should be viewed as lacking essential medical skills necessary for practice. It is not enough to see informed consent as a nonmedical, legalistic exercise designed to promote patient autonomy, one that interrupts the process of medical care.

However, available empirical evidence strongly suggests that this is precisely how physicians currently view informed consent practices. Informed consent is still seen as bureaucratic legalism rather than as part of patient care. Physicians often deny

the existence of realistic treatment alternatives, thereby attenuating the perceived need to inform the patient of meaningful options. While patients may be informed, efforts are seldom made to assess accurately the patient's actual need or desire for information, or what the patient then proceeds to do with the information provided. Physicians typically underestimate patients' desire to be informed and overestimate their desire to be involved in decision-making. Physicians may also view informed consent as an empty charade, since they are confident in their abilities to manipulate consent by how they discuss or divulge information.<sup>3</sup>

A third assumption is that there are important differences between the practice of primary care medicine and the tertiary care settings that have been most frequently discussed in the literature on informed consent. The models of informed consent discussed below typically take as the paradigm case something like surgery for breast cancer or the performance of an invasive and risky radiologic procedure. It is assumed that the risks to the patient are significant, and the values placed on alternative forms of treatment are quite weighty. Moreover, it is assumed that the specialist physician performing the procedure probably does a fairly limited number of procedures and thus could be expected to know exhaustively the precise risks, benefits, and alternatives for each.

Primary care medicine, however, fails to fit this model. The primary care physician, instead of performing five or six complicated and risky procedures frequently, may engage in several hundred treatment modalities during an average week of practice. In many cases, risks to the patient are negligible and conflicts over patient values and the goals of treatment or non-treatment are of little consequence. Moreover, in contrast to the tertiary care patient, the typical ambulatory patient is much better able to exercise freedom of choice and somewhat less likely to be intimidated by either the severity of the disease or the expertise of the physician; the opportunities for changing one's mind once treatment has begun are also much greater. Indeed, in primary care, it is much more likely for the full process of informed consent to treatment (such as the beginning and the dose adjustment of an

antihypertensive medication) to occur over several office visits rather than at one single point in time.

It might be argued that for all these reasons, the stakes are so low in primary care that it is fully appropriate for informed consent to be interpreted only with regard to the specialized or tertiary care setting. I believe that this is quite incorrect for three reasons. First, good primary care medicine ought to embrace respect for patient autonomy, and if patient autonomy is operationalized in informed consent, properly understood, then it ought to be part and parcel of good primary care. Second, the claim that the primary care physician cannot be expected to obtain the patient's informed consent seems to undermine the idea that informed consent could or ought to be part of the daily practice of medicine. Third, primary care encounters are statistically more common than the highly specialized encounters previously used as models for the concept of informed consent.<sup>4</sup>

### Accepted Legal Standards

Most of the literature on legal approaches to informed consent addresses the tension between the community practice standard, and the reasonable patient standard, with the latter seen as the more satisfactory, emerging legal standard.<sup>5</sup> However, neither standard sends the proper message to the physician about what is expected of her to promote patient autonomy effectively and to serve the informational needs of patients in daily practice.

The community practice standard sends the wrong message because it leaves the door open too wide for physician paternalism. The physician is instructed to behave as other physicians in that specialty behave, regardless of how well or how poorly that behavior serves patients' needs. Certainly, behaving the way other physicians behave is a task we might expect physicians to readily accomplish; unfortunately, the standard fails to inform them of the end toward which the task is aimed.

The reasonable patient standard does a much better job of indicating the centrality of respect for patient autonomy and the desired outcome of the informed consent process, which is revealing the information that a reasonable person would need to make an informed and rational decision. This

standard is particularly valuable when modified to include the specific informational and decisional needs of a particular patient.

If certain things were true about the relationship between medicine and law in today's society, the reasonable patient standard would provide acceptable guidance to physicians. One feature would be that physicians esteem the law as a positive force in guiding their practice, rather than as a threat to their well-being that must be handled defensively. Another element would be a prospective consideration by the law of what the physician could reasonably have been expected to do in practice, rather than a retrospective review armed with the foreknowledge that some significant patient harm has already occurred.

Unfortunately, given the present legal climate, the physician is much more likely to get a mixed or an undesirable message from the reasonable patient standard. The message the physician hears from the reasonable patient standard is that one must exhaustively lay out all possible risks as well as benefits and alternatives of the proposed procedure. If one remembers to discuss fifty possible risks, and the patient in a particular case suffers the fifty-first, the physician might subsequently be found liable for incomplete disclosure. Since lawsuits are triggered when patients suffer harm, disclosure of risk becomes relatively more important than disclosure of benefits. Moreover, disclosure of information becomes much more critical than effective patient participation in decisionmaking. Physicians consider it more important to document what they said to the patient than to document how the patient used or thought about that information subsequently.

In specialty practice, many of these concerns can be nicely met by detailed written or videotaped consent documents, which can provide the depth of information required while still putting the benefits and alternatives in proper context. This is workable when one engages in a limited number of procedures and can have a complete document or videotape for each.<sup>6</sup> However, this approach is not feasible for primary care, when the number of procedures may be much more numerous and the time available with each patient may be considerably less.

Moreover, it is simply not realistic to expect even the best educated of primary care physicians to rattle off at a moment's notice a detailed list of significant risks attached to any of the many drugs and therapeutic modalities they recommend.

This sets informed consent apart from all other aspects of medical practice in a way that I believe is widely perceived by nonpaternalistic primary care physicians, but which is almost never commented upon in the medical ethics literature. To the physician obtaining informed consent, *you never know when you are finished*. When a primary care physician is told to treat a patient for strep throat or to counsel a person suffering a normal grief reaction from the recent death of a relative, the physician has a good sense of what it means to complete the task at hand. When a physician is told to obtain the patient's informed consent for a medical intervention, the impression is quite different. A list of as many possible risks as can be thought of may still omit some significant ones. A list of all the risks that actually have occurred may still not have dealt with the patient's need to know risks in relation to benefits and alternatives. A description of all benefits, risks, and alternatives may not establish whether the patient has understood the information. If the patient says he understands, the physician has to wonder whether he really understands or whether he is simply saying this to be accommodating. As the law currently *appears* to operate (in the perception of the defensively minded physician), there never comes a point at which you can be certain that you have adequately completed your legal as well as your ethical task.

The point is not simply that physicians are paranoid about the law; more fundamentally, physicians are getting a message that informed consent is very different from any other task they are asked to perform in medicine. If physicians conclude that informed consent is therefore not properly part of medicine at all, but is rather a legalistic and bureaucratic hurdle they must overcome at their own peril, blame cannot be attributed to paternalistic attitudes or lack of respect for patient autonomy.

### **The Conversation Model**

A metaphor employed by Jay Katz, informed consent as conversation, provides an approach to

respect for patient autonomy that can be readily integrated within primary care practice.<sup>7</sup> Just as the specific needs of an individual patient for information, or the meaning that patient will attach to the information as it is presented, cannot be known in advance, one cannot always tell in advance how a conversation is going to turn out. One must follow the process along and take one's cues from the unfolding conversation itself. Despite the absence of any formal rules for carrying out or completing a conversation on a specific subject, most people have a good intuitive grasp of what it means for a conversation to be finished, what it means to change the subject in the middle of a conversation, and what it means to later reopen a conversation one had thought was completed when something new has just arisen. Thus, the metaphor suggests that informed consent consists not in a formal process carried out strictly by protocol but in a conversation designed to encourage patient participation in all medical decisions to the extent that the patient wishes to be included. The idea of informed consent as physician-patient conversation could, when properly developed, be a useful analytic tool for ethical issues in informed consent, and could also be a powerful educational tool for highlighting the skills and attitudes that a physician needs to successfully integrate this process within patient care.

If primary care physicians understand informed consent as this sort of conversation process, the idea that exact rules cannot be given for its successful management could cease to be a mystery. Physicians would instead be guided to rely on their own intuitions and communication skills, with careful attention to information received from the patient, to determine when an adequate job had been done in the informed consent process. Moreover, physicians would be encouraged to see informed consent as a genuinely mutual and participatory process, instead of being reduced to the one-way disclosure of information. In effect, informed consent could be demystified, and located within the context of the everyday relationships between physician and patient, albeit with a renewed emphasis on patient participation.<sup>8</sup>

Unfortunately, the conversation metaphor does not lend itself to ready translation into a legal

standard for determining whether or not the physician has satisfied her basic responsibilities to the patient. There seems to be an inherently subjective element to conversation that makes it ill-suited as a legal standard for review of controversial cases. A conversation in which one participates is by its nature a very different thing from the same conversation described to an outsider. It is hard to imagine how a jury could be instructed to determine in retrospect whether or not a particular conversation was adequate for its purposes. However, without the possibility for legal review, the message that patient autonomy is an important value and that patients have important rights within primary care would seem to be severely undermined. The question then is whether some of the important strengths of the conversation model can be retained in another model that does allow better guidance.

### The Transparency Standard

I propose the transparency standard as a means to operationalize the best features of the conversation model in medical practice. According to this standard, adequate informed consent is obtained when a reasonably informed patient is allowed to participate in the medical decision to the extent that the patient wishes. In turn, “reasonably informed” consists of two features: (1) the physician discloses the basis on which the proposed treatment, or alternative possible treatments, have been chosen; and (2) the patient is allowed to ask questions suggested by the disclosure of the physician’s reasoning, and those questions are answered to the patient’s satisfaction.

According to the transparency model, the key to reasonable disclosure is not adherence to existing standards of other practitioners, nor is it adherence to a list of risks that a hypothetical reasonable patient would want to know. Instead, disclosure is adequate when the physician’s basic thinking has been rendered transparent to the patient. If the physician arrives at a recommended therapeutic or diagnostic intervention only after carefully examining a list of risks and benefits, then rendering the physician’s thinking transparent requires that those risks and benefits be detailed for the patient. If the physician’s thinking has not followed that

route but has reached its conclusion by other considerations, then what needs to be disclosed to the patient is accordingly different. Essentially, the transparency standard requires the physician to engage in the typical patient-management thought process, only to *do it out loud in language understandable to the patient*.<sup>9</sup>

To see how this might work in practice, consider the following as possible general decision-making strategies that might be used by a primary physician:

1. The intervention, in addition to being presumably low-risk, is also routine and automatic. The physician, faced with a case like that presented by the patient, almost always chooses this treatment.
2. The decision is not routine but seems to offer clear benefit with minimal risk.
3. The proposed procedure offers substantial chances for benefit, but also very substantial risks.
4. The proposed intervention offers substantial risks and extremely questionable benefits. Unfortunately, possible alternative courses of action also have high risk and uncertain benefit.

The exact risks entailed by treatment loom much larger in the physician’s own thinking in cases 3 and 4 than in cases 1 and 2. The transparency standard would require that physicians at least mention the various risks to patients in scenarios 3 and 4, but would not necessarily require physicians exhaustively to describe risks, unless the patient asked, in scenarios 1 and 2.

The transparency standard seems to offer some considerable advantages for informing physicians what can legitimately be expected of them in the promotion of patient autonomy while carrying out the activities of primary care medicine. We would hope that the well-trained primary care physician generally thinks before acting. On that assumption, the physician can be told exactly when she is finished obtaining informed consent—first, she has to share her thinking with the patient; secondly, she has to encourage and answer questions; and third, she has to discover how participatory he wishes to

be and facilitate that level of participation. This seems a much more reasonable task within primary care than an exhaustive listing of often irrelevant risk factors.

There are also considerable advantages for the patient in this approach. The patient retains the right to ask for an exhaustive recital of risks and alternatives. However, the vast majority of patients, in a primary care setting particularly, would wish to supplement a standardized recital of risks and benefits of treatment with some questions like, "Yes, doctor, but what does this really mean for me? What meaning am I supposed to attach to the information that you've just given?" For example, in scenarios 1 and 2, the precise and specific risk probabilities and possibilities are very small considerations in the thinking of the physician, and reciting an exhaustive list of risks would seriously misstate just what the physician was thinking. If the physician did detail a laundry list of risk factors, the patient might very well ask, "Well, doctor, just what should I think about what you have just told me?" and the thoughtful and concerned physician might well reply, "There's certainly a small possibility that one of these bad things will happen to you; but I think the chance is extremely remote and in my own practice I have never seen anything like that occur." The patient is very likely to give much more weight to that statement, putting the risks in perspective, than he is to the listing of risks. And that emphasis corresponds with an understanding of how the physician herself has reached the decision.

The transparency standard should further facilitate and encourage useful questions from patients. If a patient is given a routine list of risks and benefits and then is asked "Do you have any questions?" the response may well be perfunctory and automatic. If the patient is told precisely the grounds on which the physician has made her recommendation, and then asked the same question, the response is much more likely to be individualized and meaningful.

There certainly would be problems in applying the transparency standard in the courtroom, but these do not appear to be materially more difficult

than those encountered in applying other standards; moreover, this standard could call attention to more important features in the ethical relationship between physician and patient. Consider the fairly typical case, in which a patient suffers harm from the occurrence of a rare but predictable complication of a procedure, and then claims that he would not have consented had he known about that risk. Under the present "enlightened" court standards, the jury would examine whether a reasonable patient would have needed to know about that risk factor prior to making a decision on the proposed intervention. Under the transparency standard, the question would instead be whether the physician thought about that risk factor as a relevant consideration prior to recommending the course of action to the patient. If the physician did seriously consider that risk factor, but failed to reveal that to the patient, he was in effect making up the patient's mind in advance about what risks were worth accepting. In that situation, the physician could easily be held liable. If, on the other hand, that risk was considered too insignificant to play a role in determining which intervention ought to be performed, the physician may still have rendered his thinking completely transparent to the patient even though that specific risk factor was not mentioned. In this circumstance, the physician would be held to have done an adequate job of disclosing information.<sup>10</sup> A question would still exist as to whether a competent physician ought to have known about that risk factor and ought to have considered it more carefully prior to doing the procedure. But that question raises the issue of negligence, which is where such considerations properly belong, and removes the problem from the context of informed consent. Obviously, the standard of informed consent is misapplied if it is intended by itself to prevent the practice of negligent medicine.

### **Transparency in Medical Practice**

Will adopting a legal standard like transparency change medical practice for the better? Ultimately only empirical research will answer this question. We know almost nothing about the sorts of

conversations primary care physicians now have with their patients, or what would happen if these physicians routinely tried harder to share their basic thinking about therapeutic choices. In this setting it is possible to argue that the transparency standard will have deleterious effects. Perhaps the physician's basic thinking will fail to include risk issues that patients, from their perspective, would regard as substantial. Perhaps how physicians think about therapeutic choice will prove to be too idiosyncratic and variable to serve as any sort of standard. Perhaps disclosing basic thinking processes will impede rather than promote optimal patient participation in decisions.

But the transparency standard must be judged, not only against ideal medical practice, but also against the present-day standard and the message it sends to practitioners. I have argued that that message is, "You can protect yourself legally only by guessing all bad outcomes that might occur and warning each patient explicitly that he might suffer any of them." The transparency standard is an attempt to send the message, "You can protect yourself legally by conversing with your patients in a way that promotes their participation in medical decisions, and more specifically by making sure that they see the basic reasoning you used to arrive at the recommended treatment." It seems at least plausible to me that the attempt is worth making.

The reasonable person standard may still be the best way to view informed consent in highly specialized settings where a relatively small number of discrete and potentially risky procedures are the daily order of business. In primary care settings, the best ethical advice we can give physicians is to view informed consent as an ongoing process of conversation designed to maximize patient participation after adequately revealing the key facts. Because the conversation metaphor does not by itself suggest measures for later judicial review, a transparency standard, or something like it, may be a reasonable way to operationalize that concept in primary care practice. Some positive side-effects of this might be more focus on good diagnostic and therapeutic decisionmaking

on the physician's part, since it will be understood that the patient will be made aware of what the physician's reasoning process has been like, and better documentation of management decisions in the patient record. If these occur, then it will be clearer that the standard of informed consent has promoted rather than impeded high quality patient care.

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## Canterbury v. Spence

UNITED STATES COURT OF APPEALS

This 1972 case helped settle the question of what standard should be used to judge the adequacy of disclosure by a physician. The court ruled that adequacy should not be judged by what the medical profession thinks is appropriate but by what information the patient finds relevant to his decision. The scope of the communication to the patient "must be measured by the patient's need, and that need is the information material to the decision."

Suits charging failure by a physician adequately to disclose the risks and alternatives of proposed treatment are not innovations in American law. They date back a good half-century, and in the last decade they have multiplied rapidly. There is, nonetheless, disagreement among the courts and the commentators on many major questions, and there is no precedent of our own directly in point. For the tools enabling resolution of the issues on this appeal, we are forced to begin at first principles.

The root premise is the concept, fundamental in American jurisprudence, that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body. . ." True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. The average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment with which to reach an intelligent decision. From these almost axiomatic considerations springs the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible.

A physician is under a duty to treat his patient skillfully, but proficiency in diagnosis and therapy is not the full measure of his responsibility. The cases demonstrate that the physician is under an obligation to communicate specific information to

the patient when the exigencies of reasonable care call for it. Due care may require a physician perceiving symptoms of bodily abnormality to alert the patient to the condition. It may call upon the physician confronting an ailment which does not respond to his ministrations to inform the patient thereof. It may command the physician to instruct the patient as to any limitations to be presently observed for his own welfare, and as to any precautionary therapy he should seek in the future. It may oblige the physician to advise the patient of the need for or desirability of any alternative treatment promising greater benefit than that being pursued. Just as plainly, due care normally demands that the physician warn the patient of any risks to his well-being which contemplated therapy may involve.

The context in which the duty of risk-disclosure arises is invariably the occasion for a decision as to whether a particular treatment procedure is to be undertaken. To the physician, whose training enables a self-satisfying evaluation, the answer may seem clear, but it is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie. To enable the patient to chart his course understandably, some familiarity with the therapeutic alternatives and their hazards becomes essential.

A reasonable revelation in these respects is not only a necessity but, as we see it, is as much a matter of the physician's duty. It is a duty to warn of the dangers lurking in the proposed treatment, and that is surely a facet of due care. It is, too, a duty to impart information which the patient has every right to expect. The patient's reliance upon the

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From U.S. Court of Appeals, District of Columbia Circuit, *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

physician is a trust of the kind which traditionally has exacted obligations beyond those associated with arms-length transactions. His dependence upon the physician for information affecting his well-being, in terms of contemplated treatment, is well-nigh abject. As earlier noted, long before the instant litigation arose, courts had recognized that the physician had the responsibility of satisfying the vital informational needs of the patient. More recently, we ourselves have found "in the fiduciary qualities of [the physician-patient] relationship the physician's duty to reveal to the patient that which in his best interests it is important that he should know." We now find, as a part of the physician's overall obligation to the patient, a similar duty of reasonable disclosure of the choices with respect to proposed therapy and the dangers inherently and potentially involved. . . . Once the circumstances give rise to a duty on the physician's part to inform his patient, the next inquiry is the scope of the disclosure the physician is legally obliged to make. The courts have frequently confronted this problem but no uniform standard defining the adequacy of the divulgence emerges from the decisions. Some have said "full" disclosure, a norm we are unwilling to adopt literally. It seems obviously prohibitive and unrealistic to expect physicians to discuss with their patients every risk of proposed treatment—no matter how small or remote—and generally unnecessary from the patient's viewpoint as well. Indeed, the cases speaking in terms of "full" disclosure appear to envision something less than total disclosure, leaving unanswered the question of just how much.

The larger number of courts, as might be expected, have applied tests framed with reference to prevailing fashion within the medical profession. Some have measured the disclosure by "good medical practice," others by what a reasonable practitioner would have bared under the circumstances, and still others by what medical custom in the community would demand. We have explored this rather considerable body of law but are unprepared to follow it. The duty to disclose, we have reasoned, arises from phenomena apart from medical custom and practice. The latter, we think, should no more establish the scope of the duty than its existence.

Any definition of scope in terms purely of a professional standard is at odds with the patient's prerogative to decide on projected therapy himself. That prerogative, we have said, is at the very foundation of the duty to disclose, and both the patient's right to know and the physician's correlative obligation to tell him are diluted to the extent that its compass is dictated by the medical profession.

In our view, the patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked. And to safeguard the patient's interest in achieving his own determination on treatment, the law must itself set the standard for adequate disclosure.

Optimally for the patient, exposure of a risk would be mandatory whenever the patient would deem it significant to his decision, either singly or in combination with other risks. Such a requirement, however, would summon the physician to second-guess the patient, whose ideas on materiality could hardly be known to the physician. That would make an undue demand upon medical practitioners, whose conduct, like that of others, is to be measured in terms of reasonableness. Consonantly with orthodox negligence doctrine, the physician's liability for nondisclosure is to be determined on the basis of foresight, not hindsight; no less than any other aspect of negligence, the issue on nondisclosure must be approached from the viewpoint of the reasonableness of the physician's divulgence in terms of what he knows or should know to be the patient's informational needs. If, but only if, the fact-finder can say that the physician's communication was unreasonably inadequate is an imposition of liability legally or morally justified.

Of necessity, the content of the disclosure rests in the first instance with the physician. Ordinarily it is only he who is in position to identify particular dangers; always he must make a judgment, in terms

of materiality, as to whether and to what extent revelation to the patient is called for. He cannot know with complete exactitude what the patient would consider important to his decision, but on the basis of his medical training and experience he can sense how the average, reasonable patient expectably would react. Indeed, with knowledge of, or ability to learn, his patient's background and current condition, he is in a position superior to that of most others—attorneys, for example—who are called upon to make judgments on pain of liability in damages for unreasonable miscalculation.

From these considerations we derive the breadth of the disclosure of risks legally to be required. The scope of the standard is not subjective as to either the physician or the patient; it remains objective with due regard for the patient's informational needs and with suitable leeway for the physician's situation. In broad outline, we agree that “[a] risk is thus material when a reasonable person, in what the physician knows or should know to be the patient's position, would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forgo the proposed therapy.”

The topics importantly demanding a communication of information are the inherent and potential hazards of the proposed treatment, the alternatives to that treatment, if any, and the results likely if the patient remains untreated. The factors contributing significance to the dangerousness of a medical technique are, of course, the incidence of injury and the degree of the harm threatened. A very small chance of death or serious disablement may well be significant; a potential disability which dramatically outweighs the potential benefit of the therapy or the detriments of the existing malady may summon discussion with the patient.

There is no bright line separating the significant from the insignificant; the answer in any case must abide a rule of reason. Some dangers—infection, for example—are inherent in any operation; there is no obligation to communicate those of which persons of average sophistication are aware. Even more clearly, the physician bears no responsibility for discussion of hazards the patient has already discovered, or those having no apparent materiality to patients' decision on therapy. The disclosure

doctrine, like others marking lines between permissible and impermissible behavior in medical practice, is in essence a requirement of conduct prudent under the circumstances. Whenever non-disclosure of particular risk information is open to debate by reasonable-minded men, the issue is for the finder of the facts.

Two exceptions to the general rule of disclosure have been noted by the courts. Each is in the nature of a physician's privilege not to disclose, and the reasoning underlying them is appealing. Each, indeed, is but a recognition that, as important as is the patient's right to know, it is greatly outweighed by the magnitudinous circumstances giving rise to the privilege. The first comes into play when the patient is unconscious or otherwise incapable of consenting, and harm from a failure to treat is imminent and outweighs any harm threatened by the proposed treatment. When a genuine emergency of that sort arises, it is settled that the impracticality of conferring with the patient dispenses with need for it. Even in situations of that character the physician should, as current law requires, attempt to secure a relative's consent if possible. But if time is too short to accommodate discussion, obviously the physician should proceed with the treatment.

The second exception obtains when risk-disclosure poses such a threat of detriment to the patient as to become unfeasible or contraindicated from a medical point of view. It is recognized that patients occasionally become so ill or emotionally distraught on disclosure as to foreclose a rational decision, or complicate or hinder the treatment, or perhaps even pose psychological damage to the patient. Where that is so, the cases have generally held that the physician is armed with a privilege to keep the information from the patient, and we think it clear that portents of that type may justify the physician in action he deems medically warranted. The critical inquiry is whether the physician responded to a sound medical judgment that communication of the risk information would present a threat to the patient's well-being.

The physician's privilege to withhold information for therapeutic reasons must be carefully circumscribed, however, for otherwise it might

devour the disclosure rule itself. The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forgo therapy the physician feels the patient really needs. That attitude presumes instability or perversity for even the normal patient, and runs counter to the foundation principle that the patient should and ordinarily can make the choice for himself. Nor does the privilege contemplate operation save where the patient's reaction to risk information, as reasonably foreseen by the physician, is menacing. And even in a situation of that kind, disclosure to a close relative with a view to securing

consent to the proposed treatment may be the only alternative open to the physician. . . .

No more than breach of any other legal duty does nonfulfillment of the physician's obligation to disclose alone establish liability to the patient. An unrevealed risk that should have been made known must materialize, for otherwise the omission however unpardonable, is legally without consequence. Occurrence of the risk must be harmful to the patient, for negligence unrelated to injury is nonactionable. And, as in malpractice actions generally, there must be a causal relationship between the physician's failure to adequately divulge and damage to the patient.

## Human Research

Two noble values help shape the vast, extraordinary enterprise known as medical science: knowledge and beneficence—the unceasing quest to know, to find out, and the aspiration to act for people’s good. When humans are the subjects of the research, these values assume their greatest importance, the stakes are at their highest, and the resulting ethical problems take on their sharpest edge. The chief difficulty is that these dual purposes do not fit together easily. Consequently, in its short history (dating from the early 1700s), systematized human research has engendered both great good and disturbing instances of evil. It has transformed our understanding of health and disease, magnified our power to treat and cure, saved millions of lives—and brought forth some astonishing moral outrages.

To medical science we owe the development of vaccines against polio, smallpox, measles, rubella, yellow fever, and hepatitis; treatments for heart disease, diabetes, cancer, and AIDS; strategies to prevent heart attacks, deadly infections, and birth defects; and diagnostic technology ranging from stethoscopes to MRIs to genetic tests. But the search for knowledge through medical research has also led down some dark paths:

- During World War II, Nazi physicians performed horrifying experiments on prisoners of war and civilians, killing and maiming many. At their 1947 trial in Nuremberg, Germany, the doctors were convicted of “murders, tortures, and other atrocities committed in the name of medical science.”<sup>1</sup> Their unwilling victims were infected with cholera, smallpox, typhus, malaria, and other diseases; given poisons to

evaluate the deadly results; shot to simulate battle wounds; frozen to death; starved to death; sterilized; and mutilated. The infamous Nazi doctor Josef Mengele liked to study twins:

He had collected children from the camps, measured their physical features, performed crosstransfusions, transplanted genitals, and other organs, and even created artificial Siamese twins. He also used his twin collection for comparative studies, infecting one child and then killing both for autopsy.<sup>2</sup>

- In 1932 the U.S. Public Health Service began a 40-year experiment to study the damaging effects of untreated syphilis in human beings. The research, known as the Tuskegee Study, involved around 600 poor Black men, about 400 of whom had syphilis when they entered the experiment. The men were deceived about the nature of the study, were never told they had syphilis, and were never treated for it even when an effective treatment (penicillin) became readily available to the researchers. Several of the men died because of their untreated disease.

- From 1944 to 1974, the U.S. government sponsored secret experiments to determine the effects of radiation on thousands of human subjects, including children. Some of the subjects were exposed to dangerously high doses of radiation, and many never consented to the research and were not told of the potential harm.

- In 1956 researchers began a study of the natural course of hepatitis in institutionalized children, hoping to understand the disease better and to test a vaccine. Their experimental subjects were several hundred children housed

at Willowbrook State Hospital in New York, the state's largest facility for persons with intellectual disabilities. In those days, conditions were such that most children admitted to Willowbrook eventually got hepatitis, which provoked flulike symptoms and immunity to future infections. For purposes of the experiment, the researchers infected the children with hepatitis when first admitted and monitored their bodies' responses. They were later condemned for using children—especially children with intellectual disabilities—in their study and for the methods they used to obtain consent from the children's parents.

Such stories shocked both the public and the medical world and provoked a sustained wave of soul-searching among policymakers and scientists about the ethics of human research. Out of the trial of Nazi doctors came the Nuremberg Code (one of the readings in this chapter), a set of minimal ethical principles meant to govern all scientific experiments involving humans. Later came other professional codes and government guidelines that reiterated and added to the principles. These included the Declaration of Helsinki, embraced by the World Medical Association (WMA) in 1964 (also a chapter reading); the 1979 Belmont Report (another selection), formulated by the congressionally established National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research; and the 1993 international guidelines for biomedical human research, created by the World Health Organization (WHO) and the Council for International Organizations of Medical Sciences (CIOMS).

Obviously the moral dilemmas inherent in human research can be intense and difficult. But in this age of ambitious scientific inquiry, they cannot be safely ignored.

### THE SCIENCE OF CLINICAL TRIALS

A scientific study designed to test a medical intervention in humans is known as a **clinical trial**. Normally the intervention is a drug or surgical procedure, and the point of the study is to

determine the treatment's effects in the human body—specifically, whether it is safe and effective. Properly conducted, clinical trials provide the strongest and most trustworthy evidence of a treatment's impact on human health. Neither animal studies nor a physician's informal observations are as reliable and convincing.

Clinical trials can derive reliable answers because they are carefully configured to maximize objectivity, minimize bias, and avoid errors—all the problems that plague unscientific inquiries. A typical clinical trial devised to test the effectiveness of a treatment will consist of two groups of subjects: (1) an experimental group that gets the treatment to be evaluated and (2) a control group that closely resembles the experimental group but does not get the treatment. To learn anything useful about the treatment, researchers must study the relevant differences that arise between the two groups. Simply giving the treatment to the experimental group and observing what happens will not provide any useful answers. Usually, without a control group, the researchers cannot tell whether the subjects would have gotten better (or worse) without treatment, or if a factor other than the treatment was what most affected the subjects' condition (such as changes in their diet or behavior), or if the subjects' condition improved because of the placebo effect. (The placebo effect is a common phenomenon in which patients sometimes feel better after receiving treatment even when the treatment is inactive or fake.) With a control group, researchers can be more confident that relevant effects in the experimental group were brought about by the treatment and not by some extraneous element.

The control groups in clinical trials that investigate efficacy are of two kinds. In a placebo control group, subjects receive a **placebo**, an inactive or sham treatment—a “sugar pill,” for example, or an inert pill that looks and tastes like the real drug. By using a placebo control group, researchers can take the placebo effect into account in assessing the worth of a treatment. For a treatment to be judged genuinely effective, subjects in the

## IN DEPTH

### THE TUSKEGEE TRAGEDY

The shocking revelations about the Tuskegee Study came decades after the research had been conducted. When finally told, the story provoked outrage, moral debate, and an apology from President Bill Clinton. Here is one of many recent news accounts:

July 25, 2002—Thirty years ago today, the *Washington Evening Star* newspaper ran this headline on its front page: “Syphilis Patients Died Untreated.” With those words, one of America’s most notorious medical studies, the Tuskegee Syphilis Study, became public.

“For 40 years, the U.S. Public Health Service has conducted a study in which human guinea pigs, not given proper treatment, have died of syphilis and its side effects,” Associated Press reporter Jean Heller wrote on July 25, 1972. “The study was conducted to determine from autopsies what the disease does to the human body.”

The next morning, every major U.S. newspaper was running Heller’s story. . . .

The Public Health Service, working with the Tuskegee Institute, began the study in 1932. Nearly 400 poor black men with syphilis from Macon County, Ala., were enrolled in the study. They were never told they had syphilis, nor were they ever treated for it. According to the Centers for Disease Control, the men were told they were being treated for “bad blood,” a local term used to describe several illnesses, including syphilis, anemia and fatigue.

For participating in the study, the men were given free medical exams, free meals and free burial insurance.

treatment group must show significantly greater improvement than those in the placebo group. Studies using placebos in this way are called placebo-controlled trials. In an active control group, subjects get the standard treatment, one already

At the start of the study, there was no proven treatment for syphilis. But even after penicillin became a standard cure for the disease in 1947, the medicine was withheld from the men. The Tuskegee scientists wanted to continue to study how the disease spreads and kills. The experiment lasted four decades, until public health workers leaked the story to the media.

By then, dozens of the men had died, and many wives and children had been infected. In 1973, the National Association for the Advancement of Colored People (NAACP) filed a class-action lawsuit. A \$9 million settlement was divided among the study’s participants. Free health care was given to the men who were still living, and to infected wives, widows and children.

But it wasn’t until 1997 that the government formally apologized for the unethical study. President Clinton delivered the apology, saying what the government had done was deeply, profoundly and morally wrong:

“To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish.

“What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say, on behalf of the American people: what the United States government did was shameful.

“And I am sorry.”

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National Public Radio, “Remembering Tuskegee,” NPR, July 25, 2002, <http://www.npr.org/programs/morning/features/2002/jul/tuskegee/>.

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proven to work. The results in the treatment group can then be compared to those in the active control group to see if the new treatment outperforms the old. Studies that use this type of control group are known as active-controlled

trials. In general, placebo-controlled trials are more trustworthy than other types of clinical trials, but sometimes active-controlled trials can also yield reliable results, especially when they are used to find out which treatment is superior (rather than merely equivalent).

Another indispensable feature of most clinical trials is **blinding**, a procedure for ensuring that subjects and researchers don't know which interventions the subjects receive (standard treatment, new treatment, or placebo). If subjects know they have received a placebo, their assessment of how they feel may be skewed or they may change their health habits, try to obtain an active treatment, or even drop out of the study. If they know they have received an active treatment, they may experience improvement regardless of whether the treatment works. Knowledge of who receives what intervention can also affect researchers, moving them to unconscious bias in evaluating study results. Thus, good clinical trials testing for treatment efficacy are blinded—preferably *double-blinded* (when both subjects and researchers are unaware of what treatments the subjects get), or at least *single-blinded* (in which only the subjects are unaware).

If clinical trials are to generate reliable data about a treatment's value, they must be not only blinded but also randomized. **Randomization** is the assigning of subjects randomly to both experimental and control groups. To draw reliable conclusions about the effects of a treatment, the control and experimental groups have to be comparable in relevant characteristics—and assigning subjects randomly helps ensure this. Randomization also minimizes the bias that can creep into a study when researchers unconsciously assign preferred subjects to a particular group. A new treatment can appear to be highly effective if healthier subjects are assigned to the experimental group and less healthy subjects to the control group.

Rarely, if ever, can a single clinical trial establish the safety and effectiveness of a treatment. Usually many studies must be conducted before scientists can be confident of such a conclusion. This hard fact is illustrated most clearly in drug

research. By law and professional assent, research to establish the safety and effectiveness of new drugs must involve several clinical trials conducted in three stages, known formally as Phases I, II, and III. Before a drug is recognized as a proven treatment, it must pass muster in each phase. Usually before the human studies can even begin, the treatment must be studied in animals.

A Phase I trial tests the drug in a few people for safety and adverse reactions and ascertains safe and unsafe doses. Researchers do not try to evaluate the drug's efficacy. This kind of trial is said to be *nontherapeutic* because it is not expected to provide a therapeutic benefit to the subjects. In Phase II trials, investigators give the drug to larger groups of subjects to get a preliminary indication of its effectiveness and to do more assessments of safety. In Phase III trials, researchers hope finally to establish whether the drug is effective, determine how it compares in efficacy with other proven treatments, and learn how to employ it in the safest way. These trials are larger still, frequently having thousands of subjects, and are capable of providing definitive answers about a treatment's worth. Unlike Phase I trials, they are generally considered *therapeutic* if they are expected to provide a therapeutic benefit to at least some of the subjects. If a drug does well in Phase III trials, it can be approved for widespread use by patients. Sometimes further studies—Phase IV trials—are done after the approved drug is marketed. Their purpose is to assess the effectiveness and side effects of taking it for a long time.

### BENEFICENCE, SCIENCE, AND PLACEBOS

Many of the key features of clinical trials have provoked moral debate, yet among the host of official codes issued on human research is a solid consensus on such trials' ethical requirements.<sup>3</sup> For a clinical trial to be morally permissible:

- Subjects must give their informed voluntary consent to participate.

- The study must be designed to minimize risks to subjects and offer an acceptable balance of risks and benefits. (Even if subjects give their informed consent, risks to them should not be unnecessary or excessive, and the risks must be offset by potential benefits derived from the research.)
- Subjects must be selected fairly to avoid exploiting or unjustly excluding them.
- The subjects' privacy should be protected, and the confidentiality of research data must be preserved.
- Before the research is conducted, it must be reviewed and approved by an independent panel (often an institutional review board, or IRB).

There is also substantial agreement in bioethics on the general moral principles that should apply to human research, standards from which the more specific requirements are derived: (1) autonomy, or respect for persons as autonomous agents; (2) beneficence, doing good for and avoiding harm to persons; and (3) justice, treating equals equally. When disagreements occur, they usually turn on how best to interpret, employ, or extend the requirements in specific kinds of cases.

The principle of beneficence is at the heart of many of the disputes because, as we have seen, the obligation to help or not harm subjects often seems to conflict with the aim of doing science. Physicians (or physician-researchers) have a duty of beneficence toward patients (or patient-subjects), but it is not obvious that clinical trials are always consistent with this duty. As we have seen, a widely accepted answer to this dilemma has been supplied in the official codes: Risks to subjects should be kept as low as possible, and the potential benefits of the research should be greater than the risks. These tenets have been joined with the further stipulations that no subject should be exposed to extreme risks even if the expected benefits are substantial; a subject's informed consent cannot justify research that is too risky; and potential benefits to both the

subjects and society should be considered, although the subjects' welfare must predominate. From this perspective, therapeutic trials—assuming the subjects' informed consent and acceptable risks and benefits—can be justified by the potential good to the subjects and future patients, or society. Nontherapeutic trials—assuming informed consent and minimal risks to the subjects—can be justified by significant potential good to society.

The use of control groups touches on most of these issues of beneficence. A clinical trial is conducted to find out which of two treatments is better for patients or whether a particular treatment has any worth, but of course this process entails that patients in the control group will often get less than the best available treatment or no genuine treatment at all (a placebo). Some argue that the permissibility of enrolling patients in such a study is questionable since by doing so they are being treated merely as a means to the end of scientific knowledge. But many reject this worry. For example:

[I]f there is uncertainty about the efficacy of any given treatment, a randomized trial is the best way to yield objectively valid results. It will tell the doctor which treatment is better for the patient. So, recruiting a patient to be a subject in a randomized clinical trial does not by itself compromise the researcher's duty as a doctor to care for the patient. The better treatment will be determined by the results of the trial. In fact, patients can benefit more from a research setting than from standard clinical care because they receive more attention with the resources available to the research team. By entering a patient in a randomized controlled clinical trial, a doctor is treating the patient as a means for the sake of generating scientific knowledge. But the doctor is also treating the patient as an end by obtaining consent to participate in the trial and by ensuring that the potential risks are commensurate with the potential benefits. The physician is at once fulfilling the primary duty of a doctor to the patient and the secondary duty of a researcher to the research subject.<sup>4</sup>

Frequently the issue is framed around the doctor's duty given what she knows about the treatments to be tested. As a physician, she has an obligation to act in the best interests of her patients, which requires that she offer to them only those treatments she judges to be the best. But in clinical trials, patients are randomized into experimental and control groups where they may not receive the treatment that the physician believes is best. Some bioethicists have concluded from this that randomized clinical trials are morally problematic because they "ask physicians to sacrifice the interests of their particular patients for the sake of the study and that of the information that it will make available for the benefit of society."<sup>5</sup>

But defenders of randomized studies contend that doctors breach no duty to their patients if the efficacy of the treatments being tested is unknown—that is, if there is no good evidence for preferring that patients be assigned to one group rather than another (control or experimental). Being in doubt about the relative merits of the treatments, physicians are said to be in *equipoise*, rationally balanced between the alternatives. They therefore cannot be guilty of offering treatments known to be less than the best available.

Still, critics insist that a physician owes patients her best judgment about available treatments, and if she believes (even on the basis of a hunch or suspicion) that one treatment is better or worse than another, then letting a randomized clinical trial choose the patients' treatment is wrong—a violation of trust. A physician with a preference is not in a state of equipoise.

Others argue that this view misunderstands the notion of equipoise. They contend that true equipoise does not depend on uncertainty in the mind of a physician, but on genuine disagreement about treatment efficacy in the medical and scientific community. The disagreement arises because of a lack of the kind of evidence generated by randomized clinical trials. As long as this form of equipoise exists, including patients in randomized studies is permissible.

Those who take this view also point out that a clinical trial may show that the physician's educated guess about a treatment is incorrect, making better care of the patient possible. As one philosopher explains,

Properly carried out, with informed consent, clinical equipoise, and a design adequate to answer the question posed, randomized clinical trials protect physicians and their patients from therapies that are ineffective or toxic. Physicians and their patients must be clear about the vast gulf separating promising and proved therapies. The only reliable way to make this distinction in the face of incomplete information about pathophysiology and treatment mechanism is to experiment, and this will increasingly involve randomized trials. The alternative—a retreat to older methods—is unacceptable.<sup>6</sup>

Whatever the value of the scientific approach, many see no conflict between (1) physicians revealing to patients their honest preferences regarding treatments and (2) giving those patients the chance to enter a clinical trial. The key element here is full disclosure and informed consent:

The physician has a strict therapeutic obligation to offer his or her best professional judgment, but also to obtain the patient's informed consent prior to initiating treatment. The latter obligation entails explaining the risks and benefits of all reasonable alternatives, including enrollment in an appropriate [randomized controlled trial] to test one treatment against another.<sup>7</sup>

Moral concern about control groups takes on added seriousness when their "treatment" is a placebo. Again the moral friction occurs at the point where beneficence and science collide. Recall that placebo-controlled trials are often the most scientifically reliable way to determine the effectiveness of a treatment. But in such studies, the placebo group receives no genuine treatment, while the experimental group gets one that is at least possibly, and perhaps probably, effective. Can this deliberate nontreatment of patients be justified?

For many bioethicists and policy-making bodies, the answer is yes—but only in a restricted range of circumstances. The most widely accepted proviso is that the use of placebos is unethical when effective treatments are already available. In its 2004 version of the Declaration of Helsinki, the WMA asserts that in general a placebo-controlled trial “should only be used in the absence of existing proven therapy.”<sup>8</sup> Testing a new, unproven treatment against a placebo is permissible, but usually only if no treatment has already been shown to work. If there is an established therapy, the new treatment must be pitted against it in an active-controlled trial.

This general rule has its greatest force in cases where the risks to subjects are large—when going without effective treatment can cause serious harm and threaten life. Some have argued that when the disease in question is potentially fatal, using placebo controls may be wrong even if there is no established treatment, just an unproven but promising one. A classic case seems to suggest this view. This is how bioethicists Tom Beauchamp and James Childress describe it:

Promising laboratory tests led to a trial (phase I) to determine the safety of AZT among patients with AIDS. Several patients showed clinical improvement during this trial. Because AIDS was considered invariably fatal, many people argued that compassion dictated making it immediately available to all patients with AIDS. . . . However . . . as required by federal regulations, [the company] used a placebo-controlled trial of AZT to determine its effectiveness for certain groups of patients with AIDS. A computer randomly assigned some patients to AZT and others to a placebo. For several months, no major differences emerged in effectiveness, but then patients receiving the placebo began to die at a significantly higher rate. Of the 137 patients on the placebo, 16 died. Of the 145 patients on AZT, only one died. In view of these results, a data and safety monitoring board advised terminating the trial. Subjects who had received the

placebo in the trial were, as promised, the first to receive the drug.<sup>9</sup>

Many authorities recognize that the “no existing proven therapy” rule for placebo studies cannot be absolute. The WMA is among them, declaring in the Helsinki code that placebo-controlled trials may be permissible even when proven treatments exist, provided that the medical condition involved is minor. The WMA also implicitly acknowledges (as most authorities do) that sometimes the only way to identify the best therapies (and thereby ease the suffering of countless future patients) is to conduct a placebo-controlled trial, which may be a scientific necessity whether proven therapies exist or not. Bioethicists who accept this fact also typically believe that this research must be subject to at least two ethical restraints: Patients should never be exposed to undue risks (regardless of the potential benefits to society), and no research should be done without the patients’ informed consent (which in itself cannot justify unsafe research).

## SCIENCE AND INFORMED CONSENT

As discussed in the previous chapter, informed consent is the action of an autonomous, informed person agreeing to submit to medical treatment or experimentation. It is universally considered a moral prerequisite for medical treatment, and equally so for medical research. The first article of the Nuremberg Code asserts, “The voluntary consent of the human subject is absolutely essential”—an ethical requirement blatantly violated by the Nazi doctors. The underlying notion is that autonomous agents have the right to decide for themselves whether to expose their persons to the rigors and risks of clinical investigations. For bona fide informed consent, the person’s decision must be informed by accurate information about the research, based on an adequate understanding of it, made voluntarily, and generated without coercion.

## IN DEPTH

### WOMEN IN CLINICAL TRIALS

Medical science has been accused of being unjust to women by frequently excluding them as subjects from studies of treatments that could help them. Too often in the past only men were included in studies of diseases that affected both men and women, and the treatments found to be effective in males would not necessarily have the same impact on females. The Institute of Medicine published a collection of papers on the ethical and legal problems arising from such research practices, including a critique by Susan Sherwin. She asserts that

[W]e can identify several specific areas of feminist concern, including: (1) some or all women may be unjustly excluded from some studies and suffer as a result; (2) women may be unjustly enrolled in studies that expose them to risk without offering appropriate benefits; (3) the research agenda may be unresponsive to the interests of oppressed groups; and (4) most generally, the process by which research decisions are made and carried out may maintain and promote oppressive practices . . .

. . . The exclusion of women from important clinical studies is the best known of the problems of injustice identified as falling within the scope of the topic of women's role in clinical studies. Historically, many studies of diseases that are common to both sexes have systematically excluded women from participation, so the necessary data for guiding treatment decisions

The checklist of relevant information that researchers are expected to give subjects has become fairly standard. According to one international panel, it includes:

- That each individual is invited to participate as a subject in research and the aims and methods of the research

for women are unavailable. Women's health care must often be based on untested inferences from data collected about men, but because there are important physiological differences between women and men, such inferences cannot always be presumed to be reliable; and, even when some data are collected about women's responses to the treatment in question, we may lack information about how a proposed treatment will affect specific groups of women (e.g., those who are disabled, elderly, or poor). Even according to traditional distributive conceptions of justice, it is clear that this sort of discrimination is unjust and bound to result in less effective health care for (some) women than for comparable men because the knowledge base which guides health care practices is unfairly skewed; if we accept the view that well-designed clinical studies are beneficial for a population, then the systematic exclusion of women from such studies must be seen as disadvantaging them unfairly. A social justice approach that is sensitive to matters of oppression helps us to recognize that this disadvantage is not random or accidental, but is a result and further dimension of women's generally oppressed status in society. According to the distributive models of justice, women ought to be represented proportionately to their health risk in any clinical studies likely to be of benefit to subject populations.

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Susan Sherwin, "Women in Clinical Studies: A Feminist View," in *Women and Health Research: Ethical and Legal Issues of Including Women in Clinical Studies* (Washington, DC: National Academy Press, 1999), 11–17, <http://www.nap.edu>.

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- The expected duration of the subject's participation
- The benefits that might reasonably be expected to result to the subjects or to others as an outcome of the research
- Any foreseeable risks or discomfort to the subject associated with participation in the research

- Any alternative procedures or courses of treatment that might be as advantageous to the subject as the procedure or treatment being tested
- The extent to which confidentiality of records in which the subject is identified will be maintained
- The extent of the investigator's responsibility, if any, to provide medical services to the subject
- That therapy will be provided free of charge for specified types of research-related injury
- Whether the subject or the subject's family or dependents will be compensated for disability or death resulting from such injury
- That the individual is free to refuse to participate and will be free to withdraw from the research at any time without penalty or loss of benefits to which he would otherwise be entitled<sup>10</sup>

Few doubt the reasonableness of such a list, but many have wondered whether the information can be conveyed to potential subjects so their consent is truly informed and voluntary. Probably the least plausible concern is an old paternalistic claim. Just as some physicians believe that patients are incapable of grasping the complexities of medical information, some researchers have argued that research subjects cannot fathom the alien language and arcane methods of science—so informed consent in clinical trials is impossible. Many bioethicists think this worry exaggerated (not to mention contemptuous of patient autonomy). They point out that subjects need not understand everything about a clinical study to give their informed consent; they need only comprehend enough to appreciate the most important implications, risks, and benefits of the research. Achieving this much understanding is possible although admittedly, in many situations and for many patients, extremely difficult.

Other concerns about informed consent relate to the unique circumstances that confront research volunteers. If patients are seriously ill and no proven treatment is available or none has helped them, they may consent to the research out

of desperation, fear, wishful thinking, or hope. Against their own best interests, they may pay little attention to the information provided, ignore all the possible risks, expect to be cured, believe that a benefit is highly probable when it is only possible, even come to believe that a nontherapeutic trial will likely help them despite written disclosures to the contrary. Their consent therefore may not be fully voluntary and informed.

Another issue concerns payments to research subjects. It is generally agreed that, in the words of one international body, "Subjects may be paid for inconvenience and time spent, and should be reimbursed for expenses incurred, in connection with their participation in research; they may also receive free medical services."<sup>11</sup> But additional payments (especially large ones) to entice patients into entering a trial might get them to consent though they ordinarily would refuse. Some think the payment could be so tempting as to be coercive (to constitute, in legal terms, "undue inducement") and thus may undermine informed consent. Several policies and regulations try to restrict the use of these inducements, but some think these edicts go too far. "All of these rules seem to be excessively paternalistic," says Baruch Brody:

If the independent review panel has already concluded that the risk-benefit ratio of the research is acceptable (otherwise, the research could not be approved), how can the large payment harm the subject? And in what way are large payments for acceptable research coercive or exploitative?<sup>12</sup>

## RESEARCH ON THE VULNERABLE

Many moral issues arise from clinical research on people thought to be easily exploited or mistreated—the most vulnerable in society. These subjects include children, people with intellectual disabilities, prisoners, minorities, and people in developing countries. The essential moral conflict is between (1) the duty to shield the vulnerable from abuse and (2) the aspiration to benefit them or society through needed research. Serious study of this clash of values has been goaded

**IN DEPTH****WHY ENTER A CLINICAL TRIAL?**

The National Cancer Institute sponsors many clinical trials and maintains the most extensive database of cancer trials in the nation. It publicizes them for cancer patients, saying, “Whenever you need treatment for your cancer, clinical trials may be an option for you.” It acknowledges that there are benefits and risks to taking part in such research and describes them like this:

**POSSIBLE BENEFITS**

- Clinical trials offer high-quality cancer care. If you are in a randomized study and do not receive the new treatment being tested, you will receive the best known standard treatment. This may be as good as, or better than, the new approach.
- If a new treatment is proven to work and you are taking it, you may be among the first to benefit.
- By looking at the pros and cons of clinical trials and your other treatment choices, you are taking an active role in a decision that affects your life.

- You have the chance to help others and improve cancer treatment.

**POSSIBLE DRAWBACKS**

- New treatments under study are not always better than, or even as good as, standard care.
- If you receive standard care instead of the new treatment being tested, it may not be as effective as the new approach.
- New treatments may have side effects that doctors do not expect or that are worse than those of standard treatment.
- Even if a new treatment has benefits, it may not work for you. Even standard treatments, proven effective for many people, do not help everyone.
- Health insurance and managed care providers do not always cover all patient care costs in a study. What they cover varies by plan and by study. To find out in advance what costs are likely to be paid in your case, check with your insurance company and talk to a doctor, nurse or social worker from the study.

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National Cancer Institute, “Taking Part in Cancer Research Studies,” *National Cancer Institute*, July 17, 2007, [http://www.cancer.gov/clinicaltrials/Taking-Part-in-Cancer-Treatment-Research-Studies/page\\_1](http://www.cancer.gov/clinicaltrials/Taking-Part-in-Cancer-Treatment-Research-Studies/page_1).

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by a sad, historical fact: Many notorious cases in the ethics of clinical science involved research using vulnerable populations—among them the poor Black men of Tuskegee, the children of Willowbrook, and the prisoners of the Nazi doctors.

The question of research on children acquires its edge partly because often the only way to devise treatments for children’s diseases is to conduct clinical trials on these subjects. The physiology and pathology of children are so different from those of adults that trying to draw useful conclusions about the former from studies of the latter is frequently difficult, impossible, or dangerous. Many effective therapies now used to treat children could only have been developed through clinical trials using children. Given the

scientific necessity of this kind of research, important ethical questions exert their pressure: Is research on children ever permissible? How is informed consent to be handled? Can children give consent? What balance of risks and benefits for child subjects can justify experimentation on them? Can nontherapeutic trials ever be morally permissible? Are there limits to the risks that children should be allowed to bear?

Most official policies assert or assume that properly designed research in children is morally acceptable if it is conducted for their sake, if it is done to generate the therapies they need. The policies also agree on the necessity for consent before any research is begun and on the importance of a proper balance of risks and benefits

for the research subjects. Disagreement comes in specifying the details of these requirements.

It is generally understood that consent to do research on children must in most cases be given by parents or guardians, who are supposed to decide in the children's best interests. Sometimes children may be allowed to give consent for themselves, provided they have reached the age of consent or maturity, but authorities disagree over when this point is reached. Existing policies require that in some circumstances child subjects must give their assent to the research (they must at least agree to it), even when parents or guardians have provided proxy informed consent. A few even claim that in some cases children may veto their participation in a trial. As one code phrases it, "The child's refusal to participate in research must always be respected unless according to the research protocol the child would receive therapy for which there is no medically-acceptable alternative."<sup>13</sup>

The prevailing view is that properly consented-to research involving children is permissible if it offers them benefits equaling or outweighing the risks and if the risks are limited. That is, therapeutic research is generally acceptable. Nontherapeutic research is another matter. Some oppose all such research, whether or not parents consent to it, on the grounds that it puts children at risk without hope of benefits for them in return. This position would rule out a great deal of science that could yield effective treatments for childhood diseases. Most official guidelines are less strict, allowing nontherapeutic research when the risk to the child subjects is minimal or close to it. The U.S. Department of Health and Human Services, for example, permits research that involves:

- No more than minimal risk to children, provided adequate steps are taken to solicit assent from the children and consent of the parents or guardians
- More than minimal risk to children and the prospect of direct benefits for them, provided (a) the benefits justify the risks, (b) no better alternative approaches exist,

and (c) adequate steps are taken to solicit assent from the children and consent of the parents or guardians

- More than minimal risk to children and no prospect of direct benefits for them, provided (a) the risk is only slightly greater than minimal risk, (b) the intervention involves experiences that are comparable to those that the subjects normally experience, (c) the intervention is likely to yield knowledge that is vitally important for understanding or treating the subjects' condition, and (d) adequate steps are taken to solicit assent from the children and consent of the parents or guardians<sup>14</sup>

Most of the pressing questions about research on children also apply to studies on the mentally impaired, and many of the answers are the same. This class of potential subjects includes adults who are intellectually disabled or suffer from psychiatric illness, in either situation being incompetent (at least much of the time) to make autonomous choices. As in the case of children, clinical research is scientifically necessary to develop therapies that could help these patients. There is widespread agreement that the research is justified if it is judged to be in their best interests and that appropriate surrogates must usually be the ones to make this judgment.

As might be expected, nontherapeutic research involving the mentally impaired is more contentious. Only if it entails minimal risk to the subjects, some argue, is this research legitimate. Others prefer a more relaxed policy. The National Institutes of Health, for example, permits studies on mentally impaired subjects if an appropriate consent process is used and if the research involves either (1) minimal risk, (2) greater than minimal risk but with the prospect of direct benefit to subjects, or (3) greater than minimal risk with no prospect of direct benefit to subjects but with the likelihood of gaining important knowledge about the subjects' illness.

An added complication in research on these vulnerable subjects is that their being in an

institution can undermine attempts to obtain their voluntary consent. (Consent remains an issue with some mentally impaired patients because they may be competent though impaired, competent to decide some aspects of their care, or intermittently competent.) Institutionalized patients are especially susceptible to many forms of coercion or undue influence that can undermine the voluntariness of their decisions. They may feel intense pressure to submit to research because they have been conditioned to defer to people in authority, because they fear punishment or less consideration from caretakers for refusing to participate, or because the slightest advantages of being in a clinical trial (special attention or a change in routine, for example) can carry tremendous weight.

Official responses to these worries have emphasized close scrutiny of the research by independent review committees (and possibly other oversight panels) to identify sources of undue pressure on the subjects. Many contend that the alternative to continued (but closely monitored) research on the mentally impaired is no research at all, which is unacceptable.

A different set of ethical questions confronts us in research on vulnerable subjects in Third World countries. As the scientific testing of therapies in developing nations has increased, ethical controversy surrounding the research has also intensified. The main points of moral conflict were dramatically illustrated a decade ago in clinical trials of HIV-infected pregnant women in several African countries and Thailand. Research had previously demonstrated that the drug AZT (zidovudine) could substantially reduce the transmission of HIV from pregnant women to their fetuses (known as vertical transmission). But the dose of AZT used in the research was expensive—too expensive for widespread use in poor countries with large numbers of people with HIV. So scientists were eager to find out if a lower, cheaper dose of AZT would work. They reasoned that the best way to discover which AZT regimens were most effective at halting vertical transmission was to test

them on women in the developing countries using placebo-controlled trials.

They ran the trials, and the results showed that a less expensive AZT treatment could indeed significantly reduce vertical transmission. Nevertheless, many observers charge on various grounds that the research was unethical. Probably the chief argument against the studies is that in using a placebo (no-treatment) group, some of the subjects were deprived of an effective treatment that could have prevented many babies from being infected with HIV. Thus, the researchers violated the widely accepted moral tenet that the welfare of the human subjects should outweigh the concerns of science and society. Marcia Angell, the executive editor of the *New England Journal of Medicine*, compares the trials to the Tuskegee Study in which African American men with syphilis were studied but never treated even after an effective treatment for syphilis was in wide use. “Only when there is no known effective treatment is it ethical to compare a potential new treatment with a placebo,” she says. “When effective treatment exists, a placebo may not be used.”<sup>15</sup> Yet before the AZT trials began, an effective treatment was already available. Thus, the women in the studies were treated merely as a means to the end of scientific inquiry.

Other commentators defend the use of placebo control groups in the trials and reject the idea that it was morally problematic. They argue that those in the placebo groups were not deprived of treatment that they would have received under normal circumstances. Nothing was taken from them that they already had, and so no injustice was done. Baruch Brody takes this line and argues that an injustice is committed only if the study participants are “denied any treatment that should otherwise be available to him or her in light of the practical realities of health care resources available in the country in question.”<sup>16</sup> Judged by this standard, he says, “the trials in question were probably not unjust.” Some defenders of the trials add the further point that if the research had not been done, many women would never have received any AZT at all.

Some critics of such trials allege a pattern of exploitation of people in developing countries. They say that researchers use impoverished or desperate subjects to determine the best therapies, and then that information is used to help people in rich countries, not the developing ones. Reflecting this concern about exploitation, international policies insist that any therapies developed through research should be shared with the community or country where the research was done. Brody thinks that these policies miss the mark. To avoid exploitation, we need not ensure that the benefits of research go to the larger community, but only to the subjects themselves:

[W]e need to ask who needs to be protected from being exploited by the trials in question. It would seem that it is the participants. Are they getting a fair share of the benefits from the trial if it proves successful? This is a particularly troubling question when we consider those in the control group, whose major benefit from participation may have been an unrealized possibility of getting treated. If we judge that the participants have not received enough, then it is they who must receive more.<sup>17</sup>

### APPLYING MAJOR THEORIES

Utilitarianism says that right actions are those that result in the most beneficial balance of good over bad consequences, everyone considered (see Chapter 2). What are the implications of this stance for human research? First, utilitarianism can provide an unequivocal justification for it. Through medical research, the causes of disease are unmasked, disease preventives are devised, treatments are developed, and the true worth of common but untested therapies is determined. Thus human well-being is advanced, and an important moral principle—*beneficence*—is satisfied.

On the utilitarian view, the moral justification for conducting any particular clinical trial depends on its offering a net benefit to all concerned. The maximization of benefit, in turn,

hangs on the quality and aims of the research—on how well and why it is done. The utilitarian would agree then with the common ethical requirements that “the experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature. . . . The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.”<sup>18</sup>

Ethical codes insist that people must not be included in clinical trials without their informed consent, but whether utilitarianism is consistent with this requirement is debatable. Some argue that there really is no inconsistency because informed consent is just another way to maximize utility. Others doubt that this tack is coherent.

In medical research, the utilitarian perspective often leads to the same conclusions about the permissibility of actions that other theories do. But frequently the judgments clash dramatically, as they did in disputes over the placebo-controlled AZT trials in developing countries. The utilitarians argued that the cheapest, fastest way to find out which treatment was best and to use it on the people who needed it most was to use a placebo group. But many rejected this view, arguing in Kantian fashion that subjects in the placebo (no-treatment) group were treated as a mere means to the end of scientific rigor, and many babies would become HIV-infected as a result.

The AZT episode was one of many in clinical research that illustrated the distinctive implications of a Kantian approach. Its mean-sends requirement—the prohibition against using persons as if they were mere things—was implicit in the strong condemnations of the Nazi medical experiments, the Cold War radiation research, the Tuskegee Study, and many others. It proscribes the coercing of research subjects, deceiving them, deliberately harming them, and diminishing or destroying their autonomy. Kant’s notion of the equal moral value of persons yields the imperative to treat equals equally,

which seems to imply that even in research, some subjects should not be treated better (or worse) than others for no morally relevant reason. For some bioethicists, this means that research subjects in poor countries should receive the same treatments in clinical trials that they would get if they lived in rich countries.

Kant would insist that these limits on what can be done to subjects can never be weakened or ignored for the sake of utility. The categorical imperative must not be breached—even to find cures for humanity's ills.

The heart of the modern doctrine of informed consent is Kantian. Because persons are autonomous, rational agents, they must be allowed the freedom to make choices and to have them respected. They may give or withhold their consent to medical treatment or research, consent that is valid only if informed, competent, and voluntary. Within limits, informed consent can legitimize the indignities of clinical trials by ensuring that even though subjects are treated as a means to an end, they are not treated *solely* as a means to an end. But if a person refuses to give her informed consent, or if it is impeded by misinformation (or no information), coercion, or undue influence, using her in research would be wrong. Respect for persons also implies that obtaining their informed consent cannot justify subjecting them to substantial risk of reduced autonomy or death.

For Rawls, social and economic inequalities are not unjust if they work to everyone's benefit, especially to the benefit of the least well off in society. This implies that (1) research efforts should be aimed primarily at helping the neediest and (2) it is impermissible to conduct research on the neediest to provide therapeutic benefits only to those who are better off. Clinical trials, then, using poor, desperate, or mentally impaired subjects to develop treatments for the rest of society could not be condoned. Applied internationally, Rawls's principles would lead us to condemn research in developing countries to benefit only people in developed ones.

## KEY TERMS

blinding  
clinical trial  
placebo  
randomization

## SUMMARY

Clinical trials are scientific studies designed to test medical interventions in humans. They can derive reliable answers because they maximize the objectivity of observations, minimize bias, and avoid errors. The main requirements for a scientifically adequate clinical trial are a control group (using either a placebo or an active treatment), blinding, and randomization.

Official ethical codes on human research agree that (1) subjects must give their informed voluntary consent to participate, (2) the study must be designed to minimize risks to subjects and offer an acceptable balance of risks and benefits, (3) subjects must be selected fairly to avoid exploiting or unjustly excluding them, (4) the subjects' privacy should be protected and the confidentiality of research data must be preserved, and (5) before the research is conducted, it must be reviewed and approved by an independent committee. There is also substantial agreement on the general moral principles that apply to human research—autonomy, beneficence, and justice.

The use of control groups has raised ethical concerns, with some critics arguing that controlled trials treat subjects merely as a means to the end of scientific knowledge. But many believe that physicians do no wrong to their patients who enter a clinical trial if the physicians are in equipoise, rationally balanced between the alternative treatments. Debate about using control groups intensifies in placebo-controlled trials. The most widely accepted view is that the use of placebos is unethical when effective treatments are already available.

Most agree that the informed consent of subjects is essential for morally acceptable research. But there is often concern about whether truly

**CLASSIC CASE FILE**

## The UCLA Schizophrenia Study

Studies in which researchers do not offer real treatment to subjects suffering from a serious illness or condition often raise troubling ethical questions. In 1994 one such study got the attention of the media, the federal government, Congress, the legal system, and clinical researchers.

In the early 1980s, scientists at the University of California at Los Angeles (UCLA) Medical School began a study to determine how well schizophrenic patients could function without their antipsychotic medication, prolixin decanoate. This knowledge would have been very valuable in treating schizophrenic patients because the drug is both boon and bane. In most patients the medication can ease (but not entirely banish) psychotic symptoms, including acute psychotic episodes. But it can also cause awful side effects, most notably tardive dyskinesia, a condition of involuntary muscle movements varying from mild to disabling and possibly becoming permanent.

People with schizophrenia are afflicted with delusions, hallucinations, depression, bizarre behavior, hostility, and—in a few cases—suicide. For many patients, taking prolixin decanoate and enduring the side effects are preferable to experiencing the symptoms of schizophrenia left untreated. But the UCLA researchers wanted to find a way around these problems. They knew that some patients who are taken off their medication can function adequately for a long time before full-blown symptoms return. Identifying these patients early would enable a physician to withdraw their medication so they could benefit from it while avoiding its drawbacks.

informed and voluntary consent can be obtained from certain kinds of patients, chief among them children, the very ill, the mentally disabled, prisoners, minorities, and people in developing countries.

So the ultimate aim of the study was to uncover these identifying characteristics, and that required discontinuing the medication of the schizophrenic subjects to observe the recurrence of symptoms (relapse).

In this double-blind study, subjects were randomly assigned to either a placebo control group or a group receiving doses of prolixin decanoate. For 12 weeks the groups received their respective doses (placebo or active drug). Then the groups switched treatments and continued that way for another 12 weeks. At the end of the 24 weeks, subjects whose symptoms were still under control were taken off the drug (or allowed to continue untreated) and monitored for up to one year until they experienced full relapse or severe symptoms. Shortly after the no-drug phase began, one subject had an extreme psychotic breakdown, and after the phase ended, another subject committed suicide.

Complaints were lodged against the UCLA researchers, alleging, among other things, that the informed consent process was invalid and that the study design was too risky because it made relapses very likely. In 1994 an office in the National Institutes of Health released a report concerning the matter. It charged that the informed consent process failed to adequately explain to subjects the distinction between regular medical care and the treatment that might be provided in the study. Other observers faulted the consent process for obscuring some vital information—the probability and severity of relapse.

Regarding all these groups there is often disagreement about the proper balance of risk and benefits in clinical trials. Research involving subjects in Third World countries raises issues of justice, especially whether these subjects are

entitled to the same level of care that subjects in developed countries get.

## Cases for Evaluation

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### CASE I

#### Giving Placebos to Children

(*New York Times*)—Researchers give a 6-year-old girl who suffers from asthma attacks a promising new drug in addition to her old medicine, then withdraw it to see how she will do without it. A depressed teenager enrolls in a study for an antidepressant, but does not know if he will get a sugar pill or the real thing. The parents of an epileptic youngster enroll her in a test of a new drug that has worked well in adults. But no one knows whether she will get the new medication, or the one that has worked only moderately well for her in the past.

These quandaries, all based on actual experiences, are likely to be faced by an increasing number of parents, children, and medical researchers around the country as the federal government steps up its efforts to test drugs on children.

Over the last three years, largely because of financial incentives that Congress has given pharmaceutical companies, pediatric studies of new drugs have boomed. In December, the Food and Drug Administration will begin mandating that such tests be done on certain drugs, and the agency wants to make sure researchers protect child participants.

“What level of discomfort or risk should a child in a study be exposed to?” asked Dr. Steven Hirschfeld, a medical officer at the F.D.A.’s Center for Drug Research and Evaluation. “If a child gets an asthma attack and starts to wheeze, are people willing to tolerate that to get complete information about a potentially helpful drug for children?”

Today, an F.D.A. advisory panel met in Bethesda, Md., to begin discussions aimed at setting the first guidelines for researchers on the controversial use of placebos in drug trials for children. Placebos are sugar pills, injections, or other treatments that resemble the drug that is being tested without having any of the same effects.

Dr. Hirschfeld said that the particular vulnerability of children often makes placebo controls necessary. “Children are not only very susceptible to their own expectations,” he said in an interview. “They are very susceptible to their parents’ expectations.”

But a panelist, Dr. Charles Weijer, a bioethicist and an assistant professor of medicine at Dalhousie University in Halifax, Nova Scotia, said it was wrong to submit children to risks while providing them no immediate benefit.

“An investigator’s chief concern ought to be the health and well-being of her patients,” Dr. Weijer said at the hearing . . .

The panel of 27 researchers that met today included several researchers from Europe who are working on international standards for clinical trials in children.

“What you people decide will affect directly not only children in the U.S., but children in Europe and the world at large,” said Francis Crawley, chairman of a group working to set standards in Europe.

Dianne Murphy, the associate director for pediatrics at the F.D.A.’s Center for Drug Evaluation and Research, said that use of placebos can reduce the number of children needed in a study and can ensure the most conclusive outcome. “If you need a placebo trial to get an answer, and you don’t do it, then you’ve wasted that child’s blood, time and possible chance, in a trial that won’t give them an answer,” she said . . .

But experts disagree on the ethics of withholding effective treatment from children when studying nonfatal conditions such as allergies or skin rashes. And there is no consensus for how to treat children with other serious ailments, such as depression, where the best treatment is unknown.\*

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*Is giving children placebos in clinical trials ever morally permissible? If so, under what conditions should placebos be used? What if in a clinical trial some children suffer asthma attacks because effective treatment is withheld from them—is that acceptable? What if no effective treatments for some childhood diseases could be developed without using*

*children in placebo-controlled trials? Would that fact outweigh any objections to such trials? Give reasons for your answers.*

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\*Alexis Jetter, "Efforts to Test Drugs on Children Hasten Drive for Research Guidelines," *New York Times*, September 12, 2000, <http://www.nytimes.com/2000/09/12/science/12ETHI.html>.

## CASE 2

### Research and Medicine Collide in Haiti

(*New York Times*)—The impoverished patients who step from the dirt sidewalk into the modern AIDS research clinic run by Cornell Medical College in Port-au-Prince, Haiti, are offered a seemingly simple arrangement.

"We would like to test your blood because you live in an area where AIDS may be common," the English version of the clinic's consent form reads. "We will provide you with medicine if you fall sick and cannot afford such care."

But the transaction is not as straightforward as it sounds. Many Haitians who visit the clinic are at once patients and subjects of United States-financed medical research, and circumstances that are bad for their health are sometimes best for research results.

That conflict is especially true in Cornell's most tantalizing research in Haiti, a study of sex partners, only one of whom is infected with the AIDS virus. Researchers, seeking clues to developing a vaccine, study the blood of both partners, particularly the uninfected ones who continue to be exposed to the virus through unprotected sex. They are trying to find out whether some people have natural protections against infection with the AIDS virus that could be replicated in a vaccine.

The Haitians are ideal research subjects, largely because they are not receiving the kind of care now standard in the world's developed countries. Condom use is low in Haiti, for cultural and other reasons. Anti-retroviral drugs that are successful at suppressing the virus are unavailable except to the

very wealthy, and are not included in Cornell's promise to provide medicine.

Nearly 20 years after Cornell opened the clinic, it provides some of the best AIDS treatment available in a country devastated by the epidemic, fighting the myriad illnesses that result from AIDS. But that is a lower standard of care than patients receive routinely at American institutions, including the hospital affiliated with Cornell in New York City.

If the research were done in the United States, experts agree, the physicians would be obligated to prescribe the anti-retrovirals and deliver the most effective possible counseling against unprotected sex.

The ethical questions posed by Cornell's work among Haiti's poor are at the heart of a global debate about AIDS research that is roiling international health organizations from Geneva to Thailand, challenging ethics formulations established decades ago.

"It's really like a Faustian bargain," said Marc Fleisher, a member of the committee at Cornell that reviews research on humans. "It's like, since we're making this a better place, we're going to exploit it in a way we could never get away with in the United States," said Mr. Fleisher, the outside member on a board made up mostly of university employees who are doctors.

Cornell doctors defended the couples study as vitally important and stressed that its subjects receive the same counseling about the dangers of AIDS and the same care as other patients at the Haitian clinic.

United States standards for research on humans were strongly influenced by outrage over the Tuskegee syphilis study earlier this century, which misled impoverished black subjects for years while tracking their disease, and withheld treatment even after penicillin was discovered.

Today's subjects are not to be pressured to participate in research, according to Federal regulations. They are to be fully informed about the research's purposes and risks. They must receive the best available therapy for their illnesses and be told about any findings relevant to their health.

In theory, the same rules apply to federally financed studies overseas. But an examination of 15

years of records related to the Haiti couples research shows that it has received scant scrutiny from Government officials in Washington.

And the Government's rules barely address the moral ambiguities of AIDS research in indigent countries....

Dr. Warren D. Johnson, the chief of international medicine and infectious diseases at Cornell, called the couples study "a very high priority," though he said it had been temporarily suspended while the university concentrated on other research in Haiti. "This is the critical group in the world—couples—that's where the war is to be fought," he said.

At least 97 couples have been enrolled in the blood study since 1991, records show, but Dr. Johnson said only 30 couples are still being followed. The study will be expanded to new couples early next year, he said, and coordinated with AIDS vaccine trials, which are expected to start in Haiti this fall using similar couples as subjects.

Cornell's clinic in Haiti offers strong inducements to subjects. It is the only center in the country providing free screening and treatment for H.I.V., venereal disease, and tuberculosis, a common complication of AIDS. The thousands who flock to it are too poor to buy food, let alone the simple medicines and vitamins that serve as "a powerful incentive for study participation," in the words of one Cornell grant report.

The head of the clinic, Dr. Jean William Pape, is a Haiti native and Cornell professor who has studied AIDS in Haiti for two decades. Dr. Pape, who trained at Cornell, defended the treatment of research subjects in the couples study, saying they benefited from the same counseling and free condoms available to everyone who visits the clinic.

Dr. Pape said that offering the life-saving drugs to the handful of research subjects would be an unethical lure to participate. Treating all H.I.V.-infected citizens, he said, would cost 10 times Haiti's health budget.

If the research on couples succeeds, he said, it could help lead to a vaccine against AIDS. "You have to take into account people who mean well for their country and not impose on them things that you feel are good for Western ideas," he said....

The Haitians were valuable for another reason. Unlike AIDS patients in the United States and Europe, they were not receiving the anti-retroviral drugs that proved effective in halting the disease's progress.

The lack of those drugs "may allow identification of novel findings not easily studied in the U.S.A.," Dr. John L. Ho, a Cornell immunologist, wrote in an application for Federal funds. In 1995, the Federal Government awarded Cornell an extra \$60,000 to expand this part of the Haitian couples study....

Ethical standards for Federally financed studies require that patients be told why researchers want to study them. But the written consent form approved at Cornell and read aloud in Creole to each potential subject does not mention that the study focuses on couples in which one sexual partner has tested positive for H.I.V.

The form tells subjects their blood is being tested because "you live in an area where AIDS may be common." It promises all patients that H.I.V. test results will be kept confidential....

After reviewing clinic materials, Marie Saint Cyr, a native of Haiti who now directs an AIDS program for women in Harlem, said there was a "clear conflict of interest" between the desire to collect information from research subjects and the obligation to effectively warn patients at risk.

"If you know somebody is positive and is having sex with a partner who is negative, you have a life and death situation in front of you," she said. "You have to do individualized counseling to really tap into what those people value in life, to confront them with the reality of H.I.V. and AIDS. This in no way addresses those serious things."\*

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*Is the Cornell research ethical? Should subjects in the study get the same AIDS treatment available to people in the United States? Should the researchers provide stronger warnings to subjects about the dangers of not using condoms? Is the informed consent process morally acceptable? Explain your answers.*

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\*Nina Bernstein, "Strings Attached: For Subjects in Haiti Study, Free AIDS Care Has a Price," *New York Times*, June 6, 1999, <http://www.nytimes.com/pages/health>.

**CASE 3****To Stop or Not to Stop  
a Clinical Trial**

(*New York Times*)—Recently, scientists made the startling decision to halt a large multinational clinical trial that was testing a new drug regimen for breast cancer. The five-year trial was stopped after just two and a half years when results showed that the study drug cut the yearly rate of breast cancer recurrence by nearly half.

The decision has already provoked controversy: breast cancer recurrence is not necessarily the same as death, the critics say, so it is not clear whether the new drug actually saves lives.

The National Breast Cancer Coalition, a patient advocacy group, argued that researchers should have continued the study to see if the new drug prolonged lives.

The issue gets to the core of biomedical research. What is ideal for researchers may not always be ideal for subjects or for the demands of public health.

In this study, the researchers were looking to see if letrozole, which blocks estrogen synthesis, was more effective than a placebo in preventing the recurrence of breast cancer in women who had already taken the estrogen-blocking drug tamoxifen.

Because the advantage of letrozole on disease-free survival was apparent early on, the researchers had to halt the study.

Dr. James N. Ingle of the Mayo Clinic and a principal investigator in the study said he was surprised by the criticism over ending the study. “Preventing disease recurrence is a valid endpoint,” he said. “If you sit down with patients, they will tell you that they don’t want their cancer to come back. That’s their first concern.”

“In fact, I can’t think of a study of breast cancer where actual survival is the primary endpoint. Disease-free survival is a well-accepted outcome with strong precedence in cancer research.”

But to some researchers, the study stopped short of answering important questions. Does letrozole promote actual survival? What are its long-term adverse effects? How long should women continue to take it?

The results, for example, suggest a slight increase in osteoporosis in women taking letrozole compared with a placebo. So, other side effects may emerge over time.

The pursuit of perfect data may be the researcher’s dream, but the perspective of a woman with breast cancer is vastly different. If you were privy to the interim analysis, you would most likely choose the new drug over the placebo.

Imagine the outcry if investigators had withheld the early evidence of the drug’s benefit and finished the study, hoping for better data. Millions of women with breast cancer could then have correctly claimed they were denied a new treatment.

“A woman with breast cancer who wakes up the next morning without a recurrence of her disease is a survivor,” said Dr. Paul Goss of Princess Margaret Hospital and lead author of the study. “What most people and even doctors don’t understand about the course of breast cancer is that it is a chronic relapsing disease over many years.”

Proving that letrozole saves lives will require a study lasting many years, Dr. Goss said. “We’ve done the first step, which is to show that letrozole works in preventing breast cancer recurrence,” he said. “The next step is to do an extended trial to find out the optimal duration of treatment and long-term side effects.”

When people enroll in research studies they sign informed consent agreements explaining the potential risks and benefits. In this case, the form promised subjects that they would be told if new information about their disease was discovered in the study. This virtually mandated early disclosure.

And although subjects are explicitly told in a consent form that they themselves may receive no direct benefit, many continue to hope for it. At the very least, they reasonably expect to be kept from all foreseeable harm.

But avoiding harm is not the same thing as getting benefit. In fact, in many clinical trials subjects are randomly assigned to take the drug or a placebo.

This has prompted some researchers to question whether the use of placebos is even ethical because some very sick people will essentially get no active treatment and may get worse.

What about using placebos in studies of serious illnesses like depression? Treatments for it are known to be effective, though imperfect. There is little doubt that the most powerful way to show a drug's efficacy and safety is to assign patients at random to the drug or a placebo. But depressed patients who get a placebo may not improve; they may get worse and even become suicidal.

Sure, scientists could compare an experimental drug with a proven standard drug, but this would require a much larger sample and would expose more people to risks of the new drug. That's because research results differ more widely between the use of placebos and active drugs, than between two active treatments.\*

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*Were the researchers right to halt the breast cancer study early? Suppose by extending the trial the scientists could gain valuable knowledge that would help save many women's lives in the future. Would halting the trial early then be wrong? Suppose extending the trial would save lives in the future but also result in the deaths of some women in the study. Would the extension then be permissible? Was the use of placebos ethical? Explain your answers.*

\*Richard Friedman, "Cases: Long-Term Questions Linger in Halted Breast Cancer Trial," *New York Times*, October 21, 2003, <http://www.nytimes.com/pages/health>.

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## READINGS

### **The Nuremberg Code**

1. The voluntary consent of the human subject is absolutely essential.

This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

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From *Trials of War Criminals Before the Nuremberg Military Tribunals under Control Council Law No. 10*, vol. 2 (Washington, DC: U.S. Government Printing Office, 1949), 181–182.

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.

4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.

5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.

6. The degree of risk to be taken should never exceed that determined by the humanitarian

importance of the problem to be solved by the experiment.

7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.

8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.

9. During the course of the experiment the human subject should be at liberty to bring the

experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.

10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

## ***Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects***

WORLD MEDICAL ASSOCIATION

This international ethical code echoes principles in the Nuremberg Code and breaks some new ground as well. In addition to affirming the importance of informed consent, it provides guidelines for conducting research on subjects who cannot give their informed consent, insists on the review of research protocols by "independent committees," discusses the use of placebo controls, and declares that "considerations related to the well-being of the human subject should take precedence over the interests of science and society."

### **A. Introduction**

1. The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to physicians and other participants in medical research involving human subjects. Medical research involving human subjects includes research on identifiable human material or identifiable data.

2. It is the duty of the physician to promote and safeguard the health of the people. The physician's knowledge and conscience are dedicated to the fulfillment of this duty.

3. The Declaration of Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical

Ethics declares that, "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient."

4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.

5. In medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society.

6. The primary purpose of medical research involving human subjects is to improve prophylactic, diagnostic and therapeutic procedures and the understanding of the aetiology and pathogenesis of disease. Even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility, and quality.

7. In current medical practice and in medical research, most prophylactic, diagnostic, and therapeutic procedures involve risks and burdens.

8. Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.

9. Research Investigators should be aware of the ethical, legal and regulatory requirements for research on human subjects in their own countries as well as applicable international requirements. No national ethical, legal or regulatory requirement should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration.

### **B. Basic Principles for All Medical Research**

10. It is the duty of the physician in medical research to protect the life, health, privacy, and dignity of the human subject.

11. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation.

12. Appropriate caution must be exercised in the conduct of research which may affect the environment, and the welfare of animals used for research must be respected.

13. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol. This protocol should be submitted for consideration, comment, guidance, and where appropriate, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. This independent committee should be in conformity with the laws and regulations of the country in which the research experiment is performed. The committee has the right to monitor

ongoing trials. The researcher has the obligation to provide monitoring information to the committee, especially any serious adverse events. The researcher should also submit to the committee, for review, information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest and incentives for subjects.

14. The research protocol should always contain a statement of the ethical considerations involved and should indicate that there is compliance with the principles enunciated in this Declaration.

15. Medical research involving human subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given consent.

16. Every medical research project involving human subjects should be preceded by careful assessment of predictable risks and burdens in comparison with foreseeable benefits to the subject or to others. This does not preclude the participation of healthy volunteers in medical research. The design of all studies should be publicly available.

17. Physicians should abstain from engaging in research projects involving human subjects unless they are confident that the risks involved have been adequately assessed and can be satisfactorily managed. Physicians should cease any investigation if the risks are found to outweigh the potential benefits or if there is conclusive proof of positive and beneficial results.

18. Medical research involving human subjects should only be conducted if the importance of the objective outweighs the inherent risks and burdens to the subject. This is especially important when the human subjects are healthy volunteers.

19. Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research.

20. The subjects must be volunteers and informed participants in the research project.

21. The right of research subjects to safeguard their integrity must always be respected. Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's

information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

22. In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study, and the discomfort it may entail. The subject should be informed of the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisal. After ensuring that the subject has understood the information, the physician should then obtain the subject's freely given informed consent, preferably in writing. If the consent cannot be obtained in writing, the non-written consent must be formally documented and witnessed.

23. When obtaining informed consent for the research project the physician should be particularly cautious if the subject is in a dependent relationship with the physician or may consent under duress. In that case the informed consent should be obtained by a well-informed physician who is not engaged in the investigation and who is completely independent of this relationship.

24. For a research subject who is legally incompetent, physically or mentally incapable of giving consent or is a legally incompetent minor, the investigator must obtain informed consent from the legally authorized representative in accordance with applicable law. These groups should not be included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.

25. When a subject deemed legally incompetent, such as a minor child, is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative.

26. Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them

unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate.

27. Both authors and publishers have ethical obligations. In publication of the results of research, the investigators are obliged to preserve the accuracy of the results. Negative as well as positive results should be published or otherwise publicly available. Sources of funding, institutional affiliations, and any possible conflicts of interest should be declared in the publication. Reports of experimentation not in accordance with the principles laid down in this Declaration should not be accepted for publication.

### **C. Additional Principles for Medical Research Combined with Medical Care**

28. The physician may combine medical research with medical care, only to the extent that the research is justified by its potential prophylactic, diagnostic, or therapeutic value. When medical research is combined with medical care, additional standards apply to protect the patients who are research subjects.

29. The benefits, risks, burdens, and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic, or therapeutic method exists.<sup>1</sup>

30. At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic, and therapeutic methods identified by the study.<sup>2</sup>

31. The physician should fully inform the patient which aspects of the care are related to the research. The refusal of a patient to participate in a study must never interfere with the patient-physician relationship.

32. In the treatment of a patient, where proven prophylactic, diagnostic, and therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new prophylactic,

diagnostic, and therapeutic measures, if in the physician's judgement it offers hope of saving life, reestablishing health or alleviating suffering. Where possible, these measures should be made the object of research, designed to evaluate their safety and efficacy. In all cases, new information should be recorded and, where appropriate, published. The other relevant guidelines of this Declaration should be followed.

#### NOTES

1. Note of clarification on paragraph 29 of the WMA Declaration of Helsinki:

The WMA hereby reaffirms its position that extreme care must be taken in making use of a placebo-controlled trial and that in general this methodology should only be used in the absence of existing proven therapy. However, a placebo-controlled trial may be ethically acceptable, even if proven therapy is available, under the following circumstances:

- Where for compelling and scientifically sound methodological reasons its use is necessary to determine the efficacy or safety of a prophylactic, diagnostic, or therapeutic method; or
- Where a prophylactic, diagnostic, or therapeutic method is being investigated for a minor condition and the patients who receive placebo will not be subject to any additional risk of serious or irreversible harm.

All other provisions of the Declaration of Helsinki must be adhered to, especially the need for appropriate ethical and scientific review.

2. Note of clarification on paragraph 30 of the WMA Declaration of Helsinki:

The WMA hereby reaffirms its position that it is necessary during the study planning process to identify post-trial access by study participants to prophylactic, diagnostic, and therapeutic procedures identified as beneficial in the study or access to other appropriate care. Post-trial access arrangements or other care must be described in the study protocol so the ethical review committee may consider such arrangements during its review.

## The Belmont Report

THE NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF  
BIOMEDICAL AND BEHAVIORAL RESEARCH

In 1974 Congress created the commission to provide guidance on the ethical issues that arise in research on human subjects. The result of the commission's work is this report, which lays out a general approach to thinking about research ethics and elucidates the three most relevant moral principles—respect for persons, beneficence, and justice.

### Ethical Principles and Guidelines for Research Involving Human Subjects

#### A. Boundaries Between Practice and Research

It is important to distinguish between biomedical and behavioral research, on the one hand, and the practice of accepted therapy on the other, in order to know what activities ought to undergo review for the

From *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (April 18, 1979), The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, <http://ohsr.od.nih.gov/guidelines/belmont.html>.

protection of human subjects of research. The distinction between research and practice is blurred partly because both often occur together (as in research designed to evaluate a therapy) and partly because notable departures from standard practice are often called "experimental" when the terms "experimental" and "research" are not carefully defined.

For the most part, the term "practice" refers to interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals. By contrast, the term "research" designates an activity designed to test an

hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge (expressed, for example, in theories, principles, and statements of relationships). Research is usually described in a formal protocol that sets forth an objective and a set of procedures designed to reach that objective.

When a clinician departs in a significant way from standard or accepted practice, the innovation does not, in and of itself, constitute research. The fact that a procedure is “experimental,” in the sense of new, untested or different, does not automatically place it in the category of research. Radically new procedures of this description should, however, be made the object of formal research at an early stage in order to determine whether they are safe and effective. Thus, it is the responsibility of medical practice committees, for example, to insist that a major innovation be incorporated into a formal research project.

Research and practice may be carried on together when research is designed to evaluate the safety and efficacy of a therapy. This need not cause any confusion regarding whether or not the activity requires review; the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects.

### B. Basic Ethical Principles

The expression “basic ethical principles” refers to those general judgments that serve as a basic justification for the many particular ethical prescriptions and evaluations of human actions. Three basic principles, among those generally accepted in our cultural tradition, are particularly relevant to the ethics of research involving human subjects: the principles of respect of persons, beneficence and justice.

*1. Respect for Persons.* Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.

An autonomous person is an individual capable of deliberation about personal goals and of acting

under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons’ considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person’s considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so.

However, not every human being is capable of self-determination. The capacity for self-determination matures during an individual’s life, and some individuals lose this capacity wholly or in part because of illness, mental disability, or circumstances that severely restrict liberty. Respect for the immature and the incapacitated may require protecting them as they mature or while they are incapacitated.

Some persons are in need of extensive protection, even to the point of excluding them from activities which may harm them; other persons require little protection beyond making sure they undertake activities freely and with awareness of possible adverse consequence. The extent of protection afforded should depend upon the risk of harm and the likelihood of benefit. The judgment that any individual lacks autonomy should be periodically reevaluated and will vary in different situations.

In most cases of research involving human subjects, respect for persons demands that subjects enter into the research voluntarily and with adequate information. In some situations, however, application of the principle is not obvious. The involvement of prisoners as subjects of research provides an instructive example. On the one hand, it would seem that the principle of respect for persons requires that prisoners not be deprived of the opportunity to volunteer for research. On the other hand, under prison conditions they may be subtly coerced or unduly influenced to engage in research activities for which they would not otherwise volunteer. Respect for persons would then dictate that prisoners be protected. Whether to allow prisoners to “volunteer” or to “protect” them presents a dilemma. Respecting persons, in most hard cases, is often a matter of balancing competing claims urged by the principle of respect itself.

2. *Beneficence.* Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term “beneficence” is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms.

The Hippocratic maxim “do no harm” has long been a fundamental principle of medical ethics. Claude Bernard extended it to the realm of research, saying that one should not injure one person regardless of the benefits that might come to others. However, even avoiding harm requires learning what is harmful; and, in the process of obtaining this information, persons may be exposed to risk of harm. Further, the Hippocratic Oath requires physicians to benefit their patients “according to their best judgment.” Learning what will in fact benefit may require exposing persons to risk. The problem posed by these imperatives is to decide when it is justifiable to seek certain benefits despite the risks involved, and when the benefits should be foregone because of the risks.

The obligations of beneficence affect both individual investigators and society at large, because they extend both to particular research projects and to the entire enterprise of research. In the case of particular projects, investigators and members of their institutions are obliged to give forethought to the maximization of benefits and the reduction of risk that might occur from the research investigation. In the case of scientific research in general, members of the larger society are obliged to recognize the longer term benefits and risks that may result from the improvement of knowledge and from the development of novel medical, psychotherapeutic, and social procedures.

The principle of beneficence often occupies a well-defined justifying role in many areas of research involving human subjects. An example is found in research involving children. Effective ways of treating childhood diseases and fostering healthy

development are benefits that serve to justify research involving children—even when individual research subjects are not direct beneficiaries. Research also makes it possible to avoid the harm that may result from the application of previously accepted routine practices that on closer investigation turn out to be dangerous. But the role of the principle of beneficence is not always so unambiguous. A difficult ethical problem remains, for example, about research that presents more than minimal risk without immediate prospect of direct benefit to the children involved. Some have argued that such research is inadmissible, while others have pointed out that this limit would rule out much research promising great benefit to children in the future. Here again, as with all hard cases, the different claims covered by the principle of beneficence may come into conflict and force difficult choices.

3. *Justice.* Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of “fairness in distribution” or “what is deserved.” An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of conceiving the principle of justice is that equals ought to be treated equally. However, this statement requires explication. Who is equal and who is unequal? What considerations justify departure from equal distribution? Almost all commentators allow that distinctions based on experience, age, deprivation, competence, merit and position do sometimes constitute criteria justifying differential treatment for certain purposes. It is necessary, then, to explain in what respects people should be treated equally. There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are (1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit.

Questions of justice have long been associated with social practice such as punishment, taxation and political representation. Until recently these questions have not generally been associated with

scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients. Subsequently, the exploitation of unwilling prisoners as research subjects in Nazi concentration camps was condemned as a particularly flagrant injustice. In this country, in the 1940's, the Tuskegee syphilis study used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available.

Against this historical background, it can be seen how conceptions of justice are relevant to research involving human subjects. For example, the selection of research subjects needs to be scrutinized in order to determine whether some classes (e.g., welfare patients, particular racial and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied. Finally, whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries of subsequent applications of the research.

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## Final Report: Human Radiation Experiments

### ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS

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This official report details the government-sponsored radiation experiments conducted on thousands of human subjects from 1944 to 1974. Subjects were exposed to harmful levels of radiation, often without their consent and without being told of the potential dangers. The report also reviews the safety of contemporary human research using radiation and recommends apologies and compensation to the victimized subjects or their next of kin.

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#### **The Creation of the Advisory Committee**

On January 15, 1994, President Clinton appointed the Advisory Committee on Human Radiation Experiments. The President created the Committee to investigate reports of possibly unethical experiments funded by the government decades ago.

The members of the Advisory Committee were fourteen private citizens from around the country: a representative of the general public and thirteen

experts in bioethics, radiation oncology and biology, nuclear medicine, epidemiology and biostatistics, public health, history of science and medicine, and law.

President Clinton asked us to deliver our recommendations to a Cabinet-level group, the Human Radiation Interagency Working Group, whose members are the Secretaries of Defense, Energy, Health and Human Services, and Veterans Affairs; the Attorney General; the Administrator of the National Aeronautics and Space Administration; the Director of Central Intelligence; and the Director of the Office of Management and Budget. Some of the experiments the Committee was asked to

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From Advisory Committee on Human Radiation Experiments, Department of Energy, *Final Report: Executive Summary*, 1995, <http://www.hss.energy.gov/healthsafety/ohre/roadmap/achre/report.html>.

investigate, and particularly a series that included the injection of plutonium into unsuspecting hospital patients, were of special concern to Secretary of Energy Hazel O'Leary. Her department had its origins in the federal agencies that had sponsored the plutonium experiments. These agencies were responsible for the development of nuclear weapons and during the Cold War their activities had been shrouded in secrecy. But now the Cold War was over.

The controversy surrounding the plutonium experiments and others like them brought basic questions to the fore: How many experiments were conducted or sponsored by the government, and why? How many were secret? Was anyone harmed? What was disclosed to those subjected to risk, and what opportunity did they have for consent? By what rules should the past be judged? What remedies are due those who were wronged or harmed by the government in the past? How well do federal rules that today govern human experimentation work? What lessons can be learned for application to the future? Our Final Report provides the details of the Committee's answers to these questions. This Executive Summary presents an overview of the work done by the Committee, our findings and recommendations, and the contents of the Final Report.

### **The President's Charge**

The President directed the Advisory Committee to uncover the history of human radiation experiments during the period 1944 through 1974. It was in 1944 that the first known human radiation experiment of interest was planned, and in 1974 that the Department of Health, Education and Welfare adopted regulations governing the conduct of human research, a watershed event in the history of federal protections for human subjects.

In addition to asking us to investigate human radiation experiments, the President directed us to examine cases in which the government had intentionally released radiation into the environment for research purposes. He further charged us with identifying the ethical and scientific standards for evaluating these events, and with making recommendations to ensure that whatever wrongdoing may have occurred in the past cannot be repeated.

We were asked to address human experiments and intentional releases that involved radiation. The ethical issues we addressed and the moral framework we developed are, however, applicable to all research involving human subjects.

The breadth of the Committee's charge was remarkable. We were called on to review government programs that spanned administrations from Franklin Roosevelt to Gerald Ford. As an independent advisory committee, we were free to pursue our charge as we saw fit. The decisions we reached regarding the course of our inquiry and the nature of our findings and recommendations were entirely our own.

### **The Committee's Approach**

At our first meeting, we immediately realized that we were embarking on an intense and challenging investigation of an important aspect of our nation's past and present, a task that required new insights and difficult judgments about ethical questions that persist even today.

Between April 1994 and July 1995, the Advisory Committee held sixteen public meetings, most in Washington, D.C. In addition, subsets of Committee members presided over public forums in cities throughout the country. The Committee heard from more than 200 witnesses and interviewed dozens of professionals who were familiar with experiments involving radiation. A special effort, called the Ethics Oral History Project, was undertaken to learn from eminent physicians about how research with human subjects was conducted in the 1940s and 1950s.

We were granted unprecedented access to government documents. The President directed all the federal agencies involved to make available to the Committee any documents that might further our inquiry, wherever they might be located and whether or not they were still secret.

As we began our search into the past, we quickly discovered that it was going to be extremely difficult to piece together a coherent picture. Many critical documents had long since been forgotten and were stored in obscure locations throughout the country. Often they were buried in collections that bore no obvious connection to human radiation experiments. There was no easy way to identify how

many experiments had been conducted, where they took place, and which government agencies had sponsored them. Nor was there a quick way to learn what rules applied to these experiments for the period prior to the mid-1960s. With the assistance of hundreds of federal officials and agency staff, the Committee retrieved and reviewed hundreds of thousands of government documents. Some of the most important documents were secret and were declassified at our request. Even after this extraordinary effort, the historical record remains incomplete. Some potentially important collections could not be located and were evidently lost or destroyed years ago.

Nevertheless, the documents that were recovered enabled us to identify nearly 4,000 human radiation experiments sponsored by the federal government between 1944 and 1974. In the great majority of cases, only fragmentary data was locatable; the identity of subjects and the specific radiation exposures involved were typically unavailable.

Given the constraints of information, even more so than time, it was impossible for the Committee to review all these experiments, nor could we evaluate the experiences of countless individual subjects. We thus decided to focus our investigation on representative case studies reflecting eight different categories of experiments that together addressed our charge and priorities. These case studies included:

- Experiments with plutonium and other atomic bomb materials
- The Atomic Energy Commission's program of radioisotope distribution
- Nontherapeutic research on children
- Total body irradiation
- Research on prisoners
- Human experimentation in connection with nuclear weapons testing
- Intentional environmental releases of radiation
- Observational research involving uranium miners and residents of the Marshall Islands

In addition to assessing the ethics of human radiation experiments conducted decades ago, it was also important to explore the current conduct of human radiation research. Insofar as wrongdoing may have occurred in the past, we needed to examine

the likelihood that such things could happen today. We therefore undertook three projects:

- A review of how each agency of the federal government that currently conducts or funds research involving human subjects regulates this activity and oversees it.
- An examination of the documents and consent forms of research projects that are today sponsored by the federal government in order to develop insight into the current status of protections for the rights and interests of human subjects.
- Interviews of nearly 1,900 patients receiving outpatient medical care in private hospitals and federal facilities throughout the country. We asked them whether they were currently, or had been, subjects of research, and why they had agreed to participate in research or had refused.

### The Historical Context

Since its discovery 100 years ago, radioactivity has been a basic tool of medical research and diagnosis. In addition to the many uses of the x-ray, it was soon discovered that radiation could be used to treat cancer and that the introduction of "tracer" amounts of radioisotopes into the human body could help to diagnose disease and understand bodily processes. At the same time, the perils of overexposure to radiation were becoming apparent.

During World War II the new field of radiation science was at the center of one of the most ambitious and secret research efforts the world has known—the Manhattan Project. Human radiation experiments were undertaken in secret to help understand radiation risks to workers engaged in the development of the atomic bomb.

Following the war, the new Atomic Energy Commission used facilities built to make the atomic bomb to produce radioisotopes for medical research and other peacetime uses. This highly publicized program provided the radioisotopes that were used in thousands of human experiments conducted in research facilities throughout the country and the world. This research, in turn, was part of a larger postwar transformation of biomedical

research through the infusion of substantial government monies and technical support.

The intersection of government and biomedical research brought with it new roles and new ethical questions for medical researchers. Many of these researchers were also physicians who operated within a tradition of medical ethics that enjoined them to put the interests of their patients first. When the doctor also was a researcher, however, the potential for conflict emerged between the advancement of science and the advancement of the patient's well-being.

Other ethical issues were posed as medical researchers were called on by government officials to play new roles in the development and testing of nuclear weapons. For example, as advisers they were asked to provide human research data that could reassure officials about the effects of radiation, but as scientists they were not always convinced that human research could provide scientifically useful data. Similarly, as scientists, they came from a tradition in which research results were freely debated. In their capacity as advisers to and officials of the government, however, these researchers found that the openness of science now needed to be constrained.

None of these tensions were unique to radiation research. Radiation represents just one of several examples of the exploration of the weapons potential of new scientific discoveries during and after World War II. Similarly, the tensions between clinical research and the treatment of patients were emerging throughout medical science, and were not found only in research involving radiation. Not only were these issues not unique to radiation, but they were not unique to the 1940s and 1950s. Today society still struggles with conflicts between the openness of science and the preservation of national security, as well as with conflicts between the advancement of medical science and the rights and interests of patients.

## **Key Findings**

### **Human Radiation Experiments**

- Between 1944 and 1974 the federal government sponsored several thousand human radiation experiments. In the great majority of cases, the experiments were conducted to advance biomedical science; some experiments were conducted to advance national interests

in defense or space exploration; and some experiments served both biomedical and defense or space exploration purposes. As noted, in the great majority of cases only fragmentary data are available.

- The majority of human radiation experiments identified by the Advisory Committee involved radioactive tracers administered in amounts that are likely to be similar to those used in research today. Most of these tracer studies involved adult subjects and are unlikely to have caused physical harm. However, in some nontherapeutic tracer studies involving children, radioisotope exposures were associated with increases in the potential lifetime risk for developing thyroid cancer that would be considered unacceptable today. The Advisory Committee also identified several studies in which patients died soon after receiving external radiation or radioisotope doses in the therapeutic range that were associated with acute radiation effects.
- Although the AEC, the Defense Department and the National Institutes of Health recognized at an early date that research should proceed only with the consent of the human subject, there is little evidence of rules or practices of consent except in research with healthy subjects. It was commonplace during the 1940s and 1950s for physicians to use patients as subjects of research without their awareness or consent. By contrast, the government and its researchers focused with substantial success on the minimization of risk in the conduct of experiments, particularly with respect to research involving radioisotopes. But little attention was paid during this period to issues of fairness in the selection of subjects.
- Government officials and investigators are blameworthy for not having had policies and practices in place to protect the rights and interests of human subjects who were used in research from which the subjects could not possibly derive direct medical benefit. To the extent that there was reason to believe that research might provide a direct medical benefit to subjects, government officials and

biomedical professionals are less blameworthy for not having had such protections and practices in place.

### Intentional Releases

- During the 1944–1974 period, the government conducted several hundred intentional releases of radiation into the environment for research purposes. Generally, these releases were not conducted for the purpose of studying the effects of radiation on humans. Instead they were usually conducted to test the operation of weapons, the safety of equipment, or the dispersal of radiation into the environment.
- For those intentional releases where dose reconstructions have been undertaken, it is unlikely that members of the public were directly harmed solely as a consequence of these tests. However, these releases were conducted in secret and despite continued requests from the public that stretch back well over a decade, some information about them was made public only during the life of the Advisory Committee.

### Uranium Miners

- As a consequence of exposure to radon and its daughter products in underground uranium mines, at least several hundred miners died of lung cancer and surviving miners remain at elevated risk. These men, who were the subject of government study as they mined uranium for use in weapons manufacturing, were subject to radon exposures well in excess of levels known to be hazardous. The government failed to act to require the reduction of the hazard by ventilating the mines, and it failed to adequately warn the miners of the hazard to which they were being exposed.

### Secrecy and the Public Trust

- The greatest harm from past experiments and intentional releases may be the legacy of distrust they created. Hundreds of intentional releases took place in secret, and remained secret for decades. Important discussion of

the policies to govern human experimentation also took place in secret. Information about human experiments was kept secret out of concern for embarrassment to the government, potential legal liability, and worry that public misunderstanding would jeopardize government programs.

- In a few instances, people used as experimental subjects and their families were denied the opportunity to pursue redress for possible wrongdoing because of actions taken by the government to keep the truth from them. Where programs were legitimately kept secret for national security reasons, the government often did not create or maintain adequate records, thereby preventing the public, and those most at risk, from learning the facts in a timely and complete fashion.

### Contemporary Human Subjects Research

- Human research involving radioisotopes is currently subjected to more safeguards and levels of review than most other areas of research involving human subjects. There are no apparent differences between the treatment of human subjects of radiation research and human subjects of other biomedical research.
- Based on the Advisory Committee's review, it appears that much of human subjects research poses only minimal risk of harm to subjects. In our review of research documents that bear on human subjects issues, we found no problems or only minor problems in most of the minimal-risk studies we examined.
- Our review of documents identified examples of complicated, higher-risk studies in which human subjects issues were carefully and adequately addressed and that included excellent consent forms. In our interview project, there was little evidence that patient-subjects felt coerced or pressured by investigators to participate in research. We interviewed patients who had declined offers to become research subjects, reinforcing the impression that there are often contexts in which potential research subjects have a genuine choice.

- At the same time, however, we also found evidence suggesting serious deficiencies in aspects of the current system for the protection of the rights and interests of human subjects. For example, consent forms do not always provide adequate information and may be misleading about the impact of research participation on people's lives. Some patients with serious illnesses appear to have unrealistic expectations about the benefits of being subjects in research.

### **Current Regulations on Secrecy in Human Research and Environmental Releases**

- Human research can still be conducted in secret today, and under some conditions informed consent in secret research can be waived.
- Events that raise the same concerns as the intentional releases in the Committee's charter could take place in secret today under current environmental laws....

### **Key Recommendations**

#### **Apologies and Compensation**

The government should deliver a personal, individualized apology and provide financial compensation to those subjects of human radiation experiments, or their next of kin, in cases where:

- Efforts were made by the government to keep information secret from these individuals or their families, or the public, for the purpose of avoiding embarrassment or potential legal liability, and where this secrecy had the effect of denying individuals the opportunity to pursue potential grievances.
- There was no prospect of direct medical benefit to the subjects, or interventions considered controversial at the time were presented as standard practice, and physical injury attributable to the experiment resulted.

#### **Uranium Miners**

- The Interagency Working Group, together with Congress, should give serious consideration to amending the provisions of the Radiation Exposure Compensation Act of 1990

relating to uranium miners in order to provide compensation to *all* miners who develop lung cancer after some minimal duration of employment underground (such as one year), without requiring a specific level of exposure. The act should also be reviewed to determine whether the documentation standards for compensation should be liberalized.

#### **Improved Protection for Human Subjects**

- The Committee found no differences between human radiation research and other areas of research with respect to human subjects issues, either in the past or the present. In comparison to the practices and policies of the 1940s and 1950s, there have been significant advances in the federal government's system for the protection of the rights and interests of human subjects. But deficiencies remain. Efforts should be undertaken on a national scale to ensure the centrality of ethics in the conduct of scientists whose research involves human subjects.
- One problem in need of immediate attention by the government and the biomedical research community is unrealistic expectations among some patients with serious illnesses about the prospect of direct medical benefit from participating in research. Also, among the consent forms we reviewed, some appear to be overly optimistic in portraying the likely benefits of research, to inadequately explain the impact of research procedures on quality of life and personal finances, and to be incomprehensible to lay people.
- A mechanism should be established to provide for continuing interpretation and application in an open and public forum of ethics rules and principles for the conduct of human subjects research. Three examples of policy issues in need of public resolution that the Advisory Committee confronted in our work are: (1) Clarification of the meaning of minimal risk in research with healthy children; (2) regulations to cover the conduct of research with institutionalized children; and (3)

guidelines for research with adults of questionable competence, particularly for research in which subjects are placed at more than minimal risk but are offered no prospect of direct medical benefit.

### **Secrecy: Balancing National Security and the Public Trust**

Current policies do not adequately safeguard against the recurrence of the kinds of events we studied that fostered distrust. The Advisory Committee concludes that there may be special circumstances in which it may be necessary to conduct human research or intentional releases in secret. However, to the extent that the government conducts such activities with elements of secrecy, special protections of the rights and interests of individuals and the public are needed.

*Research Involving Human Subjects.* The Advisory Committee recommends the adoption of federal policies requiring:

- The informed consent of all human subjects of classified research. This requirement should not be subject to exemption or waiver.

- That classified research involving human subjects be permitted only after the review and approval of an independent panel of appropriate nongovernmental experts and citizen representatives, all with the necessary security clearances.

*Environmental Releases.* There must be independent review to assure that the action is needed, that risk is minimized, and that records will be kept to assure a proper accounting to the public at the earliest date consistent with legitimate national security concerns. Specifically, the Committee recommends that:

- Secret environmental releases of hazardous substances should be permitted only after the review and approval of an independent panel. This panel should consist of appropriate, non-governmental experts and citizen representatives, all with the necessary security clearances.
- An appropriate government agency, such as the Environmental Protection Agency, should maintain a program directed at the oversight of classified programs, with suitably cleared personnel. . . .

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## **Of Mice but Not Men: Problems of the Randomized Clinical Trial**

SAMUEL HELLMAN AND DEBORAH S. HELLMAN

The Hellmans contend that randomized clinical trials place physician-scientists (physicians who simultaneously act as scientists) in a terrible ethical bind. As physicians, they have a duty to look out for the best interests of their patients; as scientists, they have an obligation to ensure the integrity of the research. But often they cannot do both, the Hellmans say. Before or during a trial, if a physician-scientist believes that a new treatment is better (or worse) than the alternative treatment, she has a physician's duty to communicate this judgment to her patient-subjects and ensure that they get the best treatment. But if she does so, the validity of the research will be compromised. Thus randomized trials often pit the good of patients against the good of society. The authors "urge that such situations be avoided and that other techniques of acquiring clinical information be adopted."

As medicine has become increasingly scientific and less accepting of unsupported opinion or proof by anecdote, the randomized controlled clinical trial has become the standard technique for changing diagnostic or therapeutic methods. The use of this technique creates an ethical dilemma.<sup>1,2</sup> Researchers participating in such studies are required to modify their ethical commitments to individual patients and do serious damage to the concept of the physician as a practicing, empathetic professional who is primarily concerned with each patient as an individual. Researchers using a randomized clinical trial can be described as physician-scientists, a term that expresses the tension between the two roles. The physician, by entering into a relationship with an individual patient, assumes certain obligations, including the commitment always to act in the patient's best interests. As Leon Kass has rightly maintained, "the physician must produce unwaveringly the virtues of loyalty and fidelity to his patient."<sup>3</sup> Though the ethical requirements of this relationship have been modified by legal obligations to report wounds of a suspicious nature and certain infectious diseases, these obligations in no way conflict with the central ethical obligation to act in the best interests of the patient medically. Instead, certain non-medical interests of the patient are preempted by other social concerns.

The role of the scientist is quite different. The clinical scientist is concerned with answering questions—i.e., determining the validity of formally constructed hypotheses. Such scientific information, it is presumed, will benefit humanity in general. The clinical scientist's role has been well described by Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, who states the goals of the randomized clinical trial in these words: "It's not to deliver therapy. It's to answer a scientific question so that the drug can be available for everybody once you've established safety and efficacy."<sup>4</sup> The demands of such a study can conflict in a number of ways with the

physician's duty to minister to patients. The study may create a false dichotomy in the physician's opinions; according to the premise of the randomized clinical trial, the physician may only know or not know whether a proposed course of treatment represents an improvement; no middle position is permitted. What the physician thinks, suspects, believes, or has a hunch about is assigned to the "not knowing" category, because knowing is defined on the basis of an arbitrary but accepted statistical test performed in a randomized clinical trial. Thus, little credence is given to information gained beforehand in other ways or to information accrued during the trial but without the required statistical degree of assurance that a difference is not due to chance. The randomized clinical trial also prevents the treatment technique from being modified on the basis of the growing knowledge of the physicians during their participation in the trial. Moreover, it limits access to the data as they are collected until specific milestones are achieved. This prevents physicians from profiting not only from their individual experience, but also from the collective experience of the other participants.

The randomized clinical trial requires doctors to act simultaneously as physicians and as scientists. This puts them in a difficult and sometimes untenable ethical position. The conflicting moral demands arising from the use of the randomized clinical trial reflect the classic conflict between rights-based moral theories and utilitarian ones. The first of these, which depend on the moral theory of Immanuel Kant (and seen more recently in neo-Kantian philosophers, such as John Rawls<sup>5</sup>), asserts that human beings, by virtue of their unique capacity for rational thought, are bearers of dignity. As such, they ought not to be treated merely as means to an end; rather, they must always be treated as ends in themselves. Utilitarianism, by contrast, defines what is right as the greatest good for the greatest number—that is, as social utility. This view, articulated by Jeremy Bentham and John Stuart Mill, requires that pleasures (understood broadly, to include such pleasures as health and well-being) and pains be added together. The morally correct act is the act that produces the most pleasure and the least pain overall.

A classic objection to the utilitarian position is that according to that theory, the distribution of pleasures and pains is of no moral consequence. This element of the theory severely restricts physicians from being utilitarians, or at least from following the theory's dictates. Physicians must care very deeply about the distribution of pain and pleasure, for they have entered into a relationship with one or a number of individual patients. They cannot be indifferent to whether it is these patients or others that suffer for the general benefit of society. Even though society might gain from the suffering of a few, and even though the doctor might believe that such a benefit is worth a given patient's suffering (i.e., that utilitarianism is right in the particular case), the ethical obligation created by the covenant between doctor and patient requires the doctor to see the interests of the individual patient as primary and compelling. In essence, the doctor-patient relationship requires doctors to see their patients as bearers of rights who cannot be merely used for the greater good of humanity.

As Fauci has suggested,<sup>4</sup> the randomized clinical trial routinely asks physicians to sacrifice the interests of their particular patients for the sake of the study and that of the information that it will make available for the benefit of society. This practice is ethically problematic. Consider first the initial formulation of a trial. In particular, consider the case of a disease for which there is no satisfactory therapy—for example, advanced cancer or the acquired immunodeficiency syndrome (AIDS). A new agent that promises more effectiveness is the subject of the study. The control group must be given either an unsatisfactory treatment or a placebo. Even though the therapeutic value of the new agent is unproved, if physicians think that it has promise, are they acting in the best interests of their patients in allowing them to be randomly assigned to the control group? Is persisting in such an assignment consistent with the specific commitments taken on in the doctor-patient relationship? As a result of interactions with patients with AIDS and their advocates, Merigan<sup>6</sup> recently suggested modifications in the design of clinical trials that attempt to deal with the unsatisfactory treatment given to the control group. The view of such activists has been expressed by Rebecca

Pringle Smith of Community Research Initiative in New York: "Even if you have a supply of compliant martyrs, trials must have some ethical validity."<sup>7</sup>

If the physician has no opinion about whether the new treatment is acceptable, then random assignment is ethically acceptable, but such lack of enthusiasm for the new treatment does not augur well for either the patient or the study. Alternatively, the treatment may show promise of beneficial results but also present a risk of undesirable complications. When the physician believes that the severity and likelihood of harm and good are evenly balanced, randomization may be ethically acceptable. If the physician has no preference for either treatment (is in a state of equipoise<sup>7,8</sup>), then randomization is acceptable. If, however, he or she believes that the new treatment may be either more or less successful or more or less toxic, the use of randomization is not consistent with fidelity to the patient.

The argument usually used to justify randomization is that it provides, in essence, a critique of the usefulness of the physician's beliefs and opinions, those that have not yet been validated by a randomized clinical trial. As the argument goes, these not-yet-validated beliefs are as likely to be wrong as right. Although physicians are ethically required to provide their patients with the best available treatment, there simply is no best treatment yet known.

The reply to this argument takes two forms. First, and most important, even if this view of the reliability of a physician's opinions is accurate, the ethical constraints of an individual doctor's relationship with a particular patient require the doctor to provide individual care. Although physicians must take pains to make clear the speculative nature of their views, they cannot withhold these views from the patient. The patient asks from the doctor both knowledge and judgment. The relationship established between them rightfully allows patients to ask for the judgment of their particular physicians, not merely that of the medical profession in general. Second, it may not be true, in fact, that the not-yet-validated beliefs of physicians are as likely to be wrong as right. The greater certainty obtained with a randomized clinical trial is beneficial, but that does not mean that a lesser degree of certainty is

without value. Physicians can acquire knowledge through methods other than the randomized clinical trial. Such knowledge, acquired over time and less formally than is required in a randomized clinical trial, may be of great value to a patient.

Even if it is ethically acceptable to begin a study, one often forms an opinion during its course—especially in studies that are impossible to conduct in a truly double-blinded fashion—that makes it ethically problematic to continue. The inability to remain blinded usually occurs in studies of cancer or AIDS, for example, because the therapy is associated by nature with serious side effects. Trials attempt to restrict the physician's access to the data in order to prevent such unblinding. Such restrictions should make physicians eschew the trial, since their ability to act in the patient's best interests will be limited. Even supporters of randomized clinical trials, such as Merigan, agree that interim findings should be presented to patients to ensure that no one receives what seems an inferior treatment.<sup>6</sup> Once physicians have formed a view about the new treatment, can they continue randomization? If random assignment is stopped, the study may be lost and the participation of the previous patients wasted. However, if physicians continue the randomization when they have a definite opinion about the efficacy of the experimental drug, they are not acting in accordance with the requirements of the doctor-patient relationship. Furthermore, as their opinion becomes more firm, stopping the randomization may not be enough. Physicians may be ethically required to treat the patients formerly placed in the control group with the therapy that now seems probably effective. To do so would be faithful to the obligations created by the doctor-patient relationship, but it would destroy the study.

To resolve this dilemma, one might suggest that the patient has abrogated the rights implicit in a doctor-patient relationship by signing an informed-consent form. We argue that such rights cannot be waived or abrogated. They are inalienable. The right to be treated as an individual deserving the physician's best judgment and care, rather than to be used as a means to determine the best treatment for others, is inherent in every person. This right, based on the concept of dignity, cannot be waived. What

of altruism, then? Is it not the patient's right to make a sacrifice for the general good? This question must be considered from both positions—that of the patient and that of the physician. Although patients may decide to waive this right, it is not consistent with the role of a physician to ask that they do so. In asking, the doctor acts as a scientist instead. The physician's role here is to propose what he or she believes is best medically for the specific patient, not to suggest participation in a study from which the patient cannot gain. Because the opportunity to help future patients is of potential value to a patient, some would say physicians should not deny it. Although this point has merit, it offers so many opportunities for abuse that we are extremely uncomfortable about accepting it. The responsibilities of physicians are much clearer; they are to minister to the current patient.

Moreover, even if patients could waive this right, it is questionable whether those with terminal illness would be truly able to give voluntary informed consent. Such patients are extremely dependent on both their physicians and the health care system. Aware of this dependence, physicians must not ask for consent, for in such cases the very asking breaches the doctor-patient relationship. Anxious to please their physicians, patients may have difficulty refusing to participate in the trial the physicians describe. The patients may perceive their refusal as damaging to the relationship, whether or not it is so. Such perceptions of coercion affect the decision. Informed-consent forms are difficult to understand, especially for patients under the stress of serious illness for which there is no satisfactory treatment. The forms are usually lengthy, somewhat legalistic, complicated, and confusing, and they hardly bespeak the compassion expected of the medical profession. It is important to remember that those who have studied the doctor-patient relationship have emphasized its empathetic nature.

[The] relationship between doctor and patient partakes of a peculiar intimacy. It presupposes on the part of the physician not only knowledge of his fellow men but sympathy. . . . This aspect of the practice of medicine has been designated as the art; yet I wonder whether it should not, most properly, be called the essence.<sup>9</sup>

How is such a view of the relationship consonant with random assignment and informed consent? The Physician's Oath of the World Medical Association affirms the primacy of the deontologic view of patients' rights: "Concern for the interests of the subject must always prevail over the interests of science and society."<sup>10</sup>

Furthermore, a single study is often not considered sufficient. Before a new form of therapy is generally accepted, confirmatory trials must be conducted. How can one conduct such trials ethically unless one is convinced that the first trial was in error? The ethical problems we have discussed are only exacerbated when a completed randomized clinical trial indicates that a given treatment is preferable. Even if the physician believes the initial trial was in error, the physician must indicate to the patient the full results of that trial.

The most common reply to the ethical arguments has been that the alternative is to return to the physician's intuition, to anecdotes, or to both as the basis of medical opinion. We all accept the dangers of such a practice. The argument states that we must therefore accept randomized, controlled clinical trials regardless of their ethical problems because of the great social benefit they make possible, and we salve our conscience with the knowledge that informed consent has been given. This returns us to the conflict between patients' rights and social utility. Some would argue that this tension can be resolved by placing a relative value on each. If the patient's right that is being compromised is not a fundamental right and the social gain is very great, then the study might be justified. When the right is fundamental, however, no amount of social gain, or almost none, will justify its sacrifice. Consider, for example, the experiments on humans done by physicians under the Nazi regime. All would agree that these are unacceptable regardless of the value of the scientific information gained. Some people go so far as to say that no use should be made of the results of those experiments because of the clearly unethical manner in which the data were collected. This extreme example may not seem relevant, but we believe that in its hyperbole it clarifies the fallacy of a utilitarian approach to the physician's relationship with the patient. To consider the utilitarian gain is

consistent neither with the physician's role nor with the patient's rights.

It is fallacious to suggest that only the randomized clinical trial can provide valid information or that all information acquired by this technique is valid. Such experimental methods are intended to reduce error and bias and therefore reduce the uncertainty of the result. Uncertainty cannot be eliminated, however. The scientific method is based on increasing probabilities and increasingly refined approximations of truth.<sup>11</sup> Although the randomized clinical trial contributes to these ends, it is neither unique nor perfect. Other techniques may also be useful.<sup>12</sup>

Randomized trials often place physicians in the ethically intolerable position of choosing between the good of the patient and that of society. We urge that such situations be avoided and that other techniques of acquiring clinical information be adopted. For example, concerning trials of treatments for AIDS, Byar et al.<sup>13</sup> have said that "some traditional approaches to the clinical-trials process may be unnecessarily rigid and unsuitable for this disease." In this case, AIDS is not what is so different; rather, the difference is in the presence of AIDS activists, articulate spokespersons for the ethical problems created by the application of the randomized clinical trial to terminal illnesses. Such arguments are equally applicable to advanced cancer and other serious illnesses. Byar et al. agree that there are even circumstances in which uncontrolled clinical trials may be justified: when there is no effective treatment to use as a control, when the prognosis is uniformly poor, and when there is a reasonable expectation of benefit without excessive toxicity. These conditions are usually found in clinical trials of advanced cancer.

The purpose of the randomized clinical trial is to avoid the problems of observer bias and patient selection. It seems to us that techniques might be developed to deal with these issues in other ways. Randomized clinical trials deal with them in a cumbersome and heavy-handed manner, by requiring large numbers of patients in the hope that random assignment will balance the heterogeneous distribution of patients into the different groups. By observing known characteristics of patients, such as age and sex, and distributing them equally

between groups, it is thought that unknown factors important in determining outcomes will also be distributed equally. Surely, other techniques can be developed to deal with both observer bias and patient selection. Prospective studies without randomization, but with the evaluation of patients by uninvolved third parties, should remove observer bias. Similar methods have been suggested by Royall.<sup>12</sup> Prospective matched-pair analysis, in which patients are treated in a manner consistent with their physicians' views, ought to help ensure equivalence between the groups and thus mitigate the effect of patient selection, at least with regard to known covariates. With regard to unknown covariates, the security would rest, as in randomized trials, in the enrollment of large numbers of patients and in confirmatory studies. This method would not pose ethical difficulties, since patients would receive the treatment recommended by their physician. They would be included in the study by independent observers matching patients with respect to known characteristics, a process that would not affect patient care and that could be performed independently any number of times.

This brief discussion of alternatives to randomized clinical trials is sketchy and incomplete. We wish only to point out that there may be satisfactory alternatives, not to describe and evaluate them completely. Even if randomized clinical trials were much better than any alternative, however, the ethical dilemmas they present may put their use at variance with the primary obligations of the physician. In this regard, Angell cautions, "If this commitment to the patient is attenuated, even for so good a cause as benefits to future patients, the implicit assumptions of the doctor-patient relationship are violated."<sup>14</sup> The risk of such attenuation by the randomized trial is great. The AIDS activists have

brought this dramatically to the attention of the academic medical community. Techniques appropriate to the laboratory may not be applicable to humans. We must develop and use alternative methods for acquiring clinical knowledge.

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## A Response to a Purported Ethical Difficulty with Randomized Clinical Trials Involving Cancer Patients

BENJAMIN FREEDMAN

Defenders of randomized clinical trials claim that physician-scientists do not violate a duty of fidelity to patients if the effectiveness of the treatments being tested is unknown and if the physicians are therefore in doubt (in a state of equipoise) about the treatments' merits. But critics say that if a physician suspects even for flimsy reasons that one treatment is better or worse than another, he cannot be in equipoise. Freedman thinks this view of equipoise is mistaken. He argues that true equipoise does not depend on uncertainty in the physician but on genuine disagreement in the medical community about a treatment's value because of a lack of good evidence gleaned from randomized clinical trials. When this kind of doubt exists, randomized clinical studies are permissible.

In recent years, for a variety of reasons, the mainstay of clinical investigation—the randomized controlled clinical trial (RCT)—has increasingly come under attack. Since Charles Fried's influential monograph,<sup>1</sup> the opponents of controlled trials have claimed the moral high ground. They claim to perceive a conflict between the medical and scientific duties of the physician-investigator, and between the conduct of the trial and a patient's rights. Samuel and Deborah Hellman write, for example, that "the randomized clinical trial routinely asks physicians to sacrifice the interests of their particular patients for the sake of the study and that of the information that it will make available for the benefit of society."<sup>2</sup> Maurie Markman's attraction to this point of view is clear when he writes that "the individual physician's principal ethical responsibility is to the *individual patient* that he or she is treating, and *not* to future patients [emphases in original]." In the interests of returning Markman to the fold, I will concentrate on resolving this central challenge to the ethics of RCTs.

It is unfortunately true that the most common responses from pro-trialists, by revealing fundamental misunderstandings of basic ethical

concepts, do not inspire confidence in the ethics of human research as it is currently conducted. Proponents of clinical trials will commonly begin their apologia by citing benefits derived from trials—by validating the safety and efficacy of new treatments, and, at least as important, by discrediting accepted forms of treatment. So far so good. But they often go on to argue that there is a need to balance the rights of subjects against the needs of society. By this tactic, the proponents of clinical trials have implicitly morally surrendered, for to admit that something is a right is to admit that it represents a domain of action protected from the claims or interests of other individuals or of society itself. A liberal society has rightly learned to look askance at claims that rights of individuals need to yield to the demands of the collective. Patients' claims, then, because of their nature as rights, supersede the requirements of the collectivity.

Sometimes, indeed, the surrender is explicit. At the conclusion of a symposium on the ethics of research on human subjects, Sir Colin Dollery, a major figure in clinical trials, complained to the speaker: "You assume a dominant role for ethics—I think to the point of arrogance. Ethical judgments will be of little value unless the scientific innovations about which they are made . . . are useful."<sup>3</sup> But it is the nature of ethical judgments that they are, indeed, "dominant" as normative or accepted guides to

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action. One may say, "I know that X is the ethical thing to do, but I won't X." That expresses no logical contradiction, but simply weakness of will. But it is, by contrast, plainly contradictory to admit that X is ethical, yet to deny or doubt that one ought to X.

Closer examination and finer distinctions reveal, however, that the conflict between patients' rights and social interests is not at all at issue in controlled clinical trials. There is no need for proponents of clinical trials to concede the moral high ground.

What is the patient right that is compromised by clinical trials? The fear most common to patients who are hesitant about enrolling is that they would not receive the best care, that their right to treatment would be sacrificed in the interests of science. This presumes, of course, that the patient has a right to treatment. Such a right must in reason be grounded in patient need (a patient who is not ill has no right to treatment) and in medical knowledge and capability (a patient with an incurable illness has rights to be cared for, but no right to be cured).

That granted, we need to specify the kind of treatment to which a patient might reasonably claim a right. It was in this connection that I introduced the concept of *clinical equipoise* as critical to understanding the ethics of clinical trials.<sup>4</sup> Clinical equipoise is a situation in which there exists (or is pending) an honest disagreement in the expert clinical community regarding the comparative merits of two or more forms of treatment for a given condition. To be ethical, a controlled clinical trial must begin and be conducted in a continuing state of clinical equipoise—as between the arms of the study—and must, moreover, offer some reasonable hope that the successful conclusion of the trial will disturb equipoise (that is, resolve the controversy in the expert clinical community).

This theory presumes that a right to a specific medical treatment must be grounded in a professional judgment, which is concretized in the term *clinical equipoise*. A patient who has rights to medical treatment has rights restricted to, though not necessarily exhaustive of, those treatments that are understood by the medical community to be appropriate for his condition. A patient may eccentrically claim some good from a physician that is not recognized by the medical community as appropriate

treatment. A physician may even grant this claim; but in so doing, he must realize that he has not provided medical treatment itself. Contrariwise, by failing to fulfill this request, the physician has not failed to satisfy the patient's right to medical treatment.

Provided that a comparative trial is ethical, therefore, it begins in a state of clinical equipoise. For that reason, by definition, nobody enrolling in the trial is denied his or her right to medical treatment, for no medical consensus for or against the treatment assignment exists.

(The modern climate requires that I introduce two simple caveats. First, I am ignoring economic and political factors that go into the grounding of a right to treatment. This is easy enough for one in Canada to write, but may be difficult for someone in the United States to read. Second, when speaking of treatment that is recognized to be condition-appropriate by the medical community, I mean to include only those judgments grounded in medical knowledge rather than social judgments. I would hope to avoid the current bioethical muddle over "medical futility," but if my claims need to be translated into terms appropriate to that controversy, "physiological futility" is close but not identical to what I mean by "inappropriate." For simplicity's sake, the best model to have in mind is the common patient demand for antibiotic treatment of an illness diagnosed as viral.)

Two errors are commonly committed in connection with the concept of clinical equipoise. The first mistake is in thinking that clinical equipoise (or its disturbance) relates to a single endpoint of a trial—commonly, efficacy. As a function of expert clinical judgment, clinical equipoise must incorporate all of the many factors that go into favoring one regimen over its competitors. Treatment A may be favored over B because it is more effective; or, because it is almost as effective but considerably less toxic; or, because it is easier to administer, allowing, for example, treatment on an outpatient basis; or, because patients are more compliant with it; and so forth.

Just as equipoise may be based upon any one or a combination of these or other factors, it may be disturbed in the same way. Markman's second example, which discusses the efficacy of a multidrug

combination chemotherapy regimen, seems vulnerable to this objection. Even were the results of the Mayo trial convincing with regard to the efficacy of this approach, it has not disturbed clinical equipoise in its favor unless other issues, such as toxicity, have been resolved as well. It is well worth pointing out that the endpoints of trials, particularly in cancer treatment, are far too narrow to disturb clinical equipoise in and of themselves, but they are necessary steps along a *seriatim* path. For that matter, in ignoring the compendious judgment involved in ascertaining equipoise, some studies spuriously claim that all of their arms are in equipoise on the basis of one variable (such as five-year survival rates), when they are clearly out of equipoise because of other factors (such as differences in pain and disfigurement).

The second mistake occurs in identifying clinical equipoise with an individual physician's point of indifference between two treatments. Citing the article in which I developed the concept and another article applying it, for example, the Hellmans write, "If the physician has no preference for either treatment (is in a state of equipoise), then randomization is acceptable."<sup>5</sup> But an individual physician is not the arbiter of appropriate or acceptable medical practice.

There are numerous occasions outside of clinical trials where outsiders need to determine whether the treatment provided was appropriate to the patient's condition. Regulators, as well as third-party payers—private or governmental—need to answer the question, as do health planners and administrators of health-care facilities. Disciplinary bodies of professional associations, and, most tellingly, courts judging allegations of malpractice, have to ascertain this as well. It is never the case that the judgment of an individual physician concerning whether a treatment is condition-appropriate (that is, whether it belongs within the therapeutic armamentarium) is sufficient. In all of these instances, however varied might be their rules of investigation and procedure, the ultimate question is: Does the expert professional community accept this treatment as appropriate for this condition? Since clinical equipoise and its disturbance applies to putative medical treatments for given conditions, this is a

matter that is determined legally, morally, and reasonably by that medical community with the recognized relevant expertise.

Markman may have fallen into this error, writing repeatedly of the judgment of the treating or enrolling physician (and, in the first page, of the responsibility of "the individual physician") with respect to the clinical trial. There is, however, another way of looking at this. Whereas the status of a putative treatment within the medical armamentarium must be settled by the medical *community*, the application of that judgment vis-à-vis a given patient is, of course, the judgment (and the responsibility) of the *individual physician*. This individual clinical judgment must be exercised when enrolling a subject, rather than subjugated to the judgment of those who constructed the trial. Indeed, many studies will list this as a criterion of exclusion: "Those subjects who, in the judgment of the accruing physician, would be put at undue risk by participating."

Another point: the Hellmans write of a physician's duty in treating a patient to employ what he "thinks, suspects, believes, or has a hunch about."<sup>6</sup> This is clearly overstated as a duty: why not add to the list the physician's hopes, fantasies, fond but dotty beliefs, and illusions? Yet patients do choose physicians, in part, because of trust in their tacit knowledge and inchoate judgment, and not merely their sapient grasp of the current medical consensus. It would be a disservice to patients for a physician to see his or her role simply as a vehicle for transmitting the wisdom received from the expert medical community in all cases (though when a departure is made, this is done at the legal peril of the doctor!).

But what follows from this inalienable duty of the treating physician? Not as much as the opponents of trials would have us believe. A physician certainly has the right to refuse to participate in a trial that he believes places some participants at a medical disadvantage. Moreover, if he or she is convinced of that, he or she has a *duty* to abstain from participating. But that only speaks to the physician, and does not necessarily affect the patient. What opponents of trials forget is that the patient—the subject—is the ultimate decision maker—in fact, in

law, and in ethics. In at least some cases, the fact that there is an open trial for which a patient meets the eligibility criteria needs to be disclosed as one medical alternative, to satisfy ethical norms of informed consent. A physician with convictions that the trial will put subjects at undue risk should inform the prospective subject of that conviction and the reasons for it, and may well recommend to the subject to decline participation. It will then be up to the patient whether to seek enrollment via another physician.

Most commonly at issue, though, is a physician's preference rather than conviction. In such cases, it is perfectly ethical—and becomingly modest—for a physician to participate in a trial, setting aside private misgivings based upon anecdote as overbalanced by the medical literature.

Finally, something should be said about the underlying philosophical buttress on which anti-trialists rely. Following Kant, the Hellmans argue that the underlying issue is that persons "ought not to be treated merely as means to an end; rather, they must always be treated as ends in themselves."<sup>7</sup> Clinical trials, however, are designed to yield reliable data and to ground scientifically valid inferences. In that sense, the treatments and examinations that a subject of a clinical trial undergoes are means to a scientific end, rather than interventions done solely for the subject's own benefit.

But the Kantian formulation is notoriously rigorous, and implausible in the form cited. We treat others as means all the time, in order to achieve ends the others do not share, and are so treated in return. When buying a carton of milk or leaving a message, I am treating the cashier or secretary as means to an end they do not share. Were this unvarnished principle to hold, all but purely altruistic transactions would be ethically deficient. Clinical trials would be in very good (and, indeed, very bad) company. Those who follow the Kantian view are not concerned about treating another as a means, but rather about treating someone in a way that contradicts the other's personhood itself—that is, in a way that denies the fact that the person is not

simply a means but is also an end. A paradigm case is when I treat someone in a way that serves my ends but, at the same time, is contrary to the other's best interests. It is time that a subject's participation in a clinical trial serves scientific ends, but what has not been shown is that it is contrary to the best interests of the subject. In cases where the two equipoise conditions are satisfied, this cannot be shown.

However, in some cases we are uncertain about whether an intervention will serve the best interests of the other, and so we ask that person. That is one reason for requiring informed consent to studies. There is another. By obtaining the consent of the other party to treat him as an end to one's own means, in effect, an identity of ends between both parties has been created. Applying this amended Kantian dictum, then, we should ask: Is there anything about clinical trials that necessarily implies that subjects are treated contrary to their personhood? And the answer is, of course, no—provided a proper consent has been obtained.

There remain many hard questions to ask about the ethics of controlled clinical studies. Many talents will be needed to address those questions and to reform current practice. Since those questions will only be asked by those who understand that such studies rest upon a sound ethical foundation, I am hopeful that Markman and others will reconsider their misgivings.

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3. Comment by Sir Colin Dollery in discussion following H.-M. Sass, "Ethics of Drug Research and Drug Development," *Arzneimittel Forschung/Drug Research* 39 (II), Number 8a (1989):1041–48, at 1048.
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6. Ibid.
7. Ibid.

## Racism and Research: The Case of the Tuskegee Syphilis Study

ALLAN M. BRANDT

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Brandt recounts in detail the abuses of human rights and the deliberate harm perpetrated in the infamous Tuskegee Syphilis Study, probably the most egregious example of unethical research in American history. Brandt declares that “the Tuskegee study revealed more about the pathology of racism than it did about the pathology of syphilis.”

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In 1932 the U.S. Public Health Service (USPHS) initiated an experiment in Macon County, Alabama, to determine the natural course of untreated, latent syphilis in black males. The test comprised 400 syphilitic men, as well as 200 uninfected men who served as controls. The first published report of the study appeared in 1936 with subsequent papers issued every four to six years, through the 1960s. When penicillin became widely available by the early 1950s as the preferred treatment for syphilis, the men did not receive therapy. In fact on several occasions, the USPHS actually sought to prevent treatment. Moreover, a committee at the federally operated Center for Disease Control decided in 1969 that the study should be continued. Only in 1972, when accounts of the study first appeared in the national press, did the Department of Health, Education and Welfare halt the experiment. At that time seventy-four of the test subjects were still alive; at least twenty-eight, but perhaps more than 100, had died directly from advanced syphilitic lesions.<sup>1</sup> In August 1972, HEW appointed an investigatory panel which issued a report the following year. The panel found the study to have been “ethically unjustified,” and argued that penicillin should have been provided to the men.<sup>2</sup>

This article attempts to place the Tuskegee Study in a historical context and to assess its ethical implications. Despite the media attention which the study received, the HEW *Final Report*, and the criticism expressed by several professional organizations, the

experiment has been largely misunderstood. The most basic questions of *how* the study was undertaken in the first place and *why* it continued for forty years were never addressed by the HEW investigation. Moreover, the panel misconstrued the nature of the experiment, failing to consult important documents available at the National Archives which bear significantly on its ethical assessment. Only by examining the specific ways in which values are engaged in scientific research can the study be understood.

### Racism and Medical Opinion

A brief review of the prevailing scientific thought regarding race and heredity in the early twentieth century is fundamental for an understanding of the Tuskegee Study. By the turn of the century, Darwinism had provided a new rationale for American racism.<sup>3</sup> Essentially primitive peoples, it was argued, could not be assimilated into a complex, white civilization. Scientists speculated that in the struggle for survival the Negro in America was doomed. Particularly prone to disease, vice, and crime, black Americans could not be helped by education or philanthropy. Social Darwinists analyzed census data to predict the virtual extinction of the Negro in the twentieth century, for they believed the Negro race in America was in the throes of a degenerative evolutionary process.<sup>4</sup>

The medical profession supported these findings of late nineteenth- and early twentieth-century anthropologists, ethnologists, and biologists. Physicians studying the effects of emancipation on health concluded almost universally that freedom had caused the mental, moral, and physical deterioration

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From Allan M. Brandt, “Racism and Research: The Case of the Tuskegee Syphilis Study,” *Hastings Center Report*, Report 8, no. 6 (Dec. 1978): 21–29.

of the black population.<sup>5</sup> They substantiated this argument by citing examples in the comparative anatomy of the black and white races. As Dr. W. T. English wrote: "A careful inspection reveals the body of the negro a mass of minor defects and imperfections from the crown of the head to the soles of the feet. . . ."<sup>6</sup> Cranial structures, wide nasal apertures, receding chins, projecting jaws, all typed the Negro as the lowest species in the Darwinian hierarchy?

Interest in racial differences centered on the sexual nature of blacks. The Negro, doctors explained, possessed an excessive sexual desire, which threatened the very foundations of white society. As one physician noted in the *Journal of the American Medical Association*, "The negro springs from a southern race, and as such his sexual appetite is strong; all of his environments stimulate this appetite, and as a general rule his emotional type of religion certainly does not decrease it."<sup>7</sup> Doctors reported a complete lack of morality on the part of blacks:

Virtue in the negro race is like angels' visits—few and far between. In a practice of sixteen years I have never examined a virgin negro over fourteen years of age.<sup>8</sup>

A particularly ominous feature of this overzealous sexuality, doctors argued, was the black males' desire for white women. "A perversion from which most races are exempt," wrote Dr. English, "prompts the negro's inclination towards white women, whereas other races incline towards females of their own."<sup>9</sup> Though English estimated the "gray matter of the negro brain" to be at least a thousand years behind that of the white races, his genital organs were overdeveloped. As Dr. William Lee Howard noted:

The attacks on defenseless white women are evidences of racial instincts that are about as amenable to ethical culture as is the inherent odor of the race. . . . When education will reduce the size of the negro's penis as well as bring about the sensitiveness of the terminal fibers which exist in the Caucasian, then will it also be able to prevent the African's birthright to sexual madness and excess.<sup>10</sup>

One southern medical journal proposed "Castration Instead of Lynching," as retribution for black

sexual crimes. "An impressive trial by a ghost-like kuklux klan [sic] and a 'ghost' physician or surgeon to perform the operation would make it an event the 'patient' would never forget," noted the editorial.<sup>12</sup>

According to these physicians, lust and immorality, unstable families, and reversion to barbaric tendencies made blacks especially prone to venereal diseases. One doctor estimated that over 50 percent of all Negroes over the age of twenty-five were syphilitic.<sup>13</sup> Virtually free of disease as slaves, they were now overwhelmed by it, according to informed medical opinion. Moreover, doctors believed that treatment for venereal disease among blacks was impossible, particularly because in its latent stage the symptoms of syphilis become quiescent. As Dr. Thomas W. Murrell wrote:

They come for treatment at the beginning and at the end. When there are visible manifestations or when harried by pain, they readily come, for as a race they are not averse to physic; but tell them not, though they look well and feel well, that they are still diseased. Here ignorance rates science a fool. . . .<sup>14</sup>

Even the best educated black, according to Murrell, could not be convinced to seek treatment for syphilis.<sup>15</sup> Venereal disease, according to some doctors, threatened the future of the race. The medical profession attributed the low birth rate among blacks to the high prevalence of venereal disease which caused stillbirths and miscarriages. Moreover, the high rates of syphilis were thought to lead to increased insanity and crime. One doctor writing at the turn of the century estimated that the number of insane Negroes had increased thirteen-fold since the end of the Civil War.<sup>16</sup> Dr. Murrell's conclusion echoed the most informed anthropological and ethnological data:

So the scourge sweeps among them. Those that are treated are only half cured, and the effort to assimilate a complex civilization driving their diseased minds until the results are criminal records. Perhaps here, in conjunction with tuberculosis, will be the end of the negro problem. Disease will accomplish what man cannot do.<sup>17</sup>

This particular configuration of ideas formed the core of medical opinion concerning blacks, sex,

and disease in the early twentieth century. Doctors generally discounted socioeconomic explanations of the state of black health, arguing that better medical care could not alter the evolutionary scheme.<sup>18</sup> These assumptions provide the backdrop for examining the Tuskegee Syphilis Study.

### The Origins of the Experiment

In 1929, under a grant from the Julius Rosenwald Fund, the USPHS conducted studies in the rural South to determine the prevalence of syphilis among blacks and explore the possibilities for mass treatment. The USPHS found Macon County, Alabama, in which the town of Tuskegee is located, to have the highest syphilis rate of the six counties surveyed. The Rosenwald Study concluded that mass treatment could be successfully implemented among rural blacks.<sup>19</sup> Although it is doubtful that the necessary funds would have been allocated even in the best economic conditions, after the economy collapsed in 1929, the findings were ignored. It is, however, ironic that the Tuskegee Study came to be based on findings of the Rosenwald Study that demonstrated the possibilities of mass treatment.

Three years later, in 1932, Dr. Taliaferro Clark, Chief of the USPHS Venereal Disease Division and author of the Rosenwald Study report, decided that conditions in Macon County merited renewed attention. Clark believed the high prevalence of syphilis offered an “unusual opportunity” for observation. From its inception, the USPHS regarded the Tuskegee Study as a classic “study in nature,”\* rather than an experiment.<sup>20</sup> As long as syphilis was so prevalent in Macon and most of the blacks went untreated throughout life, it seemed only natural to Clark that it would be valuable to observe the consequences.

\* In 1865, Claude Bernard, the famous French physiologist, outlined the distinction between a “study in nature” and experimentation. A study in nature required simple observation, an essentially passive act, while experimentation demanded intervention which altered the original condition. The Tuskegee Study was thus clearly not a study in nature. The very act of diagnosis altered the original conditions. “It is on this very possibility of acting or not acting on a body,” wrote Bernard, “that the distinction will exclusively rest between sciences called sciences of observation and sciences called experimental.”

He described it as a “ready-made situation.”<sup>21</sup> Surgeon General H. S. Cumming wrote to R. R. Moton, Director of the Tuskegee Institute:

The recent syphilis control demonstration carried out in Macon County, with the financial assistance of the Julius Rosenwald Fund, revealed the presence of an unusually high rate in this county and, what is more remarkable, the fact that 99 percent of this group was entirely without previous treatment. This combination, together with the expected cooperation of your hospital, offers an unparalleled opportunity for carrying on this piece of scientific research which probably cannot be duplicated anywhere else in the world.<sup>22</sup>

Although no formal protocol appears to have been written, several letters of Clark and Cumming suggest what the USPHS hoped to find. Clark indicated that it would be important to see how disease affected the daily lives of the men:

The results of these studies of case records suggest the desirability of making a further study of the effect of untreated syphilis on the human economy among people now living and engaged in their daily pursuits.<sup>23</sup>

It also seems that the USPHS believed the experiment might demonstrate that antisyphilitic treatment was unnecessary. As Cumming noted: “It is expected the results of this study may have a marked bearing on the treatment, or conversely the non-necessity of treatment, of cases of latent syphilis.”<sup>24</sup>

The immediate source of Cumming’s hypothesis appears to have been the famous Oslo Study of untreated syphilis. Between 1890 and 1910, Professor C. Boeck, the chief of the Oslo Venereal Clinic, withheld treatment from almost two thousand patients infected with syphilis. He was convinced that therapies then available, primarily mercurial ointment, were of no value. When arsenic therapy became widely available by 1910, after Paul Ehrlich’s historic discovery of “606,” the study was abandoned. E. Bruusgaard, Boeck’s successor, conducted a follow-up study of 473 of the untreated patients from 1925 to 1927. He found that 27.9 percent of these patients had undergone a “spontaneous cure,” and now manifested no symptoms of the disease. Moreover, he estimated that as many as 70 percent of all

syphilitics went through life without inconvenience from the disease.<sup>25</sup> His study, however, clearly acknowledged the dangers of untreated syphilis for the remaining 30 percent.

Thus every major textbook of syphilis at the time of the Tuskegee Study's inception strongly advocated treating syphilis even in its latent stages, which follow the initial inflammatory reaction. In discussing the Oslo Study, Dr. J. E. Moore, one of the nation's leading venereologists wrote, "This summary of Bruusgaard's study is by no means intended to suggest that syphilis be allowed to pass untreated."<sup>26</sup> If a complete cure could not be effected, at least the most devastating effects of the disease could be avoided. Although the standard therapies of the time, arsenical compounds and bismuth injection, involved certain dangers because of their toxicity, the alternatives were much worse. As the Oslo Study had shown, untreated syphilis could lead to cardiovascular disease, insanity, and premature death.<sup>27</sup> Moore wrote in his 1933 textbook:

Though it imposes a slight though measurable risk of its own, treatment markedly diminishes the risk from syphilis. In latent syphilis, as I shall show, the probability of progression, relapse, or death is reduced from a probable 25–30 percent without treatment to about 5 percent with it; and the gravity of the relapse if it occurs, is markedly diminished.<sup>28</sup>

"Another compelling reason for treatment," noted Moore, "exists in the fact that every patient with latent syphilis may be, and perhaps is, infectious for others."<sup>29</sup> In 1932, the year in which the Tuskegee Study began, the USPHS sponsored and published a paper by Moore and six other syphilis experts that strongly argued for treating latent syphilis.<sup>30</sup>

The Oslo Study, therefore, could not have provided justification for the USPHS to undertake a study that did not entail treatment. Rather, the suppositions that conditions in Tuskegee existed "naturally" and that the men would not be treated anyway provided the experiment's rationale. In turn, these two assumptions rested on the prevailing medical attitudes concerning blacks, sex, and disease. For example, Clark explained the prevalence of venereal disease in Macon County by emphasizing promiscuity among blacks:

This state of affairs is due to the paucity of doctors, rather low intelligence of the Negro population in this section, depressed economic conditions, and the very common promiscuous sex relations of this population group which not only contribute to the spread of syphilis but also contribute to the prevailing indifference with regard to treatment.<sup>31</sup>

In fact, Moore, who had written so persuasively in favor of treating latent syphilis, suggested that existing knowledge did not apply to Negroes. Although he had called the Oslo Study "a never-to-be-repeated human experiment,"<sup>32</sup> he served as an expert consultant to the Tuskegee Study:

I think that such a study as you have contemplated would be of immense value. It will be necessary of course in the consideration of the results to evaluate the special factors introduced by a selection of the material from negro males. Syphilis in the negro is in many respects almost a different disease from syphilis in the white.<sup>33</sup>

Dr. O. C. Wenger, chief of the federally operated venereal disease clinic at Hot Springs, Arkansas, praised Moore's judgment, adding, "This study will emphasize those differences."<sup>34</sup> On another occasion he advised Clark, "We must remember we are dealing with a group of people who are illiterate, have no conception of time, and whose personal history is always indefinite."<sup>35</sup>

The doctors who devised and directed the Tuskegee Study accepted the mainstream assumptions regarding blacks and venereal disease. The premise that blacks, promiscuous and lustful, would not seek or continue treatment, shaped the study. A test of untreated syphilis seemed "natural" because the USPHS presumed the men would never be treated; the Tuskegee Study made that a self-fulfilling prophecy.

### Selecting the Subjects

Clark sent Dr. Raymond Vonderlehr to Tuskegee in September 1932 to assemble a sample of men with latent syphilis for the experiment. The basic design of the study called for the selection of syphilitic black males between the ages of twenty-five and sixty, a thorough physical examination including x-rays, and finally, a spinal tap to determine the

incidence of neuro-syphilis.<sup>36</sup> They had no intention of providing any treatment for the infected men.<sup>37</sup> The USPHS originally scheduled the whole experiment to last six months; it seemed to be both a simple and inexpensive project.

The task of collecting the sample, however, proved to be more difficult than the USPHS had supposed. Vonderlehr canvassed the largely illiterate, poverty-stricken population of sharecroppers and tenant farmers in search of test subjects. If his circulars requested only men over twenty-five to attend his clinics, none would appear, suspecting he was conducting draft physicals. Therefore, he was forced to test large numbers of women and men who did not fit the experiment's specifications. This involved considerable expense since the USPHS had promised the Macon County Board of Health that it would treat those who were infected, but not included in the study.<sup>38</sup> Clark wrote to Vonderlehr about the situation: "It never once occurred to me that we would be called upon to treat a large part of the county as return for the privilege of making this study. . . . I am anxious to keep the expenditures for treatment down to the lowest possible point because it is the one item of expenditure in connection with the study most difficult to defend despite our knowledge of the need therefor."<sup>39</sup> Vonderlehr responded: "If we could find from 100 to 200 cases . . . we would not have to do another Wassermann on useless individuals . . ."<sup>40</sup>

Significantly, the attempt to develop the sample contradicted the prediction the USPHS had made initially regarding the prevalence of the disease in Macon County. Overall rates of syphilis fell well below expectations; as opposed to the USPHS projection of 35 percent, 20 percent of those tested were actually diseased.<sup>41</sup> Moreover, those who had sought and received previous treatment far exceeded the expectations of the USPHS. Clark noted in a letter to Vonderlehr:

I find your report of March 6th quite interesting but regret the necessity for Wassermanning [sic] . . . such a large number of individuals in order to uncover this relatively limited number of untreated cases.<sup>42</sup>

Further difficulties arose in enlisting the subjects to participate in the experiment, to be

"Wassermannned," and to return for a subsequent series of examinations. Vonderlehr found that only the offer of treatment elicited the cooperation of the men. They were told they were ill and were promised free care. Offered therapy, they became willing subjects.<sup>43</sup> The USPHS did not tell the men that they were participants in an experiment; on the contrary, the subjects believed they were being treated for "bad blood"—the rural South's colloquialism for syphilis. They thought they were participating in a public health demonstration similar to the one that had been conducted by the Julius Rosenwald Fund in Tuskegee several years earlier. In the end, the men were so eager for medical care that the number of defaulters in the experiment proved to be insignificant.<sup>44</sup>

To preserve the subjects' interest, Vonderlehr gave most of the men mercurial ointment, a non-effective drug, while some of the younger men apparently received inadequate dosages of neoarsphenamine.<sup>45</sup> This required Vonderlehr to write frequently to Clark requesting supplies. He feared the experiment would fail if the men were not offered treatment.

It is desirable and essential if the study is to be a success to maintain the interest of each of the cases examined by me through to the time when the spinal puncture can be completed. Expenditure of several hundred dollars for drugs for these men would be well worth while if their interest and co-operation would be maintained in so doing. . . . It is my desire to keep the main purpose of the work from the negroes in the county and continue their interest in treatment. That is what the vast majority wants and the examination seems relatively unimportant to them in comparison. It would probably cause the entire experiment to collapse if the clinics were stopped before the work is completed.<sup>46</sup>

On another occasion he explained:

Dozens of patients have been sent away without treatment during the past two weeks and it would have been impossible to continue without the free distribution of drugs because of the unfavorable impression made on the negro.<sup>47</sup>

The readiness of the test subjects to participate of course contradicted the notion that blacks would not seek or continue therapy.

The final procedure of the experiment was to be a spinal tap to test for evidence of neuro-syphilis. The USPHS presented this purely diagnostic exam, which often entails considerable pain and complications, to the men as a "special treatment." Clark explained to Moore:

We have not yet commenced the spinal punctures. This operation will be deferred to the last in order not to unduly disturb our field work by any adverse reports by the patients subjected to spinal puncture because of some disagreeable sensations following this procedure. These negroes are very ignorant and easily influenced by things that would be of minor significance in a more intelligent group.<sup>48</sup>

The letter to the subjects announcing the spinal tap read:

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it. . . .

**REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT. BE SURE TO MEET THE NURSE.**<sup>49</sup>

The HEW investigation did not uncover this crucial fact: the men participated in the study under the guise of treatment.

Despite the fact that their assumption regarding prevalence and black attitudes toward treatment had proved wrong, the USPHS decided in the summer of 1933 to continue the study. Once again, it seemed only "natural" to pursue the research since the sample already existed, and with a depressed economy, the cost of treatment appeared prohibitive—although there is no indication it was ever considered. Vonderlehr first suggested extending the study in letters to Clark and Wenger:

At the end of this project we shall have a considerable number of cases presenting various complications of syphilis, who have received only mercury and may still be considered untreated in the modern sense of therapy. Should these cases be followed over a period of from five to ten years many interesting facts could be learned regarding the course and complications of untreated syphilis.<sup>50</sup>

"As I see it," responded Wenger, "we have no further interest in these patients *until they die.*"<sup>51</sup> Apparently, the physicians engaged in the experiment believed that only autopsies could scientifically confirm the findings of the study. Surgeon General Cumming explained this in a letter to R. R. Moton, requesting the continued cooperation of the Tuskegee Institute Hospital:

This study which was predominantly clinical in character points to the frequent occurrence of severe complications involving the various vital organs of the body and indicates that syphilis as a disease does a great deal of damage. Since clinical observations are not considered final in the medical world, it is our desire to continue observation on the cases selected for the recent study and if possible to bring a percentage of these cases to autopsy so that pathological confirmation may be made of the disease processes.<sup>52</sup>

Bringing the men to autopsy required the USPHS to devise a further series of deceptions and inducements. Wenger warned Vonderlehr that the men must not realize that they would be autopsied:

There is one danger in the latter plan and that is if the colored population become aware that accepting free hospital care means a post-mortem, every darkey will leave Macon County and it will hurt [Dr. Eugene] Dibble's hospital.<sup>53</sup>

"Naturally," responded Vonderlehr, "it is not my intention to let it be generally known that the main object of the present activities is the bringing of the men to necropsy."<sup>54</sup> The subjects' trust in the USPHS made the plan viable. The USPHS gave Dr. Dibble, the Director of the Tuskegee Institute Hospital, an interim appointment to the Public Health Service. As Wenger noted:

One thing is certain. The only way we are going to get post-mortems is to have the demise take place in Dibble's hospital and when these colored folks are told that Doctor Dibble is now a Government doctor too they will have more confidence.<sup>55\*</sup>

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\* The degree of black cooperation in conducting the study remains unclear and would be impossible to properly assess in an article of this length. It seems certain that some members of the Tuskegee Institute staff such as R. R. Moton and Eugene Dibble understood the nature of the experiment

After the USPHS approved the continuation of the experiment in 1933, Vonderlehr decided that it would be necessary to select a group of healthy, uninfected men to serve as controls. Vonderlehr, who had succeeded Clark as Chief of the Venereal Disease Division, sent Dr. J. R. Heller to Tuskegee to gather the control group. Heller distributed drugs (noneffective) to these men, which suggests that they also believed they were undergoing treatment.<sup>56</sup> Control subjects who became syphilitic were simply transferred to the test group—a strikingly inept violation of standard research procedure.<sup>57</sup>

The USPHS offered several inducements to maintain contact and to procure the continued cooperation of the men. Eunice Rivers, a black nurse, was hired to follow their health and to secure approval for autopsies. She gave the men noneffective medicines—“spring tonic” and aspirin—as well as transportation and hot meals on the days of their examinations.<sup>58</sup> More important, Nurse Rivers provided continuity to the project over the entire forty-year period. By supplying “medicinals,” the USPHS was able to continue to deceive the participants, who believed that they were receiving therapy from the government doctors. Deceit was integral to the study. When the test subjects complained about spinal taps one doctor wrote:

They simply do not like spinal punctures. A few of those who were tapped are enthusiastic over the

and gave their support to it. There is, however, evidence that some blacks who assisted the USPHS physicians were not aware of the deceptive nature of the experiment. Dr. Joshua Williams, an intern at the John A. Andrew Memorial Hospital (Tuskegee Institute) in 1932, assisted Vonderlehr in taking blood samples of the test subjects. In 1973 he told the HEW panel: “I know we thought it was merely a service group organized to help the people in the area. We didn’t know it was a research project at all at the time.” (See “Transcript of Proceedings,” Tuskegee Syphilis Study Ad Hoc Advisory Panel, February 23, 1973, unpublished typescript. National Library of Medicine, Bethesda, Maryland.) It is also apparent that Eunice Rivers, the black nurse who had primary responsibility for maintaining contact with the men over the forty years, did not fully understand the dangers of the experiment. In any event, black involvement in the study in no way mitigates the racial assumptions of the experiment, but rather, demonstrates their power.

results but to most, the suggestion causes violent shaking of the head; others claim they were robbed of their procreative powers (regardless of the fact that I claim it stimulates them).<sup>59</sup>

Letters to the subjects announcing an impending USPHS visit to Tuskegee explained: “[The doctor] wants to make a special examination to find out how you have been feeling and whether the treatment has improved your health.”<sup>60</sup> In fact, after the first six months of the study, the USPHS had furnished no treatment whatsoever.

Finally, because it proved difficult to persuade the men to come to the hospital when they became severely ill, the USPHS promised to cover their burial expenses. The Milbank Memorial Fund provided approximately \$50 per man for this purpose beginning in 1935. This was a particularly strong inducement as funeral rites constituted an important component of the cultural life of rural blacks.<sup>61</sup> One report of the study concluded, “Without this suasion it would, we believe, have been impossible to secure the cooperation of the group and their families.”<sup>62</sup>

Reports of the study’s findings, which appeared regularly in the medical press beginning in 1936, consistently cited the ravages of untreated syphilis. The first paper, read at the 1936 American Medical Association annual meeting, found “that syphilis in this period [latency] tends to greatly increase the frequency of manifestations of cardiovascular disease.”<sup>63</sup> Only 16 percent of the subjects gave no sign of morbidity as opposed to 61 percent of the controls. Ten years later, a report noted coldly, “The fact that nearly twice as large a proportion of the syphilitic individuals as of the control group has died is a very striking one.” Life expectancy, concluded the doctors, is reduced by about 20 percent.<sup>64</sup>

A 1955 article found that slightly more than 30 percent of the test group autopsied had died directly from advanced syphilitic lesions of either the cardiovascular or the central nervous system.<sup>65</sup> Another published account stated, “Review of those still living reveals that an appreciable number have late complications of syphilis which probably will result, for some at least, in contributing materially to the ultimate cause of death.”<sup>66</sup> In 1950, Dr. Wenger had concluded, “We now know, where we could

only surmise before, that we have contributed to their ailments and shortened their lives.”<sup>67</sup> As black physician Vernal Cave, a member of the HEW panel, later wrote, “They proved a point, then proved a point, then proved a point.”<sup>68</sup>

During the forty years of the experiment the USPHS had sought on several occasions to ensure that the subjects did not receive treatment from other sources. To this end, Vonderlehr met with groups of local black doctors in 1934, to ask their cooperation in not treating the men. Lists of subjects were distributed to Macon County physicians along with letters requesting them to refer these men back to the USPHS if they sought care.<sup>69</sup> The USPHS warned the Alabama Health Department not to treat the test subjects when they took a mobile VD unit into Tuskegee in the early 1940s.<sup>70</sup> In 1941, the Army drafted several subjects and told them to begin antisyphilitic treatment immediately. The USPHS supplied the draft board with a list of 256 names they desired to have excluded from treatment, and the board complied.<sup>71</sup>

In spite of these efforts, by the early 1950s many of the men had secured some treatment on their own. By 1952, almost 30 percent of the test subjects had received some penicillin, although only 7.5 percent had received what could be considered adequate doses.<sup>72</sup> Vonderlehr wrote to one of the participating physicians, “I hope that the availability of antibiotics has not interfered too much with this project.”<sup>73</sup> A report published in 1955 considered whether the treatment that some of the men had obtained had “defeated” the study. The article attempted to explain the relatively low exposure to penicillin in an age of antibiotics, suggesting as a reason: “the stoicism of these men as a group; they still regard hospitals and medicines with suspicion and prefer an occasional dose of time-honored herbs or tonics to modern drugs.”<sup>74</sup> The authors failed to note that the men believed they already were under the care of the government doctors and thus saw no need to seek treatment elsewhere. Any treatment which the men might have received, concluded the report, had been insufficient to compromise the experiment.

When the USPHS evaluated the status of the study in the 1960s they continued to rationalize the

racial aspects of the experiment. For example, the minutes of a 1965 meeting at the Center for Disease Control recorded:

Racial issue was mentioned briefly. Will not affect the study. Any questions can be handled by saying these people were at the point that therapy would no longer help them. They are getting better medical care than they would under any other circumstances.<sup>75</sup>

A group of physicians met again at the CDC in 1969 to decide whether or not to terminate the study. Although one doctor argued that the study should be stopped and the men treated, the consensus was to continue. Dr. J. Lawton Smith remarked, “You will never have another study like this; take advantage of it.”<sup>76</sup> A memo prepared by Dr. James B. Lucas, Assistant Chief of the Venereal Disease Branch, stated: “Nothing learned will prevent, find, or cure a single case of infectious syphilis or bring us closer to our basic mission of controlling venereal disease in the United States.”<sup>77</sup> He concluded, however, that the study should be continued “along its present lines.” When the first accounts of the experiment appeared in the national press in July 1972, data were still being collected and autopsies performed.<sup>78</sup>

### The HEW Final Report

HEW finally formed the Tuskegee Syphilis Study Ad Hoc Advisory Panel on August 28, 1972, in response to criticism that the press descriptions of the experiment had triggered. The panel, composed of nine members, five of them black, concentrated on two issues. First, was the study justified in 1932 and had the men given their informed consent? Second, should penicillin have been provided when it became available in the early 1950s? The panel was also charged with determining if the study should be terminated and assessing current policies regarding experimentation with human subjects.<sup>79</sup> The group issued their report in June 1973.

By focusing on the issues of penicillin therapy and informed consent, the *Final Report* and the investigation betrayed a basic misunderstanding of the experiment’s purposes and design. The HEW report implied that the failure to provide penicillin constituted the study’s major ethical misjudgment;

implicit was the assumption that no adequate therapy existed prior to penicillin. Nonetheless medical authorities firmly believed in the efficacy of arsenotherapy for treating syphilis at the time of the experiment's inception in 1932. The panel further failed to recognize that the entire study had been predicated on nontreatment. Provision of effective medication would have violated the rationale of the experiment—to study the natural course of the disease until death. On several occasions, in fact, the USPHS had prevented the men from receiving proper treatment. Indeed, there is no evidence that the USPHS ever considered providing penicillin.

The other focus of the *Final Report*—informed consent—also served to obscure the historical facts of the experiment. In light of the deceptions and exploitations which the experiment perpetrated, it is an understatement to declare, as the *Report* did, that the experiment was “ethically unjustified,” because it failed to obtain informed consent from the subjects. The *Final Report*'s statement, “Submitting voluntarily is not informed consent,” indicated that the panel believed that the men had volunteered *for the experiment*.<sup>80</sup> The records in the National Archives make clear that the men did not submit voluntarily to an experiment; they were told and they believed that they were getting free treatment from expert government doctors for a serious disease. The failure of the HEW *Final Report* to expose this critical fact—that the USPHS lied to the subjects—calls into question the thoroughness and credibility of their investigation.

Failure to place the study in a historical context also made it impossible for the investigation to deal with the essentially racist nature of the experiment. The panel treated the study as an aberration, well-intentioned but misguided.<sup>81</sup> Moreover, concern that the *Final Report* might be viewed as a critique of human experimentation in general seems to have severely limited the scope of the inquiry. The *Final Report* is quick to remind the reader on two occasions: “The position of the Panel must not be construed to be a general repudiation of scientific research with human subjects.”<sup>82</sup> The *Report* assures us that a better designed experiment could have been justified:

It is possible that a scientific study in 1932 of untreated syphilis, properly conceived with a clear protocol and conducted with suitable subjects who fully understood the implications of their involvement, might have been justified in the pre-penicillin era. This is especially true when one considers the uncertain nature of the results of treatment of late latent syphilis and the highly toxic nature of therapeutic agents then available.<sup>83</sup>

This statement is questionable in view of the proven dangers of untreated syphilis known in 1932.

Since the publication of the HEW *Final Report*, a defense of the Tuskegee Study has emerged. These arguments, most clearly articulated by Dr. R. H. Kampmeier in the *Southern Medical Journal*, center on the limited knowledge of effective therapy for latent syphilis when the experiment began. Kampmeier argues that by 1950, penicillin would have been of no value for these men.<sup>84</sup> Others have suggested that the men were fortunate to have been spared the highly toxic treatments of the earlier period.<sup>85</sup> Moreover, even these contemporary defenses assume that the men never would have been treated anyway. As Dr. Charles Barnett of Stanford University wrote in 1974, “The lack of treatment was not contrived by the USPHS but was an established fact of which they proposed to take advantage.”<sup>86</sup> Several doctors who participated in the study continued to justify the experiment. Dr. J. R. Heller, who on one occasion had referred to the test subjects as the “Ethiopian population,” told reporters in 1972:

I don't see why they should be shocked or horrified. There was no racial side to this. It just happened to be in a black community. I feel this was a perfectly straightforward study, perfectly ethical, with controls. Part of our mission as physicians is to find out what happens to individuals with disease and without disease.<sup>87</sup>

These apologies, as well as the HEW *Final Report*, ignore many of the essential ethical issues which the study poses. The Tuskegee Study reveals the persistence of beliefs within the medical profession about the nature of blacks, sex, and disease—beliefs that had tragic repercussions long after their alleged “scientific” bases were known to be incorrect. Most strikingly, the entire health of a community was

jeopardized by leaving a communicable disease untreated.<sup>88</sup> There can be little doubt that the Tuskegee researchers regarded their subjects as less than human.<sup>89</sup> As a result, the ethical canons of experimenting on human subjects were completely disregarded.

The study also raises significant questions about professional self-regulation and scientific bureaucracy. Once the USPHS decided to extend the experiment in the summer of 1933, it was unlikely that the test would be halted short of the men's deaths. The experiment was widely reported for forty years without evoking any significant protest within the medical community. Nor did any bureaucratic mechanism exist within the government for the periodic reassessment of the Tuskegee experiment's ethics and scientific value. The USPHS sent physicians to Tuskegee every several years to check on the study's progress, but never subjected the morality or usefulness of the experiment to serious scrutiny. Only the press accounts of 1972 finally punctured the continued rationalizations of the USPHS and brought the study to an end. Even the HEW investigation was compromised by fear that it would be considered a threat to future human experimentation.

In retrospect the Tuskegee Study revealed more about the pathology of racism than it did about the pathology of syphilis; more about the nature of scientific inquiry than the nature of the disease process. The injustice committed by the experiment went well beyond the facts outlined in the press and the HEW *Final Report*. The degree of deception and damages have been seriously underestimated. As this history of the study suggests, the notion that science is a value-free discipline must be rejected. The need for greater vigilance in assessing the specific ways in which social values and attitudes affect professional behavior is clearly indicated.

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26. Joseph Earle Moore, *The Modern Treatment of Syphilis* (Baltimore: Charles C. Thomas, 1933), p. 24.
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30. J. E. Moore, H. N. Cole, P. A. O'Leary, J. H. Stokes, U. J. Wile, T. Clark, T. Parran, J. H. Usilton, "Cooperative Clinical Studies in the Treatment of Syphilis: Latent Syphilis," *Venereal Disease Information* 13 (September 20, 1932), 351. The authors also concluded that the latently syphilitic were potential carriers of the disease, thus meriting treatment.
31. Clark to Paul A. O'Leary, September 27, 1932, NA-WNRC. O'Leary, of the Mayo Clinic, misunderstood the design of the study, replying: "The investigation which you are planning in Alabama is indeed an intriguing one, particularly because of the opportunity it affords of observing treatment in a previously untreated group. I assure you such a study is of interest to me, and I shall look forward to its report in the future." O'Leary to Clark, October 3, 1932, NA-WNRC.
32. Joseph Earle Moore, "Latent Syphilis," unpublished typescript (n.d.), p. 7. American Social Hygiene Association Papers, Social Welfare History Archives Center, University of Minnesota, Minneapolis, Minnesota.
33. Moore to Clark, September 28, 1932, NA-WNRC. Moore had written in his textbook, "In late syphilis the negro is particularly prone to the development of bone or cardiovascular lesions." See Moore, *The Modern Treatment of Syphilis*, p. 35.
34. O. C. Wenger to Clark, October 3, 1932, NA-WNRC.
35. Wenger to Clark, September 29, 1932, NA-WNRC.
36. Clark Memorandum, September 26, 1932, NA-WNRC. See also, Clark to Davis, October 29, 1932, NA-WNRC.
37. As Clark wrote: "You will observe that our plan has nothing to do with treatment. It is purely a diagnostic procedure carried out to determine what has happened to the syphilitic Negro who has had no treatment." Clark to Paul A. O'Leary, September 27, 1932, NA-WNRC.
38. D. G. Gill to O. C. Wenger, October 10, 1932, NA-WNRC.
39. Clark to Vonderlehr, January 25, 1933, NA-WNRC.

40. Vonderlehr to Clark, February 28, 1933, NA-WNRC.
41. Vonderlehr to Clark, November 2, 1932, NA-WNRC. Also, Vonderlehr to Clark, February 6, 1933, NA-WNRC.
42. Clark to Vonderlehr, March 9, 1933, NA-WNRC.
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52. Cumming to Moton, July 27, 1933, NA-WNRC.
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86. Quoted in "Debate Revives on the PHS Study," *Medical World News* (April 19, 1974), p. 37.
87. Heller to Vonderlehr, November 28, 1933, NA-WNRC; quoted in *Medical Tribune* (August 23, 1972), p. 14.
88. Although it is now known that syphilis is rarely infectious after its early phase, at the time of the study's inception latent syphilis was thought to be communicable. The fact that members of the control group were placed in the test group when they became syphilitic proves that at least some infectious men were denied treatment.
89. When the subjects are drawn from minority groups, especially those with which the researcher cannot identify, basic human rights may be compromised. Hans Jonas has clearly explicated the problem in his "Philosophical Reflections on Experimentation," *Daedalus* 98 (Spring 1969), 234–37. As Jonas writes: "If the properties we adduced as the particular qualifications of the members of the scientific fraternity itself are taken as general criteria of selection, then one should look for additional subjects where a maximum of identification, understanding, and spontaneity can be expected—that is, among the most highly motivated, the most highly educated, and the least 'captive' members of the community."

## The Ethics of Clinical Research in the Third World

MARCIANGELL

Angell maintains that randomized clinical trials comparing two treatments are morally permissible only when investigators are in a state of equipoise—that is, when there is "no good reason for thinking one [treatment] is better than another." So studies comparing a potential new treatment with a placebo are unethical if an effective treatment exists. If there is an effective treatment, subjects in the control group must receive the best known treatment. By this standard, some ongoing trials in the Third World must be judged impermissible—namely, the trials testing regimens to prevent the mother–infant transmission of HIV infection. The studies use placebo control groups even though a proven preventive exists. Angell concludes that the research community needs to bolster its commitment to the highest ethical standards "no matter where the research is conducted."

An essential ethical condition for a randomized clinical trial comparing two treatments for a disease is that there be no good reason for thinking

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one is better than the other.<sup>1,2</sup> Usually, investigators hope and even expect that the new treatment will be better, but there should not be solid evidence one way or the other. If there is, not only would the trial be scientifically redundant, but the investigators would be guilty of knowingly giving inferior treatment to some participants in the trial. The necessity

for investigators to be in this state of equipoise,<sup>2</sup> applies to placebo-controlled trials, as well. Only when there is no known effective treatment is it ethical to compare a potential new treatment with a placebo. When effective treatment exists, a placebo may not be used. Instead, subjects in the control group of the study must receive the best known treatment. Investigators are responsible for all subjects enrolled in a trial, not just some of them, and the goals of the research are always secondary to the well-being of the participants. Those requirements are made clear in the Declaration of Helsinki of the World Health Organization (WHO), which is widely regarded as providing the fundamental guiding principles of research involving human subjects.<sup>3</sup> It states, “In research on man [sic], the interest of science and society should never take precedence over considerations related to the well-being of the subject,” and “In any medical study, every patient—including those of a control group, if any—should be assured of the best proven diagnostic and therapeutic method.”

One reason ethical codes are unequivocal about investigators’ primary obligation to care for the human subjects of their research is the strong temptation to subordinate the subjects’ welfare to the objectives of the study. That is particularly likely when the research question is extremely important and the answer would probably improve the care of future patients substantially. In those circumstances, it is sometimes argued explicitly that obtaining a rapid, unambiguous answer to the research question is the primary ethical obligation. With the most altruistic of motives, then, researchers may find themselves slipping across a line that prohibits treating human subjects as means to an end. When that line is crossed, there is very little left to protect patients from a callous disregard of their welfare for the sake of research goals. Even informed consent, important though it is, is not protection enough, because of the asymmetry in knowledge and authority between researchers and their subjects. And approval by an institutional review board, though also important, is highly variable in its responsiveness to patients’ interests when they conflict with the interests of researchers.

A textbook example of unethical research is the Tuskegee Study of Untreated Syphilis.<sup>4</sup> In that study, which was sponsored by the U.S. Public Health Service and lasted from 1932 to 1972, 412 poor African-American men with untreated syphilis were followed and compared with 204 men free of the disease to determine the natural history of syphilis. Although there was no very good treatment available at the time the study began (heavy metals were the standard treatment), the research continued even after penicillin became widely available and was known to be highly effective against syphilis. The study was not terminated until it came to the attention of a reporter and the outrage provoked by front-page stories in the *Washington Star* and *New York Times* embarrassed the Nixon administration into calling a halt to it.<sup>5</sup> The ethical violations were multiple: Subjects did not provide informed consent (indeed, they were deliberately deceived); they were denied the best known treatment; and the study was continued even after highly effective treatment became available. And what were the arguments in favor of the Tuskegee study? That these poor African-American men probably would not have been treated anyway, so the investigators were merely observing what would have happened if there were no study; and that the study was important (a “never-to-be-repeated opportunity,” said one physician after penicillin became available).<sup>6</sup> Ethical concern was even stood on its head when it was suggested that not only was the information valuable, but it was especially so for people like the subjects—an impoverished rural population with a very high rate of untreated syphilis. The only lament seemed to be that many of the subjects inadvertently received treatment by other doctors.

Some of these issues are raised by Lurie and Wolfe elsewhere. They discuss the ethics of ongoing trials in the Third World of regimens to prevent the vertical transmission of human immunodeficiency virus (HIV) infection.<sup>7</sup> All except one of the trials employ placebo-treated control groups, despite the fact that zidovudine has already been clearly shown to cut the rate of vertical transmission greatly and is now recommended in the United States for all HIV-infected pregnant women. The justifications are

reminiscent of those for the Tuskegee study: Women in the Third World would not receive anti-retroviral treatment anyway, so the investigators are simply observing what would happen to the subjects' infants if there were no study. And a placebo-controlled study is the fastest, most efficient way to obtain unambiguous information that will be of greatest value in the Third World. Thus, in response to protests from Wolfe and others to the secretary of Health and Human Services, the directors of the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC)—the organizations sponsoring the studies—argued, "It is an unfortunate fact that the current standard of perinatal care for the HIV-infected pregnant women in the sites of the studies does not include any HIV prophylactic intervention at all," and the inclusion of placebo controls "will result in the most rapid, accurate, and reliable answer to the question of the value of the intervention being studied compared to the local standard of care."<sup>8</sup>

Whalen et al. report the results of a clinical trial in Uganda of various regimens of prophylaxis against tuberculosis in HIV-infected adults, most of whom had positive tuberculin skin tests.<sup>9</sup> This study, too, employed a placebo-treated control group, and in some ways it is analogous to the studies criticized by Lurie and Wolfe. In the United States it would probably be impossible to carry out such a study, because of long-standing official recommendations that HIV-infected persons with positive tuberculin skin tests receive prophylaxis against tuberculosis. The first was issued in 1990 by the CDC's Advisory Committee for Elimination of Tuberculosis.<sup>10</sup> It stated that tuberculin-test-positive persons with HIV infection "should be considered candidates for preventive therapy." Three years later, the recommendation was reiterated more strongly in a joint statement by the American Thoracic Society and the CDC, in collaboration with the Infectious Diseases Society of America and the American Academy of Pediatrics.<sup>11</sup> According to this statement, ". . . the identification of persons with dual infection and the administration of preventive therapy to these persons is of great importance." However, some believe that these recommendations were premature, since they were

based largely on the success of prophylaxis in HIV-negative persons.<sup>12</sup>

Whether the study by Whalen et al. was ethical depends, in my view, entirely on the strength of the preexisting evidence. Only if there was genuine doubt about the benefits of prophylaxis would a placebo group be ethically justified. This is not the place to review the scientific evidence, some of which is discussed in the editorial of Msamanga and Fawzi.<sup>13</sup> Suffice it to say that the case is debatable. Msamanga and Fawzi conclude that "future studies should not include a placebo group, since preventive therapy should be considered the standard of care." I agree. The difficult question is whether there should have been a placebo group in the first place.

Although I believe an argument can be made that a placebo-controlled trial was ethically justifiable because it was still uncertain whether prophylaxis would work, it should not be argued that it was ethical because no prophylaxis is the "local standard of care" in sub-Saharan Africa. For reasons discussed by Lurie and Wolfe, that reasoning is badly flawed.<sup>7</sup> As mentioned earlier, the Declaration of Helsinki requires control groups to receive the "best" current treatment, not the local one. The shift in wording between "best" and "local" may be slight, but the implications are profound. Acceptance of this ethical relativism could result in widespread exploitation of vulnerable Third World populations for research programs that could not be carried out in the sponsoring country.<sup>14</sup> Furthermore, it directly contradicts the Department of Health and Human Services' own regulations governing U.S.-sponsored research in foreign countries,<sup>15</sup> as well as joint guidelines for research in the Third World issued by WHO and the Council for International Organizations of Medical Sciences,<sup>16</sup> which require that human subjects receive protection at least equivalent to that in the sponsoring country. The fact that Whalen et al. offered isoniazid to the placebo group when it was found superior to placebo indicates that they were aware of their responsibility to all the subjects in the trial.

The *Journal* has taken the position that it will not publish reports of unethical research, regardless of their scientific merit.<sup>14,17</sup> After deliberating at length

about the study by Whalen et al., the editors concluded that publication was ethically justified, although there remain differences among us. The fact that the subjects gave informed consent and the study was approved by the institutional review board at the University Hospitals of Cleveland and Case Western Reserve University and by the Ugandan National AIDS Research Subcommittee certainly supported our decision but did not allay all our misgivings. It is still important to determine whether clinical studies are consistent with preexisting, widely accepted ethical guidelines, such as the Declaration of Helsinki, and with federal regulations, since they cannot be influenced by pressures specific to a particular study.

Quite apart from the merits of the study by Whalen et al., there is a larger issue. There appears to be a general retreat from the clear principles enunciated in the Nuremberg Code and the Declaration of Helsinki as applied to research in the Third World. Why is that? Is it because the "local standard of care" is different? I don't think so. In my view, that is merely a self-serving justification after the fact. Is it because diseases and their treatments are very different in the Third World, so that information gained in the industrialized world has no relevance and we have to start from scratch? That, too, seems an unlikely explanation, although here again it is often offered as a justification. Sometimes there may be relevant differences between populations, but that cannot be assumed. Unless there are specific indications to the contrary, the safest and most reasonable position is that people everywhere are likely to respond similarly to the same treatment.

I think we have to look elsewhere for the real reasons. One of them may be a slavish adherence to the tenets of clinical trials. According to these, all trials should be randomized, double-blind, and placebo-controlled, if at all possible. That rigidity may explain the NIH's pressure on Marc Lallement to include a placebo group in his study, as described by Lurie and Wolfe.<sup>7</sup> Sometimes journals are blamed for the problem, because they are thought to demand strict conformity to the standard methods. That is not true, at least not at this journal. We do not want a scientifically neat study if it is ethically

flawed, but like Lurie and Wolfe we believe that in many cases it is possible, with a little ingenuity, to have both scientific and ethical rigor.

The retreat from ethical principles may also be explained by some of the exigencies of doing clinical research in an increasingly regulated and competitive environment. Research in the Third World looks relatively attractive as it becomes better funded and regulations at home become more restrictive. Despite the existence of codes requiring that human subjects receive at least the same protection abroad as at home, they are still honored partly in the breach. The fact remains that many studies are done in the Third World that simply could not be done in the countries sponsoring the work. Clinical trials have become a big business, with many of the same imperatives. To survive, it is necessary to get the work done as quickly as possible, with a minimum of obstacles. When these considerations prevail, it seems as if we have not come very far from Tuskegee after all. Those of us in the research community need to redouble our commitment to the highest ethical standards, no matter where the research is conducted, and sponsoring agencies need to enforce those standards, not undercut them.

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## Ethical Issues in Clinical Trials in Developing Countries

BARUCH BRODY

Brody responds to major doubts raised about the ethics of some Third World clinical trials conducted to evaluate a regimen to prevent mother-to-infant transmission of HIV. He argues that the use of placebo control groups was ethical because no subjects were denied "any treatment that should otherwise be available to him or her in light of the practical realities of health care resources available in the country in question." According to a reasonable understanding of coercion, he says, no subjects were coerced into participating in the trials. Finally, some have claimed that the trials exploit developing countries "because the interventions in question, even if proven successful, will not be available in these countries." But such trials will not be exploitative, Brody says, if after the studies the subjects themselves are given access to any treatment proven effective.

Since the publication of the results of AIDS Clinical Trials Group (ACTG) 076, it has been known that an extensive regimen of Zidovudine provided to the mother and to the newborn can drastically reduce (25.5 to 8.3 percent) the vertical transmission of HIV.<sup>1</sup> Unfortunately, the regimen in question is quite expensive and beyond the means of most developing countries, some of which are the countries

most in need of effective techniques for reducing vertical transmission. This realization led to a series of important clinical trials designed to test the effectiveness of less extensive and less expensive regimens of antiretroviral drugs. These trials were conducted by researchers from developed countries in the developing countries which were in need of these less expensive regimens.

These new trials have been very successful. The Thai CDC trial showed a 50 percent reduction (18.9 to 9.4 percent) in transmission from a much shorter antepartum regimen of Zidovudine combined with

a more modest intrapartum regimen.<sup>2</sup> The PETRA trial showed that Zidovudine and Lamivudine provided in modest intrapartum and postpartum regimens also significantly reduced transmission, whether or not they were provided antepartum.<sup>3</sup> There was a trend to more reduction of transmission if they were provided in a short antepartum regimen (16.5 to 7.8 percent) than if they were not (16.5 to 10.8 percent). Most crucially, there was no reduction (16.5 to 15.7 percent) if they were not provided postpartum. Finally, a single dose of nevirapine provided intrapartum and postpartum was shown in HIVNET 012 to significantly reduce transmission (21.3 to 11.9 percent).<sup>4</sup> In all cases except HIVNET 012, the control group received only a placebo. In HIVNET 012, the control group received a modest regimen of intrapartum and postpartum Zidovudine.

As a result of these trials, developing countries with some financial capabilities have the opportunity to drastically reduce vertical transmission by proven less expensive regimens. This constitutes an important contribution of these trials. Unfortunately, the poorest developing countries (including some in which these trials have been run) may not be able to afford even these shorter regimens unless the drugs in question are priced far less expensively for those countries. Efforts have begun to make that possible.<sup>5</sup>

There have been many critics of these trials who have argued that they were unethical. Some have gone on to attempt to explain how the information might have been obtained in other more ethical trials while others have not. My focus in this paper is not on that question. Instead, *I want to focus on the arguments offered in support of the claim that these trials were unethical.* I see the critics as advancing three very different criticisms, although the critics often do not carefully distinguish them. We will do so to enable each criticism to be analyzed. The *first criticism* is that an *injustice was done to the control group* in each of these trials (with perhaps the exception of HIVNET 012) since they were denied proven effective therapy as they only received a placebo. The *second criticism* is that the *participants in the trial were coerced into participating*, and did not give voluntary consent, because

they had no real choice about participating since antiretroviral therapy was otherwise unavailable to them. The *third criticism* is that the *countries in question were exploited* by the investigators from the developed countries since they were testing the effectiveness of regimens that would not be available after the trial to the citizens of the countries in which the trials were conducted.

### **The Justice of the Use of the Placebo Control Group**

The scientific importance of the use of concurrent placebo control groups is well illustrated by the PETRA trial. If there had been no such control group, and the various regimens had been compared to the historical control group in ACTG 076, then the intrapartum only arm would have been judged a success, since its transmission rate was only 15.7 percent as compared to the 25.5 percent transmission rate in the control group in ACTG 076. But it actually was no better than the placebo control group in PETRA (16.5 percent). When the rate of transmission varies from one setting to another, you really cannot use historical control groups. Despite this scientific value, the critics have argued that it was wrong to use a placebo control arm because the patients in that arm were being denied a proven therapy (the 076 regimen) and were being offered nothing in its place.<sup>6</sup> The critics claim that this did not meet the standard found in *earlier versions* of the Declaration at Helsinki: "In any medical study, every patient, including those of a control group, if any, should be assured of the best proven diagnostic and therapeutic method."<sup>7</sup>

Defenders of these trials quite properly note that none of the participants in these trials would otherwise have received any antiretroviral therapy, so nothing was being denied to them that they would otherwise have received. How then, ask the defenders, can the members of the control group have been treated unjustly? This led to a proposed, very controversial and eventually rejected, revision of the Declaration of Helsinki which read: "In any biomedical research protocol every patient-subject, including those of a control group, if any, should be assured that he or she will not be denied access to the best proven diagnostic, prophylactic, or

therapeutic method that would otherwise be available to him or her.”<sup>8</sup> The point is then that the justice or injustice of what is done to the control group depends on what the members of that group *would* have received if the trial had not been conducted.

While the reality of what the members of the control group would have received is obviously relevant, I am not satisfied that this proposed revision would have properly taken that into account. Would it be just, for example, to use such a placebo control group in a trial in a developed country where the antiretroviral therapy is widely available except to members of some persecuted minority, from whom the control group is drawn? They *would* not have received the treatment if the trial had not been conducted, although they *should* have been given the resources available in the developed country. Their use in a placebo control group is not therefore justified. The proposed revision made too much reference to what would have occurred and not enough to what should have occurred.

A recent workshop proposed instead that “study participants should be assured the highest standard of care practically attainable in the country in which the trial is being carried out.”<sup>9</sup> This seems better, although it may suggest too much. Suppose that the treatment is practically attainable but only by inappropriately cutting corners on other forms of health care which may have a higher priority. I would suggest therefore that the normative nature of the standard be made explicit. It would then read that all participants in the study, including those in the control group, should not be denied any treatment that *should otherwise be available to him or her in light of the practical realities of health care resources available in the country in question*. The question for IRBs reviewing proposals for such research is then precisely the question of justice.

On that standard, the trials in question were probably not unjust, although there is some debate about the Thai CDC trial in light of donated resources that became available in Thailand between its being planned and its being implemented.<sup>10</sup> Such trials will be harder to justify in the future given the current availability of proven much less expensive therapies which should be available even in some of the poorest countries. It is of interest to note that

HIVNET 012 was not a placebo-controlled trial, but it was a superiority trial, and active controlled trials are less problematic scientifically when they are superiority trials. That may well be the way future transmission trials will be run.

### **Coercive Offers**

It has been suggested by other critics that the participants in these trials were coerced into participating because of their desperation. “The very desperation of women with no alternatives to protect their children from HIV infection can be extremely coercive,” argue one set of critics.<sup>11</sup> One of the requirements of an ethical trial is that the participants voluntarily agree to participate, and how can their agreement to participate be voluntary if it was coerced?

This line of thinking is analogous to the qualms that many have about paying research subjects substantial sums of money for their participation in research. Such inducements are often rejected on the grounds that they are coercive, because they are too good to refuse. The ICH [International Conference on Harmonization] Guidelines for Good Clinical Practice is one of many standards which incorporate this approach when it stipulates that the “IRB/IEC should review both the amount and method of payment to subjects to assure that neither present problems of coercion or undue influences on the research subject.”<sup>12</sup>

Normally, coercion involves a threat to put someone below their baseline unless they cooperate with the demands of the person issuing the threat.<sup>13</sup> As the researchers were not going to do anything to those who chose not to participate, they were clearly not threatening them. Further evidence of this comes from the reflection that threats are unwelcome to the parties being threatened, and there is no reason to suppose that the potential subjects saw the request to participate as something unwelcome. Even the critics recognize this. The potential subjects were being offered an opportunity that might improve their situation. This was an offer “too good to refuse,” not a threat.

Should we expand the concept of coercion to include these very favorable offers? There are several reasons for thinking that we should not. First, it is

widely believed that offering people valuable new opportunities is desirable. Moreover, the individuals in question want to receive these offers, and denying them the opportunity to receive them seems paternalistic or moralistic.<sup>14</sup> It is important that participants understand that what they are being offered is a chance to receive a treatment that may reduce transmission (since this is a randomized placebo-controlled trial of a new regimen), and ensuring that is essential for the consent to be informed. As long as care is taken to ensure that this information is conveyed in a culturally sensitive fashion, and is understood, then there seems to be little reason to be concerned about coercion simply because a good opportunity is being offered to those with few opportunities.

A colleague and I are currently working on one residual concern in this area. It has to do with studies in which there is a potential for long-term harms to subjects which they inappropriately discount because the very substantial short-term benefits cloud their judgment. This may be a ground for concern in some cases, but it is difficult to see how it would apply to the vertical transmission trials. For those trials, it is appropriate to conclude that concerns about coercion were unfounded.

### **Exploitation of Subjects**

The final criticism of the trials is that they are exploitative of developing countries and their citizens because the interventions in question, even if proven successful, will not be available in these countries. To quote one of the critics: "To use a population as research subjects because of its poverty and its inability to obtain care, and then to not use that knowledge for the direct benefit of that population, is the very definition of exploitation. This exploitation is made worse by the fact that richer nations will unquestionably benefit from this research... [they] will begin to use these lower doses, thereby receiving economic benefit."<sup>15</sup>

There are really two claims being advanced in that quotation. The second, that the developed countries ran these trials to discover cheaper ways of treating their own citizens, is very implausible since pregnant women in developed countries are receiving even more expensive cocktails of drugs

both to treat the woman and to reduce transmission. The crucial issue is whether the trials are exploitative of the developing countries.

There seems to be a growing consensus that they are exploitative unless certain conditions about future availability in the country in question are met. The Council for International Organizations of Medical Sciences (CIOMS) is the source of this movement, as it declared in its 1992 guidelines that "as a general rule, the initiating agency should insure that, at the completion of successful testing, any products developed will be made reasonably available to residents of the host community or country."<sup>16</sup> A slightly weaker version of this requirement was adopted by a recent workshop which concluded that "studies are only appropriate if there is a reasonable likelihood that the populations in which they are carried out stand to benefit from successful results."<sup>17</sup>

This growing consensus is part of what lies behind the effort to secure these benefits by negotiating more favorable prices for the use of the tested drugs in developing countries. It seems highly desirable that this goal be achieved. But I want to suggest that it should be viewed as an aspiration, rather than a requirement, and that a different, more modest requirement must be met to avoid charges of exploitation.

A good analysis of exploitation is that it is a wrong done to individuals who do not receive a fair share of the benefits produced by an activity in which they take part, even if they receive some benefit.<sup>18</sup> This is why a mutually beneficial activity, one from which both parties will be better off, can still be exploitative if one of the parties uses their greater bargaining power to harvest most of the benefits and the other party agrees because they need whatever modest benefit is being left for them.

As we apply this concept to the trials in question, we need to ask who needs to be protected from being exploited by the trials in question. It would seem that it is the participants. Are they getting a fair share of the benefits from the trial if it proves successful? This is a particularly troubling question when we consider those in the control group, whose major benefit from participation may have been an unrealized possibility of getting treated. If we judge

that the participants have not received enough, then it is they who must receive more. An obvious suggestion is that they be guaranteed access to any regimen proved efficacious in any future pregnancies (or perhaps even that they be granted access to antiretroviral therapy for their own benefit). This would be analogous to familiar concepts of subjects receiving continued access to treatment after their participation in a trial is completed.

I certainly support every reasonable effort to increase access to treatments which will reduce vertical transmission. But imposing the types of community-wide requirements that have been suggested, but not necessarily justified if the above analysis is correct, may prevent important trials from being run because of the potential expense. Such proposals should be treated as moral aspirations, and exploitation should be avoided by focusing on what is owed to the subjects who have participated in the trials. It is they, after all, who are primarily at risk for being exploited.

These observations are about research in developing countries in general, and not just about research on vertical transmission. Three lessons have emerged. The standard for when a placebo control group is justified is a normative standard (what they should have received if they were not in the trial) rather than a descriptive standard (what they would have received if they were not in the trial). Coercion is not a serious concern in trials simply because attractive offers are made to the subjects. Legitimate concerns about exploiting subjects should be addressed by ensuring their future treatment, rather than by asking what will happen in their community at large.

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# Life and Death

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# Abortion

Abortion is among the most contentious and complex issues in bioethics. It has divided the public, exercised politicians, occupied the courts, busied the media, and engendered violence. Much of the public debate has been bitter and irrational, driven by partisans bent on racking up political points and by popular media obsessed with keeping score. But away from the scuffle and out of earshot of the quarrelers, a more useful debate has been going on—the philosophical give and take among thinkers who test claims about the morality of abortion through reasoned argument and careful reflection. They have achieved no grand consensus on the issue, but they have plumbed it, clarified it, and wrung from it some thoughtful answers worth considering. They have, in other words, done bioethics. Let us see, then, what this work can tell us.

## STARTING POINT: THE BASICS

Views on abortion—whether held by church, state, or citizenry—have varied dramatically through time and across cultures. Abortions in the ancient world were common, and there was no shortage of methods for effecting them. Some writers of the time condemned the practice, and some recommended it. “Let there be a law that no deformed child shall live,” says Aristotle, “and if couples have children in excess, let abortion be procured before life and sense have begun.”<sup>1</sup> The Hippocratic Oath proscribed the use of abortifacients (substances or devices for inducing abortions), a prohibition respected by many physicians but ignored by others.

The Hebrew and Christian scriptures do not denounce abortion and do not suggest that the

fetus is a person. A passage in Exodus Chapter 21 touches on the topic and implies that the unborn entity is not a full human being. The passage comes after the emphatic “You shall not murder” of the Ten Commandments and after a warning that the penalty for murder is death. But Exodus 21:22 says that if a man causes a woman to have a miscarriage “but [she] is not harmed in any other way,” the penalty is just a fine. Causing the death of a fetus was not considered murder.

In Judaism, a fetus has immense worth as a potential human life, but it becomes a full human person only at birth. In Jewish law, abortions are allowed if the fetus threatens the life or health of the mother, but they are disallowed for fetuses with genetic imperfections. Some authorities say abortion is permitted up until birth even if the mother’s life or health is not in jeopardy, if only to avoid the pain, anguish, or hardship that a birth would bring.

Christians have generally condemned abortion, though their ideas about the personhood of the fetus have changed through the centuries. Many contemporary Christians, especially Roman Catholics, assume that the unborn is a full human being from the moment of conception. But in the twelfth century, the church came to the view that an embryo cannot have a soul until several weeks after conception. The rationale, inspired by Aristotle, was that the unborn cannot have a soul until it is “formed”—that is, until it has a human shape, a stage that is reached long after conception. Thomas Aquinas accepted this view and maintained that male embryos are formed (and thus given a soul, or “ensouled”) 40 days after conception; female embryos, 90 days.

## Fact File U.S. Abortions

- Almost half (45 percent) of all pregnancies in 2011 were unintended.
- About 40 percent of unintended pregnancies (not including miscarriages) ended in abortions.
- In 2014, about 926,200 abortions were performed, down 12 percent from 1.06 million in 2011. Among women aged 15–44, 1.5 percent had an abortion.
- In 2014, the abortion rate was 14.6 abortions per 1,000 women aged 15–44. This is the lowest rate ever documented in the United States. The rate in 1973, when abortion became legal, was 16.3.
- At the rate of 14.6 abortions per 1,000 women, 5 percent of women will have an abortion by age 20, 19 percent by age 30, and 24 percent by age 45.
- In 2014, 12 percent of abortion patients were adolescents; 8 percent were aged 18–19.
- Thirty-nine percent of abortion procedures in 2014 were obtained by White patients, 28 percent by Blacks, and 25 percent by Hispanics.
- In 2014, 17 percent of abortion patients said they were Protestant, 13 percent evangelical Protestant, 24 percent Catholic, and 38 percent no religious affiliation.
- Fifty-one percent of women who had abortions in 2014 had used contraception during the month they became pregnant.
- Fewer than 0.5 percent of women having first-trimester abortions suffer major complications requiring hospitalization.
- First-trimester abortions pose virtually no long-term risks of infertility, ectopic pregnancy, miscarriage, or birth defects, and little or no risk of preterm or low-birth-rate deliveries.
- In 2014, 31 percent of all nonhospital abortions were medication abortions.
- The three most common reasons for having an abortion were (1) concern for or responsibility to other individuals; (2) not being able to afford raising a child; and (3) the belief that having a baby would interfere with work, school, or caring for dependents.
- A 2016, five-year study of 1,000 women who sought abortions showed that those who had the procedure did not experience more mental health problems (depression, anxiety, dissatisfaction with life, low self-esteem) than women who were denied abortions. The research was published in *JAMA Psychiatry* and was thought to be the most rigorous study to date on the psychological impact of abortions. (M. Antonia Biggs, Ushma D. Upadhyay, Charles E. McCulloch, et al., “Women’s Mental Health and Well-Being 5 Years After Receiving or Being Denied an Abortion: A Prospective, Longitudinal Cohort Study,” *JAMA Psychiatry* 74, no. 2 (2017): 169–78, doi:10.1001/jamapsychiatry.2016.3478.)

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Thus, killing a fetus, though always sinful, is not murder until after it is formed. In 1312, this doctrine became the church's official position. Only in the late nineteenth century did the church decide that ensoulment happens at conception and that any abortion after that point is the killing of a human person.

In English common law, abortion was considered a crime only if performed after **quickening** (when the mother first detects fetal movement). From its beginnings through the nineteenth century, American law mostly reflected this tradition. Accordingly, in the early 1800s, several states passed statutes outlawing abortion after quickening except to save the life of the mother. But in the next 100 years, abortion laws gradually became stricter, dropping the quickening cutoff point and banning all abortions but those thought to preserve the life (or, rarely, the health) of the mother. The medical profession generally supported the tougher laws, and the views of physicians on abortion carried great weight.

In the 1950s, a trend toward liberalized laws began, and by 1970 the American Medical Association (AMA) and the American College of Obstetricians and Gynecologists were officially advocating less severe abortion policies. The

latter declared, "It is recognized that abortion may be performed at a patient's request, or upon a physician's recommendation."<sup>2</sup> By that time, 12 states had amended their abortion statutes to make them less restrictive, and the public had warmed considerably to the idea of legalized abortion. The culmination of all these changes was the 1973 Supreme Court case of *Roe v. Wade*, which made abortions before viability legal.

The abortion policies of previous eras were handicapped by poor understanding of human development. But in modern times the facts are clear: *Fertilization*, or conception, happens when a sperm cell penetrates an egg, or ovum, forming a single cell known as a *zygote*, or *conceptus*. This meeting of sperm and egg usually takes place in one of the two fallopian tubes, the narrow tunnels linking the egg-producing ovaries with the uterus. For three to five days, the zygote moves down the fallopian tube to the uterus, dividing continually and thus getting larger along the way. In the fluid-filled uterus, it divides further, becoming a hollow sphere of cells known as a *blastocyst*. Within about five days, the blastocyst lodges firmly in the lining of the uterus (a feat called *implantation*) and is then known as an *embryo*.

The embryonic stage lasts until eight weeks after fertilization. During this time most of the embryo's internal organs form, the brain and spinal cord start to generate, and external features such as limbs and ears begin to appear. At eight weeks, though it is only about the size of a raspberry, the embryo has a rudimentary human shape.

From the end of the eighth week until birth, the unborn is technically known as a *fetus*. (In this text, however, we use the term to refer to the unborn at any stage from conception to birth.) At about 14 weeks of pregnancy, doctors can determine the fetus's sex. Around 16 to 20 weeks, the mother can feel the fetus moving inside her. Quickening was once thought to be a threshold event in pregnancy, signaling ensoulment or the presence of a human being. But it is of doubtful importance (except to the mother) since the fetus moves undetected before quickening, and the mother's sensing fetal movement is not associated with any significant change in development. A more meaningful benchmark is **viability**, the development stage at approximately 23 to 24 weeks of pregnancy when the fetus may survive outside the uterus. Babies born at this point, however, are at high risk of severe disabilities (intellectual disability and blindness, among others) and death.

Development from fertilization to birth (called gestation) is nine months long, or about 40 weeks. This span of pregnancy is calculated from the first day of the woman's last menstrual period and is traditionally divided into three 3-month intervals—first trimester (0–12 weeks), second trimester (13–24 weeks), and third trimester (25 weeks to delivery). Babies delivered in the third trimester but before 37 weeks are considered premature.

**Abortion** is the ending of a pregnancy. Abortion due to natural causes—birth defect or injury, for example—is known as **spontaneous abortion or miscarriage**. The intentional termination of pregnancy through drugs or surgery is called **induced abortion** or, more commonly, simply abortion. Abortion in this sense is the

issue over which most of the ideological and judicial struggles are waged. Such is generally not the case for **therapeutic abortion**—abortion performed to preserve the life or health of the mother. Most people believe therapeutic abortion to be morally permissible.

Several methods are used to perform abortions, some of them surgical and some pharmaceutical. The method used depends on, among other things, the woman's health and the length of her pregnancy. The most common technique is known as *suction curettage* (also, *vacuum aspiration*), which is used in the first 12 weeks of pregnancy (when nearly 90 percent of abortions are performed). A doctor inserts a thin, bendable tube through the opening of the cervix into the uterus and, using a vacuum syringe or a machine or hand pump, suctions the contents of the uterus out through the tube. The method used most often after the first 12 weeks is *dilation and evacuation*. It involves widening the cervix and employing both suction and forceps to extract the fetus and placenta.

Abortions can be induced with drugs (often referred to as “medical abortions”) but only in the first seven to nine weeks of pregnancy. The most common regimen uses two medications: mifepristone (RU-486, the so-called abortion pill) and misoprostol, a prostaglandin (hormone-like substance). Mifepristone interferes with the hormone progesterone, thinning the lining of the uterus and preventing implantation of the embryo. Misoprostol prompts the uterus to contract, forcing the embryo out. A woman sees her physician to take mifepristone and then up to three days later takes misoprostol (either at home or in the physician's office). This two-step procedure causes abortion about 95 percent of the time.

The risk of complications (such as serious bleeding or internal injury) from abortion is low and varies directly with the length of pregnancy—the earlier an abortion is performed, the lower the risk. Less than 1 percent of women having early abortions experience complications; less than 2 percent of those having later

**IN DEPTH**  
**ABORTION AND PUBLIC**  
**OPINION 2021**

Percentage of adults who say abortion should be legal/illegal

<b>Legal in all or most cases</b>	<b>Illegal in all or most cases</b>
59%	39%

Percentage of adults who say abortion should be legal/illegal, by religion

<b>Religious affiliation</b>	<b>Legal in all/most cases</b>	<b>Illegal in all/most cases</b>
White evangelical Protestant	21%	77%
Catholic	55%	43%
Black Protestant	64%	33%
White mainline Protestant	63%	37%
Unaffiliated	82%	16%

Percentage of adults who say abortion should be legal/illegal, by party identification

<b>Party identification</b>	<b>Legal in all/most cases</b>	<b>Illegal in all/most cases</b>
Republican/lean Rep.	35%	63%
Democrat/lean Dem.	80%	19%

Percentage of adults who say abortion should be legal/illegal, by education level

<b>Level of education</b>	<b>Legal in all/most cases</b>	<b>Illegal in all/most cases</b>
High school or less	50%	47%
Some college	61%	38%
College grad or more	68%	31%

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From Pew Research Center, “Public Opinion on Abortion,” survey conducted April 5–11, 2021, Public Opinion on Abortion, Pew Research Center ([pewforum.org](http://pewforum.org)).

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abortions do. Death is a risk in any surgical procedure; the risk of death for suction curettage is less than 1 in 100,000 women. The risk for medical abortion is virtually the same. The chances of a woman dying in childbirth are at least 10 times higher.<sup>3</sup> Despite the low risk, no woman is likely to be blasé about terminating a pregnancy.

Over half of women having abortions are under 25 years old, and almost one-fifth of these are teenagers. Fifty-seven percent of abortions

are performed on women who have never married; 17 percent, on married women; and 16 percent, on women who are separated, divorced, or widowed.

Their reasons for terminating a pregnancy are varied. According to a survey of women who had abortions, the reasons include:

- Having a baby would change my life (interfere with education, employment, etc.)—74 percent

- I can't afford a baby now (I'm unmarried, unemployed, destitute, etc.).—73 percent
- I don't want to be a single mother, or I'm having relationship problems.—48 percent
- My relationship or marriage may break up soon.—11 percent
- I've already completed my childbearing.—38 percent
- My husband or partner wants me to have an abortion.—14 percent
- There are possible problems affecting the health of the fetus.—13 percent
- There are physical problems with my health.—12 percent
- I was a victim of rape.—1 percent
- I became pregnant as a result of incest.—less than 0.5 percent<sup>4</sup>

Polls gauging the attitudes of the American public toward abortion have revealed many divisions but also remarkable agreement on some points. Only a small minority of people (16 percent) think that abortion should be illegal or unavailable in all circumstances. Most reject a total ban but differ on the existence or extent of restrictions placed on abortion. Roughly half consider themselves to be "pro-life" and half "pro-choice." A sizable majority (69 percent) would not like to see *Roe v. Wade* completely overturned.

### THE LEGAL STRUGGLE

As we have seen, abortion is both a moral and legal issue, and these two lines of debate must not be confused. But we cannot ignore how the legal conflict has influenced the ethical arguments, and vice versa. The former seized the attention of the nation when *Roe v. Wade* was handed down. Roe was "Jane Roe," a.k.a. Norma McCorvey, who had sought a nontherapeutic abortion in Texas where she lived. But Texas law forbade all abortions except those necessary to save the mother's life. So Roe sued the state of Texas in federal court, which ruled that the law was unconstitutional. Texas appealed the decision to the U.S. Supreme Court, and the Court sided with the federal court, declaring in *Roe v.*

*Wade* that no state can ban abortions performed before viability.

The Court saw in the Constitution (most notably the Fourteenth Amendment, which grants due process and equal protection under the law) a guaranteed right of personal privacy that limits interference by the state in people's private lives, and the majority believed that the right encompassed a woman's decision to terminate her pregnancy. But, the Court noted, "this right is not unqualified and must be considered against important state interests in regulation." So it balanced the woman's right and state interests according to trimester of pregnancy. In the first trimester, the woman's right to end her pregnancy cannot be curtailed by the state. Her decision must be respected, and "its effectuation must be left to the medical judgment of the pregnant woman's attending physician." In the second trimester, the state may limit—but not entirely prohibit—the woman's right by regulating abortion for the sake of her health. After viability, the state may regulate and even ban abortion except when it is necessary to preserve her life or health. The Court affirmed that its ruling "leaves the State free to place increasing restrictions on abortion as the period of pregnancy lengthens, so long as those restrictions are tailored to the recognized state interests."

The Court noted that the Constitution does not define "person" and that "the word 'person,' as used in the Fourteenth Amendment, does not include the unborn." In fact, the law has never maintained that the unborn are persons "in the whole sense."

After this historic case, the Supreme Court handed down numerous other decisions that circumscribed, but did not invalidate, the right to abortion defined in *Roe*. In these rulings, the Court held that (1) a woman can be required to give her written informed consent to abortion, (2) the government is not obliged to use taxpayer money to fund abortion services, (3) parental consent or a judge's authorization can be demanded of minors under age 18 who seek abortions, (4) a state can forbid the use of public

## IN DEPTH

### ABORTIONS PERFORMED LATER IN PREGNANCY

Abortions performed after 21 weeks—often mislabeled “partial-birth,” “late-term,” or “post-viability”—are politically and morally controversial. Here are the facts outlined by a nonpartisan source.

*Abortions occurring at or after 21 weeks gestational age are rare. They are often difficult to obtain, as they are typically costly, time-intensive and only performed by a small subset of abortion providers. Yet these abortions receive a disproportionate amount of attention in the news, policy and the law, and discussions on this topic are often fraught with misinformation; for example, intense public discussions have been sparked after several policymakers have theorized about abortions occurring “moments before birth” or even “after birth.” In reality, these scenarios do not occur, nor are they legal, in the U.S.*

*Members of the medical community have criticized the term “late-term” abortion, as it implies abortions are taking place after a pregnancy has reached “term” (37 weeks) or “late term” (>41 weeks) which is false. In fact, the American College of Obstetricians and Gynecologists (ACOG) has written that “late-term abortion” has no medical meaning and should not be used in clinical or legal settings.*

#### WHY DO PEOPLE HAVE ABORTIONS LATER IN PREGNANCY?

**Non-Medical Reasons:** Individuals seek abortions later in pregnancy for a number of reasons. As part of the Turnaway study out of the University of

facilities to perform abortions (except to save the woman’s life), (5) a woman who consents to an abortion can be required to wait 24 hours before the procedure is performed, (6) a state can mandate that a woman be given abortion

California San Francisco, from 2008–2010 over 440 women were asked about why they experienced delays in obtaining abortion care, if any. Almost half of individuals who obtained an abortion after 20 weeks did not suspect they were pregnant until later in pregnancy, and other barriers to care included lack of information about where to access an abortion, transportation difficulties, lack of insurance coverage and inability to pay for the procedure. This is unsurprising, given abortions can be cost-prohibitive for many.

**Fetal Anomalies:** Individuals also seek abortions later in pregnancy due to medical reasons. With medical advances, many genetic fetal anomalies can be detected early in pregnancy; for example, chorionic villus sampling can diagnose Down Syndrome or cystic fibrosis as earlier as 10 weeks gestation. Structural fetal anomalies, however, are often detected much later in pregnancy. A proportion of these are lethal fetal anomalies, meaning that the fetus will almost certainly die before or shortly after birth.

**Health Risk to the Pregnant Person:** Life threatening conditions may also develop later in pregnancy. These include conditions like early severe preeclampsia, newly diagnosed cancer requiring prompt treatment, and intrauterine infection (chorioamnionitis) often in conjunction with premature rupture of the amniotic sac (PPROM). If these conditions arise before the fetus is viable, the pregnant individual may pursue termination of pregnancy to preserve their own health.

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From KFF (Kaiser Family Foundation), “Abortions Later in Pregnancy,” December 5, 2019, <https://www.kff.org/womens-health-policy/fact-sheet/abortions-later-in-pregnancy/>.

information, and (7) states may not prohibit abortions necessary to preserve a woman’s life or health. Eventually the court came to a key doctrine concerning such limitations: Before viability, abortion can be restricted in many ways as

long as the constraints do not amount to an “undue burden” on a woman trying to get an abortion. A state regulation constitutes an undue burden if it “has the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus.”

### **PERSONS AND RIGHTS**

People generally take one of three positions on the moral permissibility of abortion. The conservative view is that abortion is never morally acceptable (except possibly to preserve the mother’s life), for the unborn is a human being in the full sense. The liberal view is that abortion is acceptable whenever the woman wants it, for the unborn is not a human being in the full sense. The moderate stance falls between these two stands, rejecting both the conservative’s zero-tolerance for abortion and the liberal’s idea of abortion on request. For the moderate, some—but not all—abortions may be morally justified. (These labels are common but sometimes misleading; being a conservative or liberal on the abortion issue does not necessarily mean you are a conservative or liberal in the broader political sense.)

Despite appearances, between the conservatives and the liberals there is at least a patch of common ground. Both sides agree on some basic moral principles—for example, that murder is wrong, that persons have a right to life, and that personal freedom should not be curtailed except for very important reasons. Conflicts arise not over such fundamentals but over the nonmoral facts (such as the nature of the fetus) and over the meaning and application of moral standards.

The main conservative argument against abortion is straightforward and based on a widely shared intuition about the wrongness of killing innocents. One popular formulation says that (1) the killing of an innocent human being is wrong; (2) the unborn is an innocent human being; (3) therefore, it is wrong to kill the unborn (abortion is immoral). At first glance, this argument may seem sound, but critics point out that

the term *human being* improperly switches meanings in mid-argument, invalidating the inference (and thus committing what is known as the fallacy of equivocation). The problem is that in premise 2, *human being* means an entity that is biologically human, a member of the genetically distinct human species. But in premise 1, *human being* refers to an entity having all the psychological attributes and capacities that we normally associate with the possession of full moral rights (including a right to life)—what philosophers call a *person*. If *human being* referred to the same thing throughout the argument, the argument would be valid. But the argument equivocates on the term and is therefore invalid.

The conservative, however, avoids these difficulties by offering an improved version of the argument: (1) The killing of an innocent person is wrong; (2) the unborn is an innocent person from the moment of conception; (3) therefore, it is wrong to kill the unborn (abortion is immoral). This argument is valid, and premise 1 is obviously true. The crux of the matter is premise 2, which the conservative asserts and the liberal denies. What arguments can the conservative offer to support it?

One option is to start with this observation: In the continuous process of development from zygote to adult human, there seems to be no precise point at which the entity becomes unmistakably a bona fide human being (with a right to life). No clear line between nonperson and person can be found. Any point we select to indicate the nonperson/person boundary would be arbitrary and unsupportable. The conservative argues that the most plausible view then would be that personhood (and the right to life) begins at conception. It is at conception that, for example, a full complement of genetic information is present to propel development of a completely formed, mature human. As one philosopher puts it,

The positive argument for conception as the decision moment of humanization is that at conception the new being receives the genetic code. It is this

genetic information which determines his characteristics, which is the biological carrier of the possibility of human wisdom, which makes him a self-evolving being. A being with a human genetic code is man.<sup>5</sup>

Critics respond in various ways to this view. They point out, for example, that just because no nonperson/person line can be drawn doesn't mean there is no difference to be observed between the two phenomena. We may not be able to specify the precise moment when a tadpole turns into a frog, but we know there is a real difference between the two states. The failure to pinpoint a distinct moment when the unborn becomes a person does not show that it must be a person from the moment of conception.

Some philosophers argue on empirical grounds that the zygote cannot be an individual human being:

[T]he very early conceptus cannot be identified with the embryo that may develop from it. This is because, for about the first two weeks of existence, it consists of a set of undifferentiated cells, any one of which could give rise to an embryo under certain circumstances. This "pre-embryo" may spontaneously divide, resulting in twins or triplets; alternatively, it may combine with another pre-embryo, giving rise to a single fetus.<sup>6</sup>

Some conservatives avoid such complications by arguing not that the fetus is a person, but that it is a *potential* person and thus has the same right to life as any existing person. The unborn may not be a person now, but its status as a possible future person puts it in the same moral category as any normal adult human being. One ethicist expresses the point like this:

What makes the difference between human beings and other life is the capacity human beings enjoy for a specially rich kind of life. The life already enjoyed by a human being cannot be taken away from him, only the prospect of such life in the future. But this prospect is possessed as much by an infant or fetus as by a full-grown adult.<sup>7</sup>

A common response to this potentiality argument is that there is a world of difference

between (1) possessing a particular trait that gives you a right and (2) *having the potential* to develop a trait that gives you a right. "[T]he right to vote in political elections may be granted to citizens who have reached the age of 18," says MaryAnne Warren, "but not to pre-adolescents—even though most of them clearly have the potential to reach the age of 18." From the fact that someone has the potential to become a Supreme Court justice does not follow that we should treat her as if she were a justice now.

Michael Tooley provides a more striking example. Suppose there existed a special chemical that could be injected into a kitten's brain to cause the kitten to gradually become a cat with a mind that was indistinguishable from the kind possessed by adult humans. The cat could think, talk, and feel just as humans do, acquiring all the proper traits that give it a right to life. Now consider:

[C]ompare a member of *Homo sapiens* that has not developed far enough to have those properties that in themselves give something a right to life, but which later will come to have them, with a kitten that has been injected with the special chemical but which has not yet had the chance to develop the relevant properties. It is clear that it cannot be any more seriously wrong to kill the human than to kill the kitten. The potentialities are the same in both cases.<sup>8</sup>

Some critics also think that the potentiality argument undermines itself because it seems to have bizarre implications. They argue, for example, that if a zygote is a potential person (and thus has the same right to life as an adult human), then other entities must also be potential persons with a right to life—human ovum and spermatozoa for starters but also countless other cells in the human body. There is no difference between a single-cell zygote and any other single diploid cell that, through cloning, could also become a human being.

The liberal says that the unborn is not a person, not a full human being, and therefore does not have a right to life. If the unborn is a person, then killing it would be murder, and its

right to life would be at least as weighty as the mother's. How can the liberal show that fetuses are not persons?

To start, the liberal will insist that merely being a *Homo sapiens*—a creature with human DNA—is not sufficient for personhood. To think so is to be guilty of a kind of prejudice called *speciesism*. The liberal argues that since whatever properties make us persons (and thus grant us a right to life) could conceivably be manifested by a nonhuman species, merely being a member of the human species cannot be sufficient for personhood status. If we assume that an entity is a person just because it happens to belong to our favored biological classification, we stand convicted of speciesism, close cousin to racism. There are properties that do qualify an entity as a person, but simply being human is not one of them.

The liberal tack is to identify these traits and point out that a fetus does not possess them. According to Louis Pojman,

These properties are intrinsically valuable traits that allow us to view ourselves as selves with plans and projects over time, properties like self-consciousness and rationality. Although it is difficult to specify exactly what are the necessary and sufficient conditions for personhood, and liberals have described these conditions differently—some emphasizing desires and interests, others emphasizing agency or the ability to project into the future, others emphasizing the capacity for a notion of the self—they all point to a cluster of characteristics which distinguish children and adults from fetuses, infants, and most animals.<sup>9</sup>

Mary Anne Warren famously identifies five traits that are “most central” to personhood: (1) consciousness and the capacity to feel pain, (2) reasoning, (3) self-motivated activity, (4) the capacity to communicate, and (5) “the presence of self-concepts, and self-awareness, either individual or racial or both.” To be considered a person, she says, a being need not possess all these traits, but surely “any being which satisfies *none* of (1)–(5) is certainly not a person.” A fetus

in fact satisfies none and is therefore not yet a person and “cannot coherently be said to have full moral rights.”<sup>10</sup>

The conservative will counter that the liberal's standards for personhood are set too high, for they imply that cognitively impaired individuals—victims of serious dementia, intellectual disability, or schizophrenia, for instance—are not persons and therefore do not have a right to life. The liberal view seems to condone the killing of these unfortunates, a repugnant implication. The liberal response is that even if cognitively impaired individuals do not qualify as persons, we may still have good reasons for not killing them—for example, because people value them or because a policy allowing them to be killed would be harmful to society (perhaps encouraging unnecessary killings or causing a general devaluing of life). In addition, the liberal points out that the personhood status of many (or most) cognitively impaired individuals is unclear, so a policy of regarding them as less than persons would be risky.

The biggest challenge to the liberal notion of personhood is the charge that it sanctions infanticide. The argument is that if killing a fetus is morally permissible because it is not a person, then killing an infant must be acceptable as well, for it is not a person either. According to the liberal's personhood criteria mentioned earlier, neither a fetus nor an infant is a person. Moreover, there is a glaring problem with the common liberal assumption that birth is the point at which a fetus becomes a person: The fetus just before birth and the infant just after are biologically almost indistinguishable. Saying that the former has no right to life but the latter does seems hard to justify.

Liberals contend that even if infants are not persons, infanticide is rarely permissible (possible exceptions include cases of horrendous birth defects and terminal illness). Some (including Warren) say that this is so because infants, though not persons, do have some moral standing. For example:

In this country, and in this period of history, the deliberate killing of viable newborns is virtually

**IN DEPTH****DOES A FETUS FEEL PAIN?**

In recent years this question has been hotly debated, with the pro-life side insisting that fetuses can experience pain as early as 20 weeks after conception (22 weeks after last menstrual period), and the pro-choice side asserting that fetuses cannot perceive pain until much later, no earlier than 24 weeks. Fetal pain has become controversial because it is now being used in an anti-abortion argument that abortions causing fetal pain are obviously immoral and therefore should be stopped. So several states have enacted laws banning abortions after 20 weeks, and in 2015 the U.S. House of Representatives passed a bill that would ban them after 22 weeks. (Such laws would pertain to relatively few abortions, since 99 percent of abortions occur before 21 weeks.)

Most scientists involved in this issue think fetal pain is probably not possible until after the time when most abortions take place. In 2005, a multidisciplinary analysis published in the *Journal of the American Medical Association* concluded that fetal perception of pain is unlikely before the third trimester, which begins at 27 weeks. In 2010, the British Royal College of Obstetricians and Gynaecologists said that fetuses cannot experience pain before 24 weeks. In 2012, the American Congress of Obstetricians and Gynecologists largely agreed with their British counterparts.

These reports, however, are hardly the last word on the subject. Abortion opponents cite research they say suggests that fetuses are conscious of pain at 20 weeks. Some experts point to the complexity of the pain response and how little science understands about it. They say it's best to assume that fetal pain can occur early and adjust our actions and attitudes accordingly.

never justified. This is in part because neonates are so very close to being persons that to kill them requires a very strong moral justification—as does the killing of dolphins, whales, chimpanzees, and other highly personlike creatures. It is certainly wrong to kill such beings just for the sake of convenience, or financial profit, or “sport.”<sup>11</sup>

Others say that infanticide is to be condemned for reasons of social utility. As Joel Feinberg explains,

The moral rule that condemns these killings [infanticide] and the legal rule that renders them punishable are both supported by “utilitarian reasons,” that is, considerations of what is called “social utility,” “the common good,” “the public interest,” and the like. Nature has apparently implanted in us an instructive tenderness toward infants that has proven extremely useful to the species, not only because it leads us to protect our young from death, and thus keep our population up, but also because infants usually grow into adults, and in Benn’s words, “if as infants *they* are not treated

with some minimal degree of tenderness and consideration, they will suffer for it later, as persons.” One might add that when they are adults, others will suffer for it, too, at their hands. Spontaneous warmth and sympathy toward babies then clearly has a great deal of social utility, and insofar as infanticide would tend to weaken that socially valuable response, it is, on utilitarian grounds, morally wrong.<sup>12</sup>

Moderate views on abortion can be sketched out in a variety of ways. Many moderates claim the middle ground by arguing that the fetus achieves personhood at a point somewhere between conception and birth—at viability, at the time when fetal brain waves occur, or at some other notable point. Other moderates reject the notion of a distinct developmental line separating persons from nonpersons. They argue instead that the moral standing or right to life of the fetus increases gradually as it develops (expanding from minimal rights to almost full rights, for example) or that there is an indistinct threshold stage (when sentience emerges, say)

beyond which the fetus has significantly increased moral standing. Departing dramatically from these strategies, some moderates stake out their position without appealing to fetal personhood.

The most famous example of the latter comes from Judith Jarvis Thomson. She argues that even if the conservative view is correct that the unborn is a person from the moment of conception, abortion may still be morally justified. A fetus may have a right to life, but this right “does not guarantee having either a right to be given the use of or a right to be allowed continued use of another person’s body—even if one needs it for life itself.”<sup>13</sup> The unborn’s right to life is not absolute. It implies not that killing a fetus is always wrong, but that killing it unjustly is always wrong. Thomson argues her point with this striking analogy:

You wake up in the morning and find yourself back to back in bed with an unconscious violinist.

A famous unconscious violinist. He has been found to have a fatal kidney ailment, and the Society of Music Lovers has canvassed all the available medical records and found that you alone have the right blood type to help. They have therefore kidnapped you, and last night the violinist’s circulatory system was plugged into yours, so that your kidneys can be used to extract poisons from his blood as well as your own. The director of the hospital now tells you, “Look, we’re sorry the Society of Music Lovers did this to you—we would never have permitted it if we had known. But still, they did it, and the violinist now is plugged into you. To unplug you would be to kill him. But never mind, it’s only for nine months. By then he will have recovered from his ailment, and can safely be unplugged from you.”<sup>14</sup>

Thomson believes that our intuitions would tell us that this arrangement is outrageous, that the violinist’s right to life would not give him the right to exploit someone’s body against her will. Analogously, a fetus’s right to life would not guarantee its unauthorized use of the mother’s body; the mother has a right of self-defense.

Abortion, therefore, is justified when the fetus takes up residence without the woman’s consent, as when pregnancy is due to rape or failed contraception.

Some reject Thomson’s argument by contending that it holds only if the woman bears no responsibility for her predicament, if the attached violinist or fetus takes up residence through no fault of her own. She may not be responsible for the fetus if she becomes pregnant through rape; she does not, after all, consent to be raped. But she can be held responsible if she voluntarily engages in sexual intercourse; she therefore is obligated to carry the fetus to term. Others maintain that the woman is obliged to sustain the life of the unborn because she has a filial obligation to it. The unborn has a natural claim to the woman’s body.

### APPLYING MAJOR THEORIES

A utilitarian can argue that abortion is morally permissible because without this option, women (and society) would suffer terrible consequences:

Throughout history women have paid a terrible price for the absence of safe and legal contraception and abortion. Forced to bear many children, at excessively short intervals, they were often physically debilitated and died young—a common fate in most pre-twentieth-century societies and much of the Third World today. Involuntary childbearing aggravates poverty, increases infant and child death rates, and places severe strains upon the resources of families and states.<sup>15</sup>

To these calamities, a utilitarian might add the woman’s physical and emotional distress caused by pregnancy; the risk of complications or death in childbirth; disruption of her employment, education, or other life plans; and unhappiness caused by a loss of personal control and freedom.

Utilitarian arguments for abortion can also appeal to the quality of life of the infant or child. By this reasoning, abortion may be acceptable if the fetus is likely to be born with severe

defects—anencephalic (essentially without a brain), terminally ill, intellectually disabled, or physically disabled. Abortion would be a way to avoid great suffering.

Utilitarians who take Mill's view of individual liberty might argue for abortion by claiming that a woman must be allowed the freedom to decide what happens to her own body, which includes the attached fetus. This position follows from Mill's liberty (or harm) principle: We may not interfere with a person's capacity for self-determination except to prevent harm to others.

Those opposed to abortion can appeal to consequences, too: Having an abortion can cause the woman tremendous emotional pain, and the child can bring much happiness to the family and to the world. Besides, as an alternative to abortion, there is always adoption.

A common response to utilitarian arguments for abortion is this: If the fetus is a person, the utilitarian considerations don't matter much, if at all. If fetuses have a right to life (the same as any normal adult human), then it does not matter that their presence will cause others grief or that their quality of life will be marginal. If it is not permissible to kill a normal adult human (a person) on such grounds, then it cannot be permissible to kill a fetus-person for the same reasons.

In Kantian ethics, much depends on whether the unborn is to be considered a person. If it is a person, it has inherent worth and therefore cannot be treated as merely a means to an end. It cannot be killed just for the convenience of the mother or of society. But if the unborn is not a person, then abortion would seem to be more easily justified. Since the woman is a person, she has a right to exercise her autonomy and sovereignty over her own body—which may include ending her pregnancy.

On Kantian grounds, some can claim justification for abortion even if the fetus is a person. According to Kant, persons have a right of self-defense, a right to preserve their own lives against those who would take them. This right includes killing another if necessary for

self-protection. If so, perhaps a woman whose pregnancy threatens her life can kill the unborn person in self-defense—a therapeutic abortion. In addition, Kant's view can be plausibly construed as sanctioning abortion as a way of respecting a fetus's personhood. If the fetus is defective and faces a demeaning, miserable existence, we can show ultimate respect for its status by averting such indignities through abortion.

The natural law position on abortion as articulated in Roman Catholicism is clear and unequivocal. The fetus is an innocent person from conception (with a right to life equal to that of the mother), and directly killing any innocent person is wrong. Thus, directly killing the unborn even for the purpose of saving the mother's life is impermissible, for "evil is never to be done that good may come of it." The doctrine of double effect, however, permits the *indirect* killing of the unborn—specifically, abortions done to save the mother's life while having the unintended yet foreseen effect of killing the fetus. Traditionally the only abortions thought to fit these requirements have involved ectopic pregnancies and uterine cancer.

## KEY TERMS

- abortion
- induced abortion
- quicken
- spontaneous abortion (miscarriage)
- therapeutic abortion
- viability

## SUMMARY

Abortion is the ending of a pregnancy. Abortion due to natural causes is known as spontaneous abortion, or miscarriage; intentional termination of pregnancy is called induced abortion; and abortion performed to preserve the life or health of the mother is referred to as therapeutic abortion. Over half of women having abortions are under 25 years old; one-fifth of these are teenagers. Women give varying reasons for having abortions, including that having a baby would interfere with their life, cause financial or

## CLASSIC CASE FILE

**Nancy Klein**

The most contentious—and usually the most agonizing—abortion cases are those involving what people take to be clashes between fetal and maternal rights or interests. Such conflicts have played out in many closely watched stories, including this one that grabbed headlines in 1989 and outraged people on all sides of the issue.

On December 13, 1988, 32-year-old Nancy Klein, wife and mother of a young daughter, was in an auto accident that damaged her brain and put her in a coma. At the time, she was 10 weeks pregnant. After six weeks she was still in the coma and still pregnant, and her doctors doubted that she would ever recover. But they did believe that her chances of coming out of the coma might improve if she had an abortion and that she could then be treated with medications that could not be safely given in pregnancy. So her husband, Martin, asked a New York State court to designate him as her guardian empowered to grant permission for the abortion.

But abortion opponents went to court to try to block the abortion. One of them petitioned to be named Nancy Klein's guardian, while another asked to become guardian for the fetus. "These people are ruining our family," Martin Klein declared. But one of the anti-abortion petitioners said, "I don't see

this as interfering in the family's business. What we're trying to do is protect and support Nancy Klein and her child."

For two weeks, the legal battles raged, but ultimately Martin Klein won, and the requests of the abortion opponents were turned down by three state courts as well as by U.S. Supreme Court Justices Marshall and Scalia. Referring to the two anti-abortion petitioners, one court asserted, "The record confirms that these absolute strangers to the Klein family, whatever their motivation, have no place in the midst of this family tragedy."

Finally, at 18 weeks of pregnancy, the abortion was performed. Martin Klein and his wife's parents were relieved and said they expected that after the abortion Nancy would recover from her coma. Several weeks later, she did.

For the next two years, she struggled in rehabilitation hospitals to regain her memory and her ability to speak and walk. She eventually recovered much of what she had lost, though her speech and walking remained impaired. She condemned the actions of the abortion opponents: "I feel very strongly that it was my problem, not theirs, and that they had no right to interfere."

social difficulties, or put their health or life at risk. They also cite possible problems affecting the health of the fetus.

Since 1973 the legal status of abortion in the United States has been dominated by the Supreme Court's ruling in *Roe v. Wade*. The justices held that in the first trimester, the woman's right to end her pregnancy cannot be curtailed by the state; in the second trimester, the state may limit—but not entirely prohibit—the woman's right by regulating abortion for the sake of her health; and after viability, the state may regulate and even ban abortion except when it's necessary to preserve her life or

health. The Court affirmed that its ruling "leaves the State free to place increasing restrictions on abortion as the period of pregnancy lengthens, so long as those restrictions are tailored to the recognized state interests." In several cases after *Roe*, the Court circumscribed the right of abortion by, among other things, holding that a woman can be required to give her written informed consent to abortion, that the government is not obliged to use taxpayer money to fund abortion services, and that parental consent or a judge's authorization can be demanded of minors under age 18 who seek abortions. In 2007 the Court upheld the

Partial-Birth Abortion Ban Act, which outlawed a type of late-term abortion (referred to rhetorically as “partial-birth abortion”) even when a woman’s health might be threatened.

There are three main positions on the moral permissibility of abortion. The conservative view is that abortion is never morally acceptable (except possibly to preserve the mother’s life), for the unborn is a human being in the full sense. The liberal view is that abortion is acceptable whenever the woman wants it, for the unborn is not a human being in the full sense. The moderate stance falls between these two stands, rejecting both the conservative’s zero tolerance for abortion and the liberal’s idea of abortion on request. All sides tend to accept that murder is wrong, that persons have a right to life, and that personal freedom should not be curtailed except for very important reasons. Conservatives try to establish that the unborn should be recognized as an innocent person from the moment of conception by appealing to the lack of a precise cutoff point between zygote and adult human and by arguing that the fetus is a potential person. Liberals contend that merely being biologically human is not sufficient to establish personhood and that a fetus does not possess the properties that qualify an entity as a person. Taking a moderate position, Judith Jarvis Thomson argues that even if the conservative view is correct that the unborn is a person from the moment of conception, abortion may still be morally justified in some cases. The unborn’s right to life is not absolute; it implies not that killing a fetus is always wrong, but that killing it unjustly is always wrong.

A utilitarian position can be staked out either for abortion or against it, depending on how the overall consequences of abortion are calculated. Kantian ethics can also yield pro- or anti-abortion positions depending on whether the unborn is considered a person. The natural law position on abortion as articulated in Roman Catholicism is that the fetus is an innocent person from conception, and directly killing any innocent person is wrong. Thus, directly killing the unborn even for the purpose of saving the

mother’s life is impermissible. The doctrine of double effect, however, permits the indirect killing of the unborn—specifically, abortions done to save the mother’s life while having the unintended yet foreseen effect of killing the fetus.

## Cases for Evaluation

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### CASE I

#### Abortions for Minor Disabilities

(*London Times*)—More than 50 babies with club feet were aborted in just one area of England in a three-year period, according to new statistics.

Thirty-seven babies with cleft lips or palates and 26 with extra or webbed fingers or toes were also aborted.

The data have raised concerns about abortions being carried out for minor disabilities that could be cured by surgery.

Abortions are allowed up to birth in Britain in cases of serious handicap, but the law does not define what conditions should be considered grave enough to allow a termination late in the pregnancy. That is left to the discretion of doctors.

The Commons science and technology committee is carrying out an inquiry into whether the law should be made more specific.

Some parents, doctors and campaign groups are worried by what they see as a tendency to stretch the definition of serious handicap.

In 2003 Joanna Jepson, a Church of England curate, instigated a legal challenge against West Mercia police for failing to prosecute doctors who carried out an abortion on a baby with a cleft palate at 28 weeks’ gestation. The challenge failed but raised public concerns over terminations for minor disabilities.

However, the latest figures—released by the South West Congenital Register—show that dozens of abortions are still carried out after the condition is discovered.

Jepson, now vicar of St Peter’s church in Fulham, west London, said: “These figures raise grave questions about how the law is being implemented for babies diagnosed with a disability. I have strong doubts that the law is being used to protect the unborn.”

Julia Millington, political director of the ProLife Alliance, added: "It is incomprehensible that a baby would be rejected for what amounts to little more than a cosmetic imperfection. Equality for the disabled cannot be achieved until we remove this discriminatory provision in the law."\*

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*Do you think it is ever morally permissible to perform an abortion on a defective fetus? What about a fetus that is so deformed that it will certainly die within a few days after birth? Or a fetus with deformities that will guarantee it a lifetime of pain and serious disability and years of emotional and financial trauma for its family? Can abortions performed on fetuses with minor disabilities such as a cleft lip ever be justified? Give reasons for your answers.*

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\*Sarah-Kate Templeton, "Babies Aborted for Minor Disabilities," *TimesOnline*, October 21, 2007, <http://www.timesonline.co.uk/tol/news/uk/health/article2689787.ece>.

## CASE 2

### Sex-Selection Abortions

More than 10 [million] female births in India may have been lost to abortion and sex selection in the past 20 years, research published in the *Lancet* has claimed.

Researchers in India and Canada said prenatal selection and selective abortion was causing the loss of 500,000 girls a year. Their research was based on a national survey of 1.1 [million] households in 1998.

The research, by Prabhat Jha of St. Michael's Hospital at the University of Toronto, Canada, and Rajesh Kumar of the Postgraduate Institute of Medical Research in Chandigarh, India, found that there was an increasing tendency to select boys when previous children had been girls. In cases where the preceding child was a girl, the ratio of girls to boys in the next birth was 759 to 1,000. This fell even further when the two preceding children were both girls. Then the ratio for the third child born was just 719 girls to 1,000 boys. However, for a child following the birth of a male child, the gender ratio was roughly equal.

Prabhat Jha said conservative estimates in the research suggested half a million girls were being lost

each year. "If this practice has been common for most of the past two decades since access to ultrasound became widespread, then a figure of 10 [million] missing female births would not be unreasonable." In 1994, India banned the use of technology to determine the sex of unborn children and the termination of pregnancies on the basis of gender. Leading campaigners say many of India's fertility clinics continue to offer a seemingly legitimate facade for a multi-billion-pound racket and that gender determination is still big business in India.

However, a top Indian doctors' association disputed the report. The Indian Medical Association said pre-birth gender checks had waned since a Supreme Court crackdown in 2001. A spokesman acknowledged that prenatal selections used to take place, but said they were not as widespread as before and that the *Lancet* report was exaggerated. "This has not been happening for the past four or five years after strict laws were put in place," the spokesman, Dr. Narendra Saini, said. Other experts say it is impossible that India could have lost 10 [million] females. "If there were half a million feticides a year, the sex ratio would have been very skewed indeed," said Prof. S.C. Gulati of Delhi's Institute of Economic Growth.

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*Are sex-selection abortions ever justified? Is the practice of "female foeticide" a form of discrimination against females? If so, can it ever be morally permissible? Explain your answers.*

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\* "India: Dispute over Sex Ratio," <http://www.reproductivereview.org/>.

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## CASE 3

### Abortions and Prenatal Testing

(*New York Times*) Sarah Itoh, a self-described "almost-eleven-and-a-half," betrayed no trace of nervousness as she told a roomful of genetic counselors and obstetricians about herself one recent afternoon.

She likes to read, she said. Math used to be hard, but it is getting easier. She plays clarinet in her school band. She is a junior girl scout and an aunt, and she likes to organize, so her room is very clean. Last year, she won three medals in the Special Olympics.

"I am so lucky I get to do so many things," she concluded. "I just want you to know, even though I have Down syndrome, it is O.K."

Sarah's appearance at Henry Ford Hospital here is part of an unusual campaign being undertaken by parents of children with Down syndrome who worry about their future in the face of broader prenatal testing that could sharply reduce the number of those born with the genetic condition.

Until this year, only pregnant women 35 and older were routinely tested to see if their fetuses had the extra chromosome that causes Down syndrome. As a result many couples were given the diagnosis only at birth. But under a new recommendation from the American College of Obstetricians and Gynecologists, doctors have begun to offer a new, safer screening procedure to all pregnant women, regardless of age.

About 90 percent of pregnant women who are given a Down syndrome diagnosis have chosen to have an abortion.

Convinced that more couples would choose to continue their pregnancies if they better appreciated what it meant to raise a child with Down syndrome, a growing group of parents is seeking to insert their own positive perspectives into a decision often dominated by daunting medical statistics and doctors who feel obligated to describe the difficulties of life with a disabled child.

They are pressing obstetricians to send them couples who have been given a prenatal diagnosis and inviting prospective parents into their homes to meet their children. In Massachusetts, for example, volunteers in a "first call" network linking veteran parents to new ones are now offering support to couples deciding whether to continue a pregnancy.

The parent evangelists are driven by a deep-seated fear for their children's well-being in a world where there are fewer people like them. But as prenatal tests become available for a range of other perceived genetic imperfections, they may also be heralding a broader cultural skirmish over where to draw the line between preventing disability and accepting human diversity.

"We want people who make this decision to know our kids," said Lucy Talbot, the president of a support group here who prevailed on the hospital to

give Sarah and two teenage friends an audience. "We want them to talk to us."

The focus on the unborn is new for most parent advocates, who have traditionally directed their energy toward support for the born. But after broader testing was recommended in January, the subject began to hijack agendas at local support group meetings.

A dwindling Down syndrome population, which now stands at about 350,000, could mean less institutional support and reduced funds for medical research. It could also mean a lonelier world for those who remain.

"The impact of these changes on the Down syndrome community is going to be huge," said Dani Archer, a mother in Omaha who has set aside other Down syndrome volunteer work to strategize about how to reach prospective parents.

The 5,500 children born with Down syndrome each year in the United States suffer from mild to moderate mental retardation, are at high risk for congenital heart defects and a variety of other medical problems, and have an average life expectancy of 49. As adults, some hold jobs, but many have difficulty living independently.

"There are many couples who do not want to have a baby with Down syndrome," said Deborah A. Driscoll, chief of the obstetrics department at the University of Pennsylvania and a lead author of the new recommendation from the obstetricians' group. "They don't have the resources, don't have the emotional stamina, don't have the family support. We are recommending this testing be offered so that parents have a choice."\*

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*Is it right for parents to have abortions to avoid giving birth to a Down syndrome baby? Should society encourage such abortions to prevent disabilities or discourage them to promote a respect for human diversity? Should the quality of a Down syndrome baby's future life be a factor in deciding whether to have the abortion? Explain your answers.*

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## READINGS

### A Defense of Abortion

JUDITH JARVIS THOMSON

In this classic essay, Thomson argues that even if a fetus is a person at conception, at least some abortions could still be morally permissible. A fetus may have a right to life, but this right “does not guarantee having either a right to be given the use of or a right to be allowed continued use of another person’s body—even if one needs it for life itself.” A woman has a right not to have her body used by someone else against her will, which is essentially the case when she is pregnant due to no fault of her own (as a result of rape, for instance). The correct lesson about the unborn’s right to life is not that killing a fetus is always wrong, but that killing it unjustly is always wrong.

Most opposition to abortion relies on the premise that the fetus is a human being, a person, from the moment of conception. The premise is argued for, but, as I think, not well. Take, for example, the most common argument. We are asked to notice that the development of a human being from conception through birth into childhood is continuous; then it is said that to draw a line, to choose a point in this development and say “before this point the thing is not a person, after this point it is a person” is to make an arbitrary choice, a choice for which in the nature of things no good reason can be given. It is concluded that the fetus is, or anyway that we had better say it is, a person from the moment of conception. But this conclusion does not follow. Similar things might be said about the development of an acorn into an oak tree, and it does not follow that acorns are oak trees, or that we had better say they are. Arguments of this form are sometimes called “slippery slope arguments”—the phrase is perhaps self-explanatory—and it is dismaying that opponents of abortion rely on them so heavily and uncritically.

I am inclined to agree, however, that the prospects for “drawing a line” in the development of the fetus look dim. I am inclined to think also that we

shall probably have to agree that the fetus has already become a human person well before birth. Indeed, it comes as a surprise when one first learns how early in its life it begins to acquire human characteristics. By the tenth week, for example, it already has a face, arms and legs, fingers and toes; it has internal organs, and brain activity is detectable.<sup>1</sup> On the other hand, I think that the premise is false, that the fetus is not a person from the moment of conception. A newly fertilized ovum, a newly implanted clump of cells, is no more a person than an acorn is an oak tree. But I shall not discuss any of this. For it seems to me to be of great interest to ask what happens if, for the sake of argument, we allow the premise. How, precisely, are we supposed to get from there to the conclusion that abortion is morally impermissible? Opponents of abortion commonly spend most of their time establishing that the fetus is a person, and hardly any time explaining the step from there to the impermissibility of abortion. Perhaps they think the step too simple and obvious to require much comment. Or perhaps instead they are simply being economical in argument. Many of those who defend abortion rely on the premise that the fetus is not a person, but only a bit of tissue that will become a person at birth; and why pay out more arguments than you have to? Whatever the explanation, I suggest that the step they take is neither easy nor obvious, that it calls for closer examination than it is commonly given, and

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From “A Defense of Abortion,” *Philosophy & Public Affairs* 1, no. 1 (Fall 1971). Copyright © 1971. Reprinted with permission of Blackwell Publishing. (Notes edited.)

that when we do give it this closer examination we shall feel inclined to reject it.

I propose, then, that we grant that the fetus is a person from the moment of conception. How does the argument go from here? Something like this, I take it. Every person has a right to life. So the fetus has a right to life. No doubt the mother has a right to decide what shall happen in and to her body; everyone would grant that. But surely a person's right to life is stronger and more stringent than the mother's right to decide what happens in and to her body, and so outweighs it. So the fetus may not be killed; an abortion may not be performed.

It sounds plausible. But now let me ask you to imagine this. You wake up in the morning and find yourself back to back in bed with an unconscious violinist. A famous unconscious violinist. He has been found to have a fatal kidney ailment, and the Society of Music Lovers has canvassed all the available medical records and found that you alone have the right blood type to help. They have therefore kidnapped you, and last night the violinist's circulatory system was plugged into yours, so that your kidneys can be used to extract poisons from his blood as well as your own. The director of the hospital now tells you, "Look, we're sorry the Society of Music Lovers did this to you—we would never have permitted it if we had known. But still, they did it, and the violinist now is plugged into you. To unplug you would be to kill him. But never mind, it's only for nine months. By then he will have recovered from his ailment, and can safely be unplugged from you." Is it morally incumbent on you to accede to this situation? No doubt it would be very nice of you if you did, a great kindness. But do you *have* to accede to it? What if it were not nine months, but nine years? Or longer still? What if the director of the hospital says, "Tough luck, I agree, but you've now got to stay in bed, with the violinist plugged into you, for the rest of your life. Because remember this. All persons have a right to life, and violinists are persons. Granted you have a right to decide what happens in and to your body, but a person's right to life outweighs your right to decide what happens in and to your body. So you

cannot ever be unplugged from him." I imagine you would regard this as outrageous, which suggests that something really is wrong with that plausible-sounding argument I mentioned a moment ago.

In this case, of course, you were kidnapped; you didn't volunteer for the operation that plugged the violinist into your kidneys. Can those who oppose abortion on the ground I mentioned make an exception for a pregnancy due to rape? Certainly. They can say that persons have a right to life only if they didn't come into existence because of rape; or they can say that all persons have a right to life, but that some have less of a right to life than others, in particular, that those who came into existence because of rape have less. But these statements have a rather unpleasant sound. Surely the question of whether you have a right to life at all, or how much of it you have, shouldn't turn on the question of whether or not you are the product of a rape. And in fact the people who oppose abortion on the ground I mentioned do not make this distinction, and hence do not make an exception in case of rape.

Nor do they make an exception for a case in which the mother has to spend the nine months of her pregnancy in bed. They would agree that would be a great pity, and hard on the mother; but all the same, all persons have a right to life, the fetus is a person, and so on. I suspect, in fact, that they would not make an exception for a case in which, miraculously enough, the pregnancy went on for nine years, or even the rest of the mother's life.

Some won't even make an exception for a case in which continuation of the pregnancy is likely to shorten the mother's life; they regard abortion as impermissible even to save the mother's life. Such cases are nowadays very rare, and many opponents of abortion do not accept this extreme view. All the same, it is a good place to begin: a number of points of interest come out in respect to it.

1. Let us call the view that abortion is impermissible even to save the mother's life "the extreme view." I want to suggest first that it does not issue

from the argument I mentioned earlier without the addition of some fairly powerful premises. Suppose a woman has *become pregnant*, and now learns that she has a cardiac condition such that she will die if she carries the baby to term. What may be done for her? The fetus, being a person, has a right to life, but as the mother is a person too, so has she a right to life. Presumably they have an equal right to life. How is it supposed to come out that an abortion may not be performed? If mother and child have an equal right to life, shouldn't we perhaps flip a coin? Or should we add to the mother's right to life her right to decide what happens in and to her body, which everybody seems to be ready to grant—the sum of her rights now outweighing the fetus' right to life?

The most familiar argument here is the following. We are told that performing the abortion would be directly killing<sup>2</sup> the child, whereas doing nothing would not be killing the mother, but only letting her die. Moreover, in killing the child, one would be killing an innocent person, for the child has committed no crime, and is not aiming at his mother's death. And then there are a variety of ways in which this might be continued. (1) But as directly killing an innocent person is always and absolutely impermissible, an abortion may not be performed. Or, (2) as directly killing an innocent person is murder, and murder is always and absolutely impermissible, an abortion may not be performed.<sup>3</sup> Or, (3) as one's duty to refrain from directly killing an innocent person is more stringent than one's duty to keep a person from dying, an abortion may not be performed. Or, (4) if one's only options are directly killing an innocent person or letting a person die, one must prefer letting the person die, and thus an abortion may not be performed.<sup>4</sup>

Some people seem to have thought that these are not further premises which must be added if the conclusion is to be reached, but that they follow from the very fact that an innocent person has a right to life.<sup>5</sup> But this seems to me to be a mistake, and perhaps the simplest way to show this is to bring out that while we must certainly grant that innocent persons have a right to life, the theses in

(1) through (4) are all false. Take (2), for example. If directly killing an innocent person is murder, and thus is impermissible, then the mother's directly killing the innocent person inside her is murder, and thus is impermissible. But it cannot seriously be thought to be murder if the mother performs an abortion on herself to save her life. It cannot seriously be said that she *must* refrain, that she *must* sit passively by and wait for her death. Let us look again at the case of you and the violinist. There you are, in bed with the violinist, and the director of the hospital says to you, "It's all most distressing, and I deeply sympathize, but you see this is putting an additional strain on your kidneys, and you'll be dead within the month. But you *have* to stay where you are all the same. Because unplugging you would be directly killing an innocent violinist, and that's murder, and that's impermissible." If anything in the world is true, it is that you do not commit murder, you do not do what is impermissible, if you reach around to your back and unplug yourself from that violinist to save your life.

The main focus of attention in writings on abortion has been on what a third party may or may not do in answer to a request from a woman for an abortion. This is in a way understandable. Things being as they are, there isn't much a woman can safely do to abort herself. So the question asked is what a third party may do, and what the mother may do, if it is mentioned at all, is deduced, almost as an after-thought, from what it is concluded that third parties may do. But it seems to me that to treat the matter in this way is to refuse to grant to the mother that very status of person which is so firmly insisted on for the fetus. For we cannot simply read off what a person may do from what a third party may do. Suppose you find yourself trapped in a tiny house with a growing child. I mean a very tiny house, and a rapidly growing child—you are already up against the wall of the house and in a few minutes you'll be crushed to death. The child on the other hand won't be crushed to death; if nothing is done to stop him from growing he'll be hurt, but in the end he'll simply burst open the house and

walk out a free man. Now I could well understand it if a bystander were to say, "There's nothing we can do for you. We cannot choose between your life and his, we cannot be the ones to decide who is to live, we cannot intervene." But it cannot be concluded that you too can do nothing, that you cannot attack it to save your life. However innocent the child may be, you do not have to wait passively while it crushes you to death. Perhaps a pregnant woman is vaguely felt to have the status of house, to which we don't allow the right of self-defense. But if the woman houses the child, it should be remembered that she is a person who houses it.

I should perhaps stop to say explicitly that I am not claiming that people have a right to do anything whatever to save their lives. I think, rather, that there are drastic limits to the right of self-defense. If someone threatens you with death unless you torture someone else to death, I think you have not the right, even to save your life, to do so. But the case under consideration here is very different. In our case there are only two people involved, one whose life is threatened, and one who threatens it. Both are innocent: the one who is threatened is not threatened because of any fault, the one who threatens does not threaten because of any fault. For this reason we may feel that we bystanders cannot intervene. But the person threatened can.

In sum, a woman surely can defend her life against the threat to it posed by the unborn child, even if doing so involves its death. And this shows not merely that the theses in (1) through (4) are false; it shows also that the extreme view of abortion is false, and so we need not canvass any other possible ways of arriving at it from the argument I mentioned at the outset.

2. The extreme view could of course be weakened to say that while abortion is permissible to save the mother's life, it may not be performed by a third party, but only by the mother herself. But this cannot be right either. For what we have to keep in mind is that the mother and the unborn child are not like two tenants in a small house which has, by an unfortunate mistake, been rented to both: the

mother *owns* the house. The fact that she does adds to the offensiveness of deducing that the mother can do nothing from the supposition that third parties can do nothing. But it does more than this: it casts a bright light on the supposition that third parties can do nothing. Certainly it lets us see that a third party who says "I cannot choose between you" is fooling himself if he thinks this is impartiality. If Jones has found and fastened on a certain coat, which he needs to keep him from freezing, but which Smith also needs to keep him from freezing, then it is not impartiality that says "I cannot choose between you" when Smith owns the coat. Women have said again and again "This body is *my* body!" and they have reason to feel angry, reason to feel that it has been like shouting into the wind. Smith, after all, is hardly likely to bless us if we say to him, "Of course it's your coat, anybody would grant that it is. But no one may choose between you and Jones who is to have it."

We should really ask what it is that says "no one may choose" in the face of the fact that the body that houses the child is the mother's body. It may be simply a failure to appreciate this fact. But it may be something more interesting, namely the sense that one has a right to refuse to lay hands on people, even where it would be just and fair to do so, even where justice seems to require that somebody do so. Thus justice might call for somebody to get Smith's coat back from Jones, and yet you have a right to refuse to be the one to lay hands on Jones, a right to refuse to do physical violence to him. This, I think, must be granted. But then what should be said is not "no one may choose," but only "I cannot choose," and indeed not even this, but "I will not act," leaving it open that somebody else can or should, and in particular that anyone in a position of authority, with the job of securing people's rights, both can and should. So this is no difficulty. I have not been arguing that any given third party must accede to the mother's request that he perform an abortion to save her life, but only that he may.

I suppose that in some views of human life the mother's body is only on loan to her, the loan not being one which gives her any prior claim to it.

One who held this view might well think it impartiality to say "I cannot choose." But I shall simply ignore this possibility. My own view is that if a human being has any just, prior claim to anything at all, he has a just, prior claim to his own body. And perhaps this needn't be argued for here anyway, since, as I mentioned, the arguments against abortion we are looking at do grant that the woman has a right to decide what happens in and to her body.

But although they do grant it, I have tried to show that they do not take seriously what is done in granting it. I suggest the same thing will reappear even more clearly when we turn away from cases in which the mother's life is at stake, and attend, as I propose we now do, to the vastly more common cases in which a woman wants an abortion for some less weighty reason than preserving her own life.

3. Where the mother's life is not at stake, the argument I mentioned at the outset seems to have a much stronger pull. "Everyone has a right to life, so the unborn person has a right to life." And isn't the child's right to life weightier than anything other than the mother's own right to life, which she might put forward as ground for an abortion?

This argument treats the right to life as if it were unproblematic. It is not, and this seems to me to be precisely the source of the mistake.

For we should now, at long last, ask what it comes to, to have a right to life. In some views having a right to life includes having a right to be given at least the bare minimum one needs for continued life. But suppose that what in fact *is* the bare minimum a man needs for continued life is something he has no right at all to be given? If I am sick unto death, and the only thing that will save my life is the touch of Henry Fonda's cool hand on my fevered brow, then all the same, I have no right to be given the touch of Henry Fonda's cool hand on my fevered brow. It would be frightfully nice of him to fly in from the West Coast to provide it. It would be less nice, though no doubt well meant, if my friends flew out to the West Coast and carried Henry Fonda back with them. But I have no right

at all against anybody that he should do this for me. Or again, to return to the story I told earlier, the fact that for continued life that violinist needs the continued use of your kidneys does not establish that he has a right to be given the continued use of your kidneys. He certainly has no right against you that *you* should give him continued use of your kidneys. For nobody has any right to use your kidneys unless you give him such a right; and nobody has the right against you that you shall give him this right—if you do allow him to go on using your kidneys, this is a kindness on your part, and not something he can claim from you as his due. Nor has he any right against anybody else that *they* should give him continued use of your kidneys. Certainly he had no right against the Society of Music Lovers that they should plug him into you in the first place. And if you now start to unplug yourself, having learned that you will otherwise have to spend nine years in bed with him, there is nobody in the world who must try to prevent you, in order to see to it that he is given something he has a right to be given.

Some people are rather stricter about the right to life. In their view, it does not include the right to be given anything, but amounts to, and only to, the right not to be killed by anybody. But here a related difficulty arises. If everybody is to refrain from killing that violinist, then everybody must refrain from doing a great many different sorts of things. Everybody must refrain from slitting his throat, everybody must refrain from shooting him—and everybody must refrain from unplugging you from him. But does he have a right against everybody that they shall refrain from unplugging you from him? To refrain from doing this is to allow him to continue to use your kidneys. It could be argued that he has a right against us that *we* should allow him to continue to use your kidneys. That is, while he had no right against us that we should give him the use of your kidneys, it might be argued that he anyway has a right against us that we shall not now intervene and deprive him of the use of your kidneys. I shall come back to third-party interventions later. But certainly the violinist has no

right against you that *you* shall allow him to continue to use your kidneys. As I said, if you do allow him to use them, it is a kindness on your part, and not something you owe him.

The difficulty I point to here is not peculiar to the right to life. It reappears in connection with all the other natural rights; and it is something which an adequate account of rights must deal with. For present purposes it is enough just to draw attention to it. But I would stress that I am not arguing that people do not have a right to life—quite to the contrary, it seems to me that the primary control we must place on the acceptability of an account of rights is that it should turn out in that account to be a truth that all persons have a right to life. I am arguing only that having a right to life does not guarantee having either a right to be given the use of or a right to be allowed continued use of another person's body—even if one needs it for life itself. So the right to life will not serve the opponents of abortion in the very simple and clear way in which they seem to have thought it would.

4. There is another way to bring out the difficulty. In the most ordinary sort of case, to deprive someone of what he has a right to is to treat him unjustly. Suppose a boy and his small brother are jointly given a box of chocolates for Christmas. If the older boy takes the box and refuses to give his brother any of the chocolates, he is unjust to him, for the brother has been given a right to half of them. But suppose that, having learned that otherwise it means nine years in bed with that violinist, you unplug yourself from him. You surely are not being unjust to him, for you gave him no right to use your kidneys, and no one else can have given him any such right. But we have to notice that in unplugging yourself, you are killing him; and violinists, like everybody else, have a right to life, and thus in the view we were considering just now, the right not to be killed. So here you do what he supposedly has a right you shall not do, but you do not act unjustly to him in doing it.

The emendation which may be made at this point is this: the right to life consists not in the

right not to be killed, but rather in the right not to be killed unjustly. This runs a risk of circularity, but never mind: it would enable us to square the fact that the violinist has a right to life with the fact that you do not act unjustly toward him in unplugging yourself, thereby killing him. For if you do not kill him unjustly, you do not violate his right to life, and so it is no wonder you do him no injustice.

But if this emendation is accepted, the gap in the argument against abortion stares us plainly in the face: it is by no means enough to show that the fetus is a person, and to remind us that all persons have a right to life—we need to be shown also that killing the fetus violates its right to life, i.e., that abortion is unjust killing. And is it?

I suppose we may take it as a datum that in a case of pregnancy due to rape the mother has not given the unborn person a right to the use of her body for food and shelter. Indeed, in what pregnancy could it be supposed that the mother has given the unborn person such a right? It is not as if there were unborn persons drifting about the world, to whom a woman who wants a child says "I invite you in."

But it might be argued that there are other ways one can have acquired a right to the use of another person's body than by having been invited to use it by that person. Suppose a woman voluntarily indulges in intercourse, knowing of the chance it will issue in pregnancy, and then she does become pregnant; is she not in part responsible for the presence, in fact the very existence, of the unborn person inside her? No doubt she did not invite it in. But doesn't her partial responsibility for its being there itself give it a right to the use of her body?<sup>6</sup> If so, then her aborting it would be more like the boy's taking away the chocolates, and less like your unplugging yourself from the violinist—doing so would be depriving it of what it does have a right to, and thus would be doing it an injustice.

And then, too, it might be asked whether or not she can kill it even to save her own life: If she voluntarily called it into existence, how can she now kill it, even in self-defense?

The first thing to be said about this is that it is something new. Opponents of abortion have been so concerned to make out the independence of the fetus, in order to establish that it has a right to life, just as its mother does, that they have tended to overlook the possible support they might gain from making out that the fetus is *dependent* on the mother, in order to establish that she has a special kind of responsibility for it, a responsibility that gives it rights against her which are not possessed by any independent person—such as an ailing violinist who is a stranger to her.

On the other hand, this argument would give the unborn person a right to its mother's body only if her pregnancy resulted from a voluntary act, undertaken in full knowledge of the chance a pregnancy might result from it. It would leave out entirely the unborn person whose existence is due to rape. Pending the availability of some further argument, then, we would be left with the conclusion that unborn persons whose existence is due to rape have no right to the use of their mothers' bodies, and thus that aborting them is not depriving them of anything they have a right to and hence is not unjust killing.

And we should also notice that it is not at all plain that this argument really does go even as far as it purports to. For there are cases and cases, and the details make a difference. If the room is stuffy, and I therefore open a window to air it, and a burglar climbs in, it would be absurd to say, "Ah, now he can stay, she's given him a right to the use of her house—for she is partially responsible for his presence there, having voluntarily done what enabled him to get in, in full knowledge that there are such things as burglars, and that burglars burgle." It would be still more absurd to say this if I had had bars installed outside my windows, precisely to prevent burglars from getting in, and a burglar got in only because of a defect in the bars. It remains equally absurd if we imagine it is not a burglar who climbs in, but an innocent person who blunders or falls in. Again, suppose it were like this: people-seeds drift about in the air like pollen, and if you open your windows, one may drift in and

take root in your carpets or upholstery. You don't want children, so you fix up your windows with fine mesh screens, the very best you can buy. As can happen, however, and on very, very rare occasions does happen, one of the screens is defective; and a seed drifts in and takes root. Does the person-plant who now develops have a right to the use of your house? Surely not—despite the fact that you voluntarily opened your windows, you knowingly kept carpets and upholstered furniture, and you knew that screens were sometimes defective. Someone may argue that you are responsible for its rooting, that it does have a right to your house, because after all you *could* have lived out your life with bare floors and furniture, or with sealed windows and doors. But this won't do—for by the same token anyone can avoid a pregnancy due to rape by having a hysterectomy, or anyway by never leaving home without a (reliable!) army.

It seems to me that the argument we are looking at can establish at most that there are *some* cases in which the unborn person has a right to the use of its mother's body, and therefore *some* cases in which abortion is unjust killing. There is room for much discussion and argument as to precisely which, if any. But I think we should sidestep this issue and leave it open, for at any rate the argument certainly does not establish that all abortion is unjust killing.

5. There is room for yet another argument here, however. We surely must all grant that there may be cases in which it would be morally indecent to detach a person from your body at the cost of his life. Suppose you learn that what the violinist needs is not nine years of your life, but only one hour: all you need do to save his life is to spend one hour in that bed with him. Suppose also that letting him use your kidneys for that one hour would not affect your health in the slightest. Admittedly you were kidnapped. Admittedly you did not give anyone permission to plug him into you. Nevertheless it seems to me plain you *ought* to allow him to use your kidneys for that hour—it would be indecent to refuse.

Again, suppose pregnancy lasted only an hour, and constituted no threat to life or health. And

suppose that a woman becomes pregnant as a result of rape. Admittedly she did not voluntarily do anything to bring about the existence of a child. Admittedly she did nothing at all which would give the unborn person a right to the use of her body. All the same it might well be said, as in the newly emended violinist story, that she *ought* to allow it to remain for that hour—that it would be indecent in her to refuse.

Now some people are inclined to use the term “right” in such a way that it follows from the fact that you ought to allow a person to use your body for the hour he needs, that he has a right to use your body for the hour he needs, even though he has not been given that right by any person or act. They may say that it follows also that if you refuse, you act unjustly toward him. This use of the term is perhaps so common that it cannot be called wrong; nevertheless it seems to me to be an unfortunate loosening of what we would do better to keep a tight rein on. Suppose that box of chocolates I mentioned earlier had not been given to both boys jointly, but was given only to the older boy. There he sits, stolidly eating his way through the box, his small brother watching enviously. Here we are likely to say “You ought not to be so mean. You ought to give your brother some of those chocolates.” My own view is that it just does not follow from the truth of this that the brother has any right to any of the chocolates. If the boy refuses to give his brother any, he is greedy, stingy, callous—but not unjust. I suppose that the people I have in mind will say it does follow that the brother has a right to some of the chocolates, and thus that the boy does act unjustly if he refuses to give his brother any. But the effect of saying this is to obscure what we should keep distinct, namely the difference between the boy’s refusal in this case and the boy’s refusal in the earlier case, in which the box was given to both boys jointly, and in which the small brother thus had what was from any point of view clear title to half.

A further objection to so using the term “right” that from the fact that A ought to do a thing for B, it follows that B has a right against A that A do it

for him, is that it is going to make the question of whether or not a man has a right to a thing turn on how easy it is to provide him with it; and this seems not merely unfortunate, but morally unacceptable. Take the case of Henry Fonda again. I said earlier that I had no right to the touch of his cool hand on my fevered brow, even though I needed it to save my life. I said it would be frightfully nice of him to fly in from the West Coast to provide me with it, but that I had no right against him that he should do so. But suppose he isn’t on the West Coast. Suppose he has only to walk across the room, place a hand briefly on my brow—and lo, my life is saved. Then surely he ought to do it, it would be indecent to refuse. Is it to be said “Ah, well, it follows that in this case she has a right to the touch of his hand on her brow, and so it would be an injustice in him to refuse”? So that I have a right to it when it is easy for him to provide it, though no right when it’s hard? It’s rather a shocking idea that anyone’s rights should fade away and disappear as it gets harder and harder to accord them to him.

So my own view is that even though you ought to let the violinist use your kidneys for the one hour he needs, we should not conclude that he has a right to do so—we should say that if you refuse, you are, like the boy who owns all the chocolates and will give none away, self-centered and callous, indecent in fact, but not unjust. And similarly, that even supposing a case in which a woman pregnant due to rape ought to allow the unborn person to use her body for the hour he needs, we should not conclude that he has a right to do so; we should conclude that she is self-centered, callous, indecent, but not unjust, if she refuses. The complaints are no less grave; they are just different. However, there is no need to insist on this point. If anyone does wish to deduce “he has a right” from “you ought,” then all the same he must surely grant that there are cases in which it is not morally required of you that you allow that violinist to use your kidneys, and in which he does not have a right to use them, and in which you do not do him an injustice if you refuse. And so also for mother and unborn child. Except in such cases as the unborn person

has a right to demand it—and we were leaving open the possibility that there may be such cases—nobody is morally *required* to make large sacrifices, of health, of all other interests and concerns, of all other duties and commitments, for nine years, or even for nine months, in order to keep another person alive.

6. We have in fact to distinguish between two kinds of Samaritan: the Good Samaritan and what we might call the Minimally Decent Samaritan. The story of the Good Samaritan, you will remember, goes like this:

A certain man went down from Jerusalem to Jericho, and fell among thieves, which stripped him of his raiment, and wounded him, and departed, leaving him half dead.

And by chance there came down a certain priest that way; and when he saw him, he passed by on the other side.

And likewise a Levite, when he was at the place, came and looked on him, and passed by on the other side.

But a certain Samaritan, as he journeyed, came where he was; and when he saw him he had compassion on him.

And went to him, and bound up his wounds, pouring in oil and wine, and set him on his own beast, and brought him to an inn, and took care of him.

And on the morrow, when he departed, he took out two pence, and gave them to the host, and said unto him, "Take care of him; and whatsoever thou spendest more, when I come again, I will repay thee." (Luke 10:30–35)

The Good Samaritan went out of his way, at some cost to himself, to help one in need of it. We are not told what the options were, that is, whether or not the priest and the Levite could have helped by doing less than the Good Samaritan did, but assuming they could have, then the fact they did nothing at all shows they were not even Minimally Decent Samaritans, not because they were not Samaritans, but because they were not even minimally decent.

These things are a matter of degree, of course, but there is a difference, and it comes out perhaps most clearly in the story of Kitty Genovese, who, as you will remember, was murdered while thirty-eight people watched or listened, and did

nothing at all to help her. A Good Samaritan would have rushed out to give direct assistance against the murderer. Or perhaps we had better allow that it would have been a Splendid Samaritan who did this, on the ground that it would have involved a risk of death for himself. But the thirty-eight not only did not do this, they did not even trouble to pick up a phone to call the police. Minimally Decent Samaritanism would call for doing at least that, and their not having done it was monstrous.

After telling the story of the Good Samaritan, Jesus said "Go, and do thou likewise." Perhaps he meant that we are morally required to act as the Good Samaritan did. Perhaps he was urging people to do more than is morally required of them. At all events it seems plain that it was not morally required of any of the thirty-eight that he rush out to give direct assistance at the risk of his own life, and that it is not morally required of anyone that he give long stretches of his life—nine years or nine months—to sustaining the life of a person who has no special right (we were leaving open the possibility of this) to demand it.

Indeed, with one rather striking class of exceptions, no one in any country in the world is *legally* required to do anywhere near as much as this for anyone else. The class of exceptions is obvious. My main concern here is not the state of the law in respect to abortion, but it is worth drawing attention to the fact that in no state in this country is any man compelled by law to be even a Minimally Decent Samaritan to any person; there is no law under which charges could be brought against the thirty-eight who stood by while Kitty Genovese died. By contrast, in most states in this country women are compelled by law to be not merely Minimally Decent Samaritans, but Good Samaritans to unborn persons inside them. This doesn't by itself settle anything one way or the other, because it may well be argued that there should be laws in this country—as there are in many European countries—compelling at least Minimally Decent Samaritanism.<sup>7</sup> But it does show that there is a gross injustice in the existing state of the law. And it shows also that the groups currently

working against liberalization of abortion laws, in fact working toward having it declared unconstitutional for a state to permit abortion, had better start working for the adoption of Good Samaritan laws generally, or earn the charge that they are acting in bad faith.

I should think, myself, that Minimally Decent Samaritan laws would be one thing, Good Samaritan laws quite another, and in fact highly improper. But we are not here concerned with the law. What we should ask is not whether anybody should be compelled by law to be a Good Samaritan, but whether we must accede to a situation in which somebody is being compelled—by nature, perhaps—to be a Good Samaritan. We have, in other words, to look now at third-party interventions. I have been arguing that no person is morally required to make large sacrifices to sustain the life of another who has no right to demand them, and this even where the sacrifices do not include life itself; we are not morally required to be Good Samaritans or anyway Very Good Samaritans to one another. But what if a man cannot extricate himself from such a situation? What if he appeals to us to extricate him? It seems to me plain that there are cases in which we can, cases in which a Good Samaritan would extricate him. There you are, you were kidnapped, and nine years in bed with that violinist lie ahead of you. You have your own life to lead. You are sorry, but you simply cannot see giving up so much of your life to the sustaining of his. You cannot extricate yourself, and ask us to do so. I should have thought that—in light of his having no right to the use of your body—it was obvious that we do not have to accede to your being forced to give up so much. We can do what you ask. There is no injustice to the violinist in our doing so.

7. Following the lead of the opponents of abortion, I have throughout been speaking of the fetus merely as a person, and what I have been asking is whether or not the argument we began with, which proceeds only from the fetus' being a person, really does establish its conclusion. I have argued that it does not.

But of course there are arguments and arguments, and it may be said that I have simply

fastened on the wrong one. It may be said that what is important is not merely the fact that the fetus is a person, but that it is a person for whom the woman has a special kind of responsibility issuing from the fact that she is its mother. And it might be argued that all my analogies are therefore irrelevant—for you do not have that special kind of responsibility for that violinist, Henry Fonda does not have that special kind of responsibility for me. And our attention might be drawn to the fact that men and women both *are* compelled by law to provide support for their children.

I have in effect dealt (briefly) with this argument in section 4; but a (still briefer) recapitulation now may be in order. Surely we do not have any such “special responsibility” for a person unless we have assumed it, explicitly or implicitly. If a set of parents do not try to prevent pregnancy, do not obtain an abortion, and then at the time of birth of the child do not put it out for adoption, but rather take it home with them, then they have assumed responsibility for it, they have given it rights, and they cannot *now* withdraw support from it at the cost of its life because they now find it difficult to go on providing for it. But if they have taken all reasonable precautions against having a child, they do not simply by virtue of their biological relationship to the child who comes into existence have a special responsibility for it. They may wish to assume responsibility for it, or they may not wish to. And I am suggesting that if assuming responsibility for it would require large sacrifices, then they may refuse. A Good Samaritan would not refuse—or anyway, a Splendid Samaritan, if the sacrifices that had to be made were enormous. But then so would a Good Samaritan assume responsibility for that violinist; so would Henry Fonda, if he is a Good Samaritan, fly in from the West Coast and assume responsibility for me.

8. My argument will be found unsatisfactory on two counts by many of those who want to regard abortion as morally permissible. First, while I do argue that abortion is not impermissible, I do not argue that it is always permissible. There may well be cases in which carrying the child to term requires only Minimally Decent

Samaritanism of the mother, and this is a standard we must not fall below. I am inclined to think it a merit of my account precisely that it does *not* give a general yes or a general no. It allows for and supports our sense that, for example, a sick and desperately frightened fourteen-year-old schoolgirl, pregnant due to rape, may *of course* choose abortion, and that any law which rules this out is an insane law. And it also allows for and supports our sense that in other cases resort to abortion is even positively indecent. It would be indecent in the woman to request an abortion, and indecent in a doctor to perform it, if she is in her seventh month, and wants the abortion just to avoid the nuisance of postponing a trip abroad. The very fact that the arguments I have been drawing attention to treat all cases of abortion, or even all cases of abortion in which the mother's life is not at stake, as morally on a par ought to have made them suspect at the outset.

Secondly, while I am arguing for the permissibility of abortion in some cases, I am not arguing for the right to secure the death of the unborn child. It is easy to confuse these two things in that up to a certain point in the life of the fetus it is not able to survive outside the mother's body; hence removing it from her body guarantees its death. But they are importantly different. I have argued that you are not morally required to spend nine months in bed, sustaining the life of that violinist; but to say this is by no means to say that if, when you unplug yourself, there is a miracle and he survives, you then have a right to turn round and slit his throat. You may detach yourself even if this costs him his life; you have no right to be guaranteed his death, by some other means, if unplugging yourself does not kill him. There are some people who will feel dissatisfied by this feature of my argument. A woman may be utterly devastated by the thought of a child, a bit of herself, put out for adoption and never seen or heard of again. She may therefore want not merely that the child be detached from her, but more, that it die. Some opponents of abortion are inclined to regard this as beneath contempt—thereby showing insensitivity to what is surely a

powerful source of despair. All the same, I agree that the desire for the child's death is not one which anybody may gratify, should it turn out to be possible to detach the child alive.

At this place, however, it should be remembered that we have only been pretending throughout that the fetus is a human being from the moment of conception. A very early abortion is surely not the killing of a person, and so is not dealt with by anything I have said here.

#### NOTES

I am very much indebted to James Thomson for discussion, criticism, and many helpful suggestions.

1. Daniel Callahan, *Abortion: Law, Choice and Morality* (New York, 1970), p. 373. This book gives a fascinating survey of the available information on abortion. The Jewish tradition is surveyed in David M. Feldman, *Birth Control in Jewish Law* (New York, 1968), Part 5, the Catholic tradition in John T. Noonan, Jr., "An Almost Absolute Value in History," in *The Morality of Abortion*, ed. John T. Noonan, Jr. (Cambridge, Mass., 1970).
2. The term "direct" in the arguments I refer to is a technical one. Roughly, what is meant by "direct killing" is either killing as an end in itself, or killing as a means to some end, for example, the end of saving someone else's life. See note 5 for an example of its use.
3. Cf. *Encyclical Letter of Pope Pius XI on Christian Marriage*, St. Paul Editions (Boston, n.d.), p. 32: "however much we may pity the mother whose health and even life is gravely imperiled in the performance of the duty allotted to her by nature, nevertheless what could ever be a sufficient reason for excusing in any way the direct murder of the innocent? This is precisely what we are dealing with here." Noonan (*The Morality of Abortion*, p. 43) reads this as follows: "What cause can ever avail to excuse in any way the direct killing of the innocent? For it is a question of that."
4. The thesis in (4) is in an interesting way weaker than those in (1), (2), and (3): they rule out abortion even in cases in which both mother *and* child will die if the abortion is not performed. By contrast, one who held the view expressed in (4) could consistently say that one needn't prefer letting two persons die to killing one.
5. Cf. the following passage from Pius XII, *Address to the Italian Catholic Society of Midwives*: "The baby in the maternal breast has the right to life immediately from God.—Hence there is no man, no human authority, no science, no medical, eugenic, social,

economic or moral ‘indication’ which can establish or grant a valid juridical ground for a direct deliberate position of an innocent human life, that is a disposition which looks to its destruction either as an end or as a means to another end perhaps in itself not illicit.—The baby, still not born, is a man in the same degree and for the same reason as the mother” (quoted in Noonan, *The Morality of Abortion*, p. 45).

6. The need for a discussion of this argument was brought home to me by members of the Society for Ethical and Legal Philosophy, to whom this paper was originally presented.
7. For a discussion of the difficulties involved, and a survey of the European experience with such laws, see *The Good Samaritan and the Law*, ed. James M. Ratcliffe (New York, 1966).

## Why Abortion Is Immoral

DON MARQUIS

Marquis first identifies what it is that makes murder wrong and then applies this understanding to the case of abortion. He argues that murdering someone is wrong because it robs him or her of a future—a loss of all possible “experiences, activities, projects, and enjoyments.” Likewise, abortion is almost always wrong because it deprives the fetus of all prospects of such future experiencing and being.

The view that abortion is, with rare exceptions, seriously immoral has received little support in the recent philosophical literature. No doubt most philosophers affiliated with secular institutions of higher education believe that the anti-abortion position is either a symptom of irrational religious dogma or a conclusion generated by seriously confused philosophical argument. The purpose of this essay is to undermine this general belief. This essay sets out an argument that purports to show, as well as any argument in ethics can show, that abortion is, except possibly in rare cases, seriously immoral, that it is in the same moral category as killing an innocent adult human being.

The argument is based on a major assumption. Many of the most insightful and careful writers on the ethics of abortion—such as Joel Feinberg, Michael Tooley, Mary Anne Warren, H. Tristram Engelhardt, Jr., L. W. Sumner, John T. Noonan, Jr., and Philip Devine<sup>1</sup>—believe that whether or not abortion is morally permissible stands or falls on

whether or not a fetus is the sort of being whose life it is seriously wrong to end. The argument of this essay will assume, but not argue, that they are correct.

Also, this essay will neglect issues of great importance to a complete ethics of abortion. Some anti-abortionists will allow that certain abortions, such as abortion before implantation or abortion when the life of a woman is threatened by a pregnancy or abortion after rape, may be morally permissible. This essay will not explore the casuistry of these hard cases. The purpose of this essay is to develop a general argument for the claim that the overwhelming majority of deliberate abortions are seriously immoral.

### I

A sketch of standard anti-abortion and pro-choice arguments exhibits how those arguments possess certain symmetries that explain why partisans of those positions are so convinced of the correctness of their own positions, why they are not successful in convincing their opponents, and why, to others, this issue seems to be unresolvable. An analysis of the nature of this standoff suggests a strategy for surmounting it.

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Consider the way a typical anti-abortionist argues. She will argue or assert that life is present from the moment of conception or that fetuses look like babies or that fetuses possess a characteristic such as a genetic code that is both necessary and sufficient for being human. Anti-abortionists seem to believe that (1) the truth of all of these claims is quite obvious, and (2) establishing any of these claims is sufficient to show that abortion is morally akin to murder.

A standard pro-choice strategy exhibits similarities. The pro-choicer will argue or assert that fetuses are not persons or that fetuses are not rational agents or that fetuses are not social beings. Pro-choicers seem to believe that (1) the truth of any of these claims is quite obvious, and (2) establishing any of these claims is sufficient to show that an abortion is not a wrongful killing.

In fact, both the pro-choice and the anti-abortion claims do seem to be true, although the “it looks like a baby” claim is more difficult to establish the earlier the pregnancy. We seem to have a standoff. How can it be resolved?

As everyone who has taken a bit of logic knows, if any of these arguments concerning abortion is a good argument, it requires not only some claim characterizing fetuses, but also some general moral principle that ties a characteristic of fetuses to having or not having the right to life or to some other moral characteristic that will generate the obligation or the lack of obligation not to end the life of a fetus. Accordingly, the arguments of the anti-abortionist and the pro-choicer need a bit of filling in to be regarded as adequate.

Note what each partisan will say. The anti-abortionist will claim that her position is supported by such generally accepted moral principles as “It is always *prima facie* seriously wrong to take a human life” or “It is always *prima facie* seriously wrong to end the life of a baby.” Since these are generally accepted moral principles, her position is certainly not obviously wrong. The pro-choicer will claim that her position is supported by such plausible moral principles as “Being a person is what gives an individual intrinsic moral worth” or “It is only seriously *prima facie* wrong to take the life of a member

of the human community.” Since these are generally accepted moral principles, the pro-choice position is certainly not obviously wrong. Unfortunately, we have again arrived at a standoff.

Now, how might one deal with this standoff? The standard approach is to try to show how the moral principles of one’s opponent lose their plausibility under analysis. It is easy to see how this is possible. On the one hand, the anti-abortionist will defend a moral principle concerning the wrongness of killing which tends to be broad in scope in order that even fetuses at an early stage of pregnancy will fall under it. The problem with broad principles is that they often embrace too much. In this particular instance, the principle “It is always *prima facie* wrong to take a human life” seems to entail that it is wrong to end the existence of a living human cancer-cell culture, on the grounds that the culture is both living and human. Therefore, it seems that the anti-abortionist’s favored principle is too broad.

On the other hand, the pro-choicer wants to find a moral principle concerning the wrongness of killing which tends to be narrow in scope in order that fetuses will *not* fall under it. The problem with narrow principles is that they often do not embrace enough. Hence, the needed principles such as “It is *prima facie* seriously wrong to kill only persons” or “It is *prima facie* wrong to kill only rational agents” do not explain why it is wrong to kill infants or young children or the severely retarded or even perhaps the severely mentally ill. Therefore, we seem again to have a standoff. The anti-abortionist charges, not unreasonably, that pro-choice principles concerning killing are too narrow to be acceptable; the pro-choicer charges, not unreasonably, that anti-abortionist principles concerning killing are too broad to be acceptable.

Attempts by both sides to patch up the difficulties in their positions run into further difficulties. The anti-abortionist will try to remove the problem in her position by reformulating her principle concerning killing in terms of human beings. Now we end up with: “It is always *prima facie* seriously wrong to end the life of a human being.” This principle has the advantage of avoiding the problem of the human cancer-cell culture counterexample. But

this advantage is purchased at a high price. For although it is clear that a fetus is both human and alive, it is not at all clear that a fetus is a human *being*. There is at least something to be said for the view that something becomes a human being only after a process of development, and that therefore first trimester fetuses and perhaps all fetuses are not yet human beings. Hence, the anti-abortionist, by this move, has merely exchanged one problem for another.<sup>2</sup>

The pro-choicer fares no better. She may attempt to find reasons why killing infants, young children, and the severely retarded is wrong which are independent of her major principle that is supposed to explain the wrongness of taking human life, but which will not also make abortion immoral. This is no easy task. Appeals to social utility will seem satisfactory only to those who resolve not to think of the enormous difficulties with a utilitarian account of the wrongness of killing and the significant social costs of preserving the lives of the unproductive.<sup>3</sup> A pro-choice strategy that extends the definition of "person" to infants or even to young children seems just as arbitrary as an anti-abortion strategy that extends the definition of "human being" to fetuses. Again, we find symmetries in the two positions and we arrive at a standoff.

There are even further problems that reflect symmetries in the two positions. In addition to counterexample problems, or the arbitrary application problems that can be exchanged for them, the standard anti-abortionist principle "It is *prima facie* seriously wrong to kill a human being," or one of its variants, can be objected to on the grounds of ambiguity. If "human being" is taken to be a *biological* category, then the anti-abortionist is left with the problem of explaining why a merely biological category should make a moral difference. Why, it is asked, is it any more reasonable to base a moral conclusion on the number of chromosomes in one's cells than on the color of one's skin?<sup>4</sup> If "human being," on the other hand, is taken to be a *moral* category, then the claim that a fetus is a human being cannot be taken to be a premise in the anti-abortion argument, for it is precisely what needs to be established. Hence, either the

anti-abortionist's main category is a morally irrelevant, merely biological category, or it is of no use to the anti-abortionist in establishing (noncircularly, of course) that abortion is wrong.

Although this problem with the anti-abortionist position is often noticed, it is less often noticed that the pro-choice position suffers from an analogous problem. The principle "Only persons have the right to life" also suffers from an ambiguity. The term "person" is typically defined in terms of psychological characteristics, although there will certainly be disagreement concerning which characteristics are most important. Supposing that this matter can be settled, the pro-choicer is left with the problem of explaining why *psychological* characteristics should make a *moral* difference. If the pro-choicer should attempt to deal with this problem by claiming that an explanation is not necessary, that in fact we do treat such a cluster of psychological properties as having moral significance, the sharp-witted anti-abortionist should have a ready response. We do treat being both living and human as having moral significance. If it is legitimate for the pro-choicer to demand that the anti-abortionist provide an explanation of the connection between the biological character of being a human being and the wrongness of being killed (even though people accept this connection), then it is legitimate for the anti-abortionist to demand that the pro-choicer provide an explanation of the connection between psychological criteria for being a person and the wrongness of being killed (even though that connection is accepted).<sup>5</sup>

Feinberg has attempted to meet this objection (he calls psychological personhood "commonsense personhood"):

The characteristics that confer commonsense personhood are not arbitrary bases for rights and duties, such as race, sex or species membership; rather they are traits that make sense out of rights and duties and without which those moral attributes would have no point or function. It is because people are conscious; have a sense of their personal identities; have plans, goals, and projects; experience emotions; are liable to pains, anxieties, and frustrations; can reason and bargain, and so on—it is because of these attributes that people have

values and interests, desires and expectations of their own, including a stake in their own futures, and a personal well-being of a sort we cannot ascribe to unconscious or nonrational beings. Because of their developed capacities they can assume duties and responsibilities and can have and make claims on one another. Only because of their sense of self, their life plans, their value hierarchies, and their stakes in their own futures can they be ascribed fundamental rights. There is nothing arbitrary about these linkages. ("Abortion," p. 270)

The plausible aspects of this attempt should not be taken to obscure its implausible features. There is a great deal to be said for the view that being a psychological person under some description is a necessary condition for having duties. One cannot have a duty unless one is capable of behaving morally, and a being's capability of behaving morally will require having a certain psychology. It is far from obvious, however, that having rights entails consciousness or rationality, as Feinberg suggests. We speak of the rights of the severely retarded or the severely mentally ill, yet some of these persons are not rational. We speak of the rights of the temporarily unconscious. The New Jersey Supreme Court based their decision in the Quinlan case on Karen Ann Quinlan's right to privacy, and she was known to be permanently unconscious at that time. Hence, Feinberg's claim that having rights entails being conscious is, on its face, obviously false.

Of course, it might not make sense to attribute rights to a being that would never in its natural history have certain psychological traits. This modest connection between psychological personhood and moral personhood will create a place for Karen Ann Quinlan and the temporarily unconscious. But then it makes a place for fetuses also. Hence, it does not serve Feinberg's pro-choice purposes. Accordingly, it seems that the pro-choicer will have as much difficulty bridging the gap between psychological personhood and personhood in the moral sense as the anti-abortionist has bridging the gap between being a biological human being and being a human being in the moral sense.

Furthermore, the pro-choicer cannot any more escape her problem by making person a

purely moral category than the anti-abortionist could escape by the analogous move. For if person is a moral category, then the pro-choicer is left without the resources for establishing (noncircumferentially, of course) the claim that a fetus is not a person, which is an essential premise in her argument. Again, we have both a symmetry and a standoff between prochoice and anti-abortion views.

Passions in the abortion debate run high. There are both plausibilities and difficulties with the standard positions. Accordingly, it is hardly surprising that partisans of either side embrace with fervor the moral generalizations that support the conclusions they preanalytically favor, and reject with disdain the moral generalizations of their opponents as being subject to inescapable difficulties. It is easy to believe that the counterexamples to one's own moral principles are merely temporary difficulties that will dissolve in the wake of further philosophical research, and that the counterexamples to the principles of one's opponents are as straightforward as the contradiction between *A* and *O* propositions in traditional logic. This might suggest to an impartial observer (if there are any) that the abortion issue is unresolvable.

There is a way out of this apparent dialectical quandary. The moral generalizations of both sides are not quite correct. The generalizations hold for the most part, for the usual cases. This suggests that they are all *accidental* generalizations, that the moral claims made by those on both sides of the dispute do not touch on the *essence* of the matter.

This use of the distinction between essence and accident is not meant to invoke obscure metaphysical categories. Rather, it is intended to reflect the rather atheoretical nature of the abortion discussion. If the generalization a partisan in the abortion dispute adopts were derived from the reason why ending the life of a human being is wrong, then there could not be exceptions to that generalization unless some special case obtains in which there are even more powerful countervailing reasons. Such generalizations would not be merely accidental generalizations; they would point to, or be based upon, the essence of the wrongness of killing, what

it is that makes killing wrong. All this suggests that a necessary condition of resolving the abortion controversy is a more theoretical account of the wrongness of killing. After all, if we merely believe, but do not understand, why killing adult human beings such as ourselves is wrong, how could we conceivably show that abortion is either immoral or permissible?

## II

In order to develop such an account, we can start from the following unproblematic assumption concerning our own case: it is wrong to kill *us*. Why is it wrong? Some answers can be easily eliminated. It might be said that what makes killing us wrong is that a killing brutalizes the one who kills. But the brutalization consists of being inured to the performance of an act that is hideously immoral; hence, the brutalization does not explain the immorality. It might be said that what makes killing us wrong is the great loss others would experience due to our absence. Although such hubris is understandable, such an explanation does not account for the wrongness of killing hermits, or those whose lives are relatively independent and whose friends find it easy to make new friends.

A more obvious answer is better. What primarily makes killing wrong is neither its effect on the murderer nor its effect on the victim's friends and relatives, but its effect on the victim. The loss of one's life is one of the greatest losses one can suffer. The loss of one's life deprives one of all the experiences, activities, projects, and enjoyments that would otherwise have constituted one's future. Therefore, killing someone is wrong, primarily because the killing inflicts (one of) the greatest possible losses on the victim. To describe this as the loss of life can be misleading, however. The change in my biological state does not by itself make killing me wrong. The effect of the loss of my biological life is the loss to me of all those activities, projects, experiences, and enjoyments which would otherwise have constituted my future personal life. These activities, projects, experiences, and enjoyments are either valuable for their own sakes or are means to something else that is valuable for its own sake.

Some parts of my future are not valued by me now, but will come to be valued by me as I grow older and as my values and capacities change. When I am killed, I am deprived both of what I now value which would have been part of my future personal life, but also what I would come to value. Therefore, when I die, I am deprived of all of the value of my future. Inflicting this loss on me is ultimately what makes killing me wrong. This being the case, it would seem that what makes killing *any* adult human being *prima facie* seriously wrong is the loss of his or her future.<sup>6</sup>

How should this rudimentary theory of the wrongness of killing be evaluated? It cannot be faulted for deriving an "ought" from an "is," for it does not. The analysis assumes that killing me (or you, reader) is *prima facie* seriously wrong. The point of the analysis is to establish which natural property ultimately explains the wrongness of the killing, given that it is wrong. A natural property will ultimately explain the wrongness of killing, only if (1) the explanation fits with our intuitions about the matter and (2) there is no other natural property that provides the basis for a better explanation of the wrongness of killing. This analysis rests on the intuition that what makes killing a particular human or animal wrong is what it does to that particular human or animal. What makes killing wrong is some natural effect or other of the killing. Some would deny this. For instance, a divine-command theorist in ethics would deny it. Surely this denial is, however, one of those features of divine-command theory which renders it so implausible.

The claim that what makes killing wrong is the loss of the victim's future is directly supported by two considerations. In the first place, this theory explains why we regard killing as one of the worst of crimes. Killing is especially wrong, because it deprives the victim of more than perhaps any other crime. In the second place, people with AIDS or cancer who know they are dying believe, of course, that dying is a very bad thing for them. They believe that the loss of a future to them that they would otherwise have experienced is what makes their premature death a very bad thing for them. A better

theory of the wrongness of killing would require a different natural property associated with killing which better fits with the attitudes of the dying. What could it be?

The view that what makes killing wrong is the loss to the victim of the value of the victim's future gains additional support when some of its implications are examined. In the first place, it is incompatible with the view that it is wrong to kill only beings who are biologically human. It is possible that there exists a different species from another planet whose members have a future like ours. Since having a future like that is what makes killing someone wrong, this theory entails that it would be wrong to kill members of such a species. Hence, this theory is opposed to the claim that only life that is biologically human has great moral worth, a claim which many anti-abortionists have seemed to adopt. This opposition, which this theory has in common with personhood theories, seems to be a merit of the theory.

In the second place, the claim that the loss of one's future is the wrong-making feature of one's being killed entails the possibility that the futures of some actual nonhuman mammals on our own planet are sufficiently like ours that it is seriously wrong to kill them also. Whether some animals do have the same right to life as human beings depends on adding to the account of the wrongness of killing some additional account of just what it is about my future or the futures of other adult human beings which makes it wrong to kill us. No such additional account will be offered in this essay. Undoubtedly, the provision of such an account would be a very difficult matter. Undoubtedly, any such account would be quite controversial. Hence, it surely should not reflect badly on this sketch of an elementary theory of the wrongness of killing that it is indeterminate with respect to some very difficult issues regarding animal rights.

In the third place, the claim that the loss of one's future is the wrong-making feature of one's being killed does not entail, as sanctity of human life theories do, that active euthanasia is wrong. Persons who are severely and incurably ill, who face a future of pain and despair, and who wish to die will not

have suffered a loss if they are killed. It is, strictly speaking, the value of a human's future which makes killing wrong in this theory. This being so, killing does not necessarily wrong some persons who are sick and dying. Of course, there may be other reasons for a prohibition of active euthanasia, but that is another matter. Sanctity-of-human-life theories seem to hold that active euthanasia is seriously wrong even in an individual case where there seems to be good reason for it independently of public policy considerations. This consequence is most implausible, and it is a plus for the claim that the loss of a future of value is what makes killing wrong that it does not share this consequence.

In the fourth place, the account of the wrongness of killing defended in this essay does straightforwardly entail that it is *prima facie* seriously wrong to kill children and infants, for we do presume that they have futures of value. Since we do believe that it is wrong to kill defenseless little babies, it is important that a theory of the wrongness of killing easily account for this. Personhood theories of the wrongness of killing, on the other hand, cannot straightforwardly account for the wrongness of killing infants and young children.<sup>7</sup> Hence, such theories must add special *ad hoc* accounts of the wrongness of killing the young. The plausibility of such *ad hoc* theories seems to be a function of how desperately one wants such theories to work. The claim that the primary wrong-making feature of a killing is the loss to the victim of the value of its future accounts for the wrongness of killing young children and infants directly; it makes the wrongness of such acts as obvious as we actually think it is. This is a further merit of this theory. Accordingly, it seems that this value of a future-like-ours theory of the wrongness of killing shares strengths of both sanctity-of-life and personhood accounts while avoiding weaknesses of both. In addition, it meshes with a central intuition concerning what makes killing wrong.

The claim that the primary wrong-making feature of a killing is the loss to the victim of the value of its future has obvious consequences for the ethics of abortion. The future of a standard fetus includes a set of experiences, projects, activities, and such

which are identical with the futures of adult human beings and are identical with the futures of young children. Since the reason that is sufficient to explain why it is wrong to kill human beings after the time of birth is a reason that also applies to fetuses, it follows that abortion is *prima facie* seriously morally wrong.

This argument does not rely on the invalid inference that, since it is wrong to kill persons, it is wrong to kill potential persons also. The category that is morally central to this analysis is the category of having a valuable future like ours; it is not the category of personhood. The argument to the conclusion that abortion is *prima facie* seriously morally wrong proceeded independently of the notion of person or potential person or any equivalent. Someone may wish to start with this analysis in terms of the value of a human future, conclude that abortion is, except perhaps in rare circumstances, seriously morally wrong, infer that fetuses have the right to life, and then call fetuses "persons" as a result of their having the right to life. Clearly, in this case, the category of person is being used to state the *conclusion* of the analysis rather than to generate the *argument* of the analysis.

The structure of this anti-abortion argument can be both illuminated and defended by comparing it to what appears to be the best argument for the wrongness of the wanton infliction of pain on animals. This latter argument is based on the assumption that it is *prima facie* wrong to inflict pain on me (or you, reader). What is the natural property associated with the infliction of pain which makes such infliction wrong? The obvious answer seems to be that the infliction of pain causes suffering and that suffering is a misfortune. The suffering caused by the infliction of pain is what makes the wanton infliction of pain on me wrong. The wanton infliction of pain on other adult humans causes suffering. The wanton infliction of pain on animals causes suffering. Since causing suffering is what makes the wanton infliction of pain wrong and since the wanton infliction of pain on animals causes suffering, it follows that the wanton infliction of pain on animals is wrong.

This argument for the wrongness of the wanton infliction of pain on animals shares a number of structural features with the argument for the serious *prima facie* wrongness of abortion. Both arguments start with an obvious assumption concerning what it is wrong to do to me (or you, reader). Both then look for the characteristic or the consequence of the wrong action which makes the action wrong. Both recognize that the wrong-making feature of these immoral actions is a property of actions sometimes directed at individuals other than postnatal human beings. If the structure of the argument for the wrongness of the wanton infliction of pain on animals is sound, then the structure of the argument for the *prima facie* serious wrongness of abortion is also sound, for the structure of the two arguments is the same. The structure common to both is the key to the explanation of how the wrongness of abortion can be demonstrated without recourse to the category of person. In neither argument is that category crucial.

This defense of an argument for the wrongness of abortion in terms of a structurally similar argument for the wrongness of the wanton infliction of pain on animals succeeds only if the account regarding animals is the correct account. Is it? In the first place, it seems plausible. In the second place, its major competition is Kant's account. Kant believed that we do not have direct duties to animals at all, because they are not persons. Hence, Kant had to explain and justify the wrongness of inflicting pain on animals on the grounds that "he who is hard in his dealings with animals becomes hard also in his dealing with men."<sup>8</sup> The problem with Kant's account is that there seems to be no reason for accepting this latter claim unless Kant's account is rejected. If the alternative to Kant's account is accepted, then it is easy to understand why someone who is indifferent to inflicting pain on animals is also indifferent to inflicting pain on humans, for one is indifferent to what makes inflicting pain wrong in both cases. But, if Kant's account is accepted, there is no intelligible reason why one who is hard in his dealings with animals (or crabgrass or stones) should also be hard in his dealings with men. After all, men are persons: animals are no

more persons than crabgrass or stones. Persons are Kant's crucial moral category. Why, in short, should a Kantian accept the basic claim in Kant's argument?

Hence, Kant's argument for the wrongness of inflicting pain on animals rests on a claim that, in a world of Kantian moral agents, is demonstrably false. Therefore, the alternative analysis, being more plausible anyway, should be accepted. Since this alternative analysis has the same structure as the anti-abortion argument being defended here, we have further support for the argument for the immorality of abortion being defended in this essay.

Of course, this value of a future-like-ours argument, if sound, shows only that abortion is *prima facie* wrong, not that it is wrong in any and all circumstances. Since the loss of the future to a standard fetus, if killed, is, however, at least as great a loss as the loss of the future to a standard adult human being who is killed, abortion, like ordinary killing, could be justified only by the most compelling reasons. The loss of one's life is almost the greatest misfortune that can happen to one. Presumably abortion could be justified in some circumstances, only if the loss consequent on failing to abort would be at least as great. Accordingly, morally permissible abortions will be rare indeed unless, perhaps, they occur so early in pregnancy that a fetus is not yet definitely an individual. Hence, this argument should be taken as showing that abortion is presumptively very seriously wrong, where the presumption is very strong—as strong as the presumption that killing another adult human being is wrong.

### III

How complete an account of the wrongness of killing does the value of a future-like-ours account have to be in order that the wrongness of abortion is a consequence? This account does not have to be an account of the necessary conditions for the wrongness of killing. Some persons in nursing homes may lack valuable human futures, yet it may be wrong to kill them for other reasons. Furthermore, this account does not obviously have to be the sole reason killing is wrong where the victim did have a

valuable future. This analysis claims only that, for any killing where the victim did have a valuable future like ours, having that future by itself is sufficient to create the strong presumption that the killing is seriously wrong.

One way to overturn the value of a future-like-ours argument would be to find some account of the wrongness of killing which is at least as intelligible and which has different implications for the ethics of abortion. Two rival accounts possess at least some degree of plausibility. One account is based on the obvious fact that people value the experience of living and wish for that valuable experience to continue. Therefore, it might be said, what makes killing wrong is the discontinuation of that experience for the victim. Let us call this the *discontinuation account*.<sup>9</sup> Another rival account is based upon the obvious fact that people strongly desire to continue to live. This suggests that what makes killing us so wrong is that it interferes with the fulfillment of a strong and fundamental desire, the fulfillment of which is necessary for the fulfillment of any other desires we might have. Let us call this the *desire account*.<sup>10</sup>

Consider first the desire account as a rival account of the ethics of killing which would provide the basis for rejecting the anti-abortion position. Such an account will have to be stronger than the value of a future-like-ours account of the wrongness of abortion if it is to do the job expected of it. To entail the wrongness of abortion, the value of a future-like-ours account has only to provide a sufficient, but not a necessary, condition for the wrongness of killing. The desire account, on the other hand, must provide us also with a necessary condition for the wrongness of killing in order to generate a pro-choice conclusion on abortion. The reason for this is that presumably the argument from the desire account moves from the claim that what makes killing wrong is interference with a very strong desire to the claim that abortion is not wrong because the fetus lacks a strong desire to live. Obviously, this inference fails if someone's having the desire to live is not a necessary condition of its being wrong to kill that individual.

One problem with the desire account is that we do regard it as seriously wrong to kill persons who have little desire to live or who have no desire to live or, indeed, have a desire not to live. We believe it is seriously wrong to kill the unconscious, the sleeping, those who are tired of life, and those who are suicidal. The value-of-a-human-future account renders standard morality intelligible in these cases; these cases appear to be incompatible with the desire account.

The desire account is subject to a deeper difficulty. We desire life, because we value the goods of this life. The goodness of life is not secondary to our desire for it. If this were not so, the pain of one's own premature death could be done away with merely by an appropriate alteration in the configuration of one's desires. This is absurd. Hence, it would seem that it is the loss of the goods of one's future, not the interference with the fulfillment of a strong desire to live, which accounts ultimately for the wrongness of killing.

It is worth noting that, if the desire account is modified so that it does not provide a necessary, but only a sufficient, condition for the wrongness of killing, the desire account is compatible with the value of a future-like-ours account. The combined accounts will yield an anti-abortion ethic. This suggests that one can retain what is intuitively plausible about the desire account without a challenge to the basic argument of this paper.

It is also worth noting that, if future desires have moral force in a modified desire account of the wrongness of killing, one can find support for an anti-abortion ethic even in the absence of a value of a future-like-ours account. If one decides that a morally relevant property, the possession of which is sufficient to make it wrong to kill some individual, is the desire at some future time to live—one might decide to justify one's refusal to kill suicidal teenagers on these grounds, for example—then, since typical fetuses will have the desire in the future to live, it is wrong to kill typical fetuses. Accordingly, it does not seem that a desire account of the wrongness of killing can provide a justification of a pro-choice ethic of abortion which is nearly as adequate as the value of a human-future justification of an anti-abortion ethic.

The discontinuation account looks more promising as an account of the wrongness of killing. It seems just as intelligible as the value of a future-like-ours account, but it does not justify an anti-abortion position. Obviously, if it is the continuation of one's activities, experiences, and projects, the loss of which makes killing wrong, then it is not wrong to kill fetuses for that reason, for fetuses do not have experiences, activities, and projects to be continued or discontinued. Accordingly, the discontinuation account does not have the anti-abortion consequences that the value of a future-like-ours account has. Yet, it seems as intelligible as the value of a future-like-ours account, for when we think of what would be wrong with our being killed, it does seem as if it is the discontinuation of what makes our lives worthwhile which makes killing us wrong.

Is the discontinuation account just as good an account as the value of a future-like-ours account? The discontinuation account will not be adequate at all, if it does not refer to the *value* of the experience that may be discontinued. One does not want the discontinuation account to make it wrong to kill a patient who begs for death and who is in severe pain that cannot be relieved short of killing. (I leave open the question of whether it is wrong for other reasons.) Accordingly, the discontinuation account must be more than a bare discontinuation account. It must make some reference to the positive value of the patient's experiences. But, by the same token, the value of a future-like-ours account cannot be a bare future account either. Just having a future surely does not itself rule out killing the above patient. This account must make some reference to the value of the patient's future experiences and projects also. Hence, both accounts involve the value of experiences, projects, and activities. So far we still have symmetry between the accounts.

The symmetry fades, however, when we focus on the time period of the value of the experiences, etc., which has moral consequences. Although both accounts leave open the possibility that the patient in our example may be killed, this possibility is left open only in virtue of the utterly bleak future for the patient. It makes no difference whether the patient's immediate past contains intolerable pain, or consists in being in a coma (which we can imagine

is a situation of indifference), or consists in a life of value. If the patient's future is a future of value, we want our account to make it wrong to kill the patient. If the patient's future is intolerable, whatever his or her immediate past, we want our account to allow killing the patient. Obviously, then, it is the value of that patient's future which is doing the work in rendering the morality of killing the patient intelligible.

This being the case, it seems clear that whether one has immediate past experiences or not does no work in the explanation of what makes killing wrong. The addition the discontinuation account makes to the value of a human future account is otiose. Its addition to the value-of-a-future account plays no role at all in rendering intelligible the wrongness of killing. Therefore, it can be discarded with the discontinuation account of which it is a part.

#### IV

The analysis of the previous section suggests that alternative general accounts of the wrongness of killing are either inadequate or unsuccessful in getting around the anti-abortion consequences of the value of a future-like-ours argument. A different strategy for avoiding these anti-abortion consequences involves limiting the scope of the value of a future argument. More precisely, the strategy involves arguing that fetuses lack a property that is essential for the value-of-a-future argument (or for any anti-abortion argument) to apply to them.

One move of this sort is based upon the claim that a necessary condition of one's future being valuable is that one values it. Value implies a valuer. Given this one might argue that, since fetuses cannot value their futures, their futures are not valuable to them. Hence, it does not seriously wrong them deliberately to end their lives.

This move fails, however, because of some ambiguities. Let us assume that something cannot be of value unless it is valued by someone. This does not entail that my life is of no value unless it is valued by me. I may think, in a period of despair, that my future is of no worth whatsoever, but I may be wrong because others rightly see value—even great value—in it. Furthermore, my future can be

valuable to me even if I do not value it. This is the case when a young person attempts suicide, but is rescued and goes on to significant human achievements. Such young people's futures are ultimately valuable to them, even though such futures do not seem to be valuable to them at the moment of attempted suicide. A fetus's future can be valuable to it in the same way. Accordingly, this attempt to limit the anti-abortion argument fails.

Another similar attempt to reject the anti-abortion position is based on Tooley's claim that an entity cannot possess the right to life unless it has the capacity to desire its continued existence. It follows that, since fetuses lack the conceptual capacity to desire to continue to live, they lack the right to life. Accordingly, Tooley concludes that abortion cannot be seriously *prima facie* wrong.

What could be the evidence for Tooley's basic claim? Tooley once argued that individuals have a *prima facie* right to what they desire and that the lack of the capacity to desire something undercuts the basis of one's right to it. This argument plainly will not succeed in the context of the analysis of this essay, however, since the point here is to establish the fetus's right to life on other grounds. Tooley's argument assumes that the right to life cannot be established in general on some basis other than the desire for life. This position was considered and rejected in the preceding section of this paper.

One might attempt to defend Tooley's basic claim on the grounds that, because a fetus cannot apprehend continued life as a benefit, its continued life cannot be a benefit or cannot be something it has a right to or cannot be something that is in its interest. This might be defended in terms of the general proposition that, if an individual is literally incapable of caring about or taking an interest in some X, then one does not have a right to X or X is not a benefit or X is not something that is in one's interest.<sup>11</sup>

Each member of this family of claims seems to be open to objections. As John C. Stevens<sup>12</sup> has pointed out, one may have a right to be treated with a certain medical procedure (because of a health insurance policy one has purchased), even though one cannot conceive of the nature of the procedure. And, as Tooley himself has pointed out,

persons who have been indoctrinated, or drugged, or rendered temporarily unconscious may be literally incapable of caring about or taking an interest in something that is in their interest or is something to which they have a right, or is something that benefits them. Hence, the Tooley claim that would restrict the scope of the value of a future-like-ours argument is undermined by counterexamples.<sup>13</sup>

Finally, Paul Bassen<sup>14</sup> has argued that, even though the prospects of an embryo might seem to be a basis for the wrongness of abortion, an embryo cannot be a victim and therefore cannot be wronged. An embryo cannot be a victim, he says, because it lacks sentience. His central argument for this seems to be that, even though plants and the permanently unconscious are alive, they clearly cannot be victims. What is the explanation of this? Bassen claims that the explanation is that their lives consist of mere metabolism and mere metabolism is not enough to ground victimizability. Mentation is required.

The problem with this attempt to establish the absence of victimizability is that both plants and the permanently unconscious clearly lack what Bassen calls “prospects” or what I have called “a future life like ours.” Hence, it is surely open to one to argue that the real reason we believe plants and the permanently unconscious cannot be victims is that killing them cannot deprive them of a future life like ours; the real reason is not their absence of present mentation.

Bassen recognizes that his view is subject to this difficulty, and he recognizes that the case of children seems to support this difficulty, for “much of what we do for children is based on prospects.” He argues, however, that, in the case of children and in other such cases, “potentiality comes into play only where victimizability has been secured on other grounds” (p. 333).

Bassen’s defense of his view is patently question-begging, since what is adequate to secure victimizability is exactly what is at issue. His examples do not support his own view against the thesis of this essay. Of course, embryos can be victims: when their lives are deliberately terminated, they are deprived of their futures of value, their prospects. This makes them victims, for it directly wrongs them.

The seeming plausibility of Bassen’s view stems from the fact that paradigmatic cases of imagining someone as a victim involve empathy, and empathy requires mentation of the victim. The victims of flood, famine, rape, or child abuse are all persons with whom we can empathize. That empathy seems to be part of seeing them as victims.<sup>15</sup>

In spite of the strength of these examples, the attractive intuition that a situation in which there is victimization requires the possibility of empathy is subject to counterexamples. Consider a case that Bassen himself offers: “Posthumous obliteration of an author’s work constitutes a misfortune for him only if he had wished his work to endure” (p. 318). The conditions Bassen wishes to impose upon the possibility of being victimized here seem far too strong. Perhaps this author, due to his unrealistic standards of excellence and his low self-esteem, regarded his work as unworthy of survival, even though it possessed genuine literary merit. Destruction of such work would surely victimize its author. In such a case, empathy with the victim concerning the loss is clearly impossible.

Of course, Bassen does not make the possibility of empathy a necessary condition of victimizability; he requires only mentation. Hence, on Bassen’s actual view, this author, as I have described him, can be a victim. The problem is that the basic intuition that renders Bassen’s view plausible is missing in the author’s case. In order to attempt to avoid counterexamples, Bassen has made his thesis too weak to be supported by the intuitions that suggested it.

Even so, the mentation requirement on victimizability is still subject to counterexamples. Suppose a severe accident renders me totally unconscious for a month, after which I recover. Surely killing me while I am unconscious victimizes me, even though I am incapable of mentation during that time. It follows that Bassen’s thesis fails. Apparently, attempts to restrict the value of a future-like-ours argument so that fetuses do not fall within its scope do not succeed.

## ▼

In this essay, it has been argued that the correct ethic of the wrongness of killing can be extended to fetal life and used to show that there is

a strong presumption that any abortion is morally impermissible. If the ethic of killing adopted here entails, however, that contraception is also seriously immoral, then there would appear to be a difficulty with the analysis of this essay.

But this analysis does not entail that contraception is wrong. Of course, contraception prevents the actualization of a possible future of value. Hence, it follows from the claim that if futures of value should be maximized that contraception is *prima facie* immoral. This obligation to maximize does not exist, however; furthermore, nothing in the ethics of killing in this paper entails that it does. The ethics of killing in this essay would entail that contraception is wrong only if something were denied a human future of value by contraception. Nothing at all is denied such a future by contraception, however.

Candidates for a subject of harm by contraception fall into four categories: (1) some sperm or other, (2) some ovum or other, (3) a sperm and an ovum separately, and (4) a sperm and an ovum together. Assigning the harm to some sperm is utterly arbitrary, for no reason can be given for making a sperm the subject of harm rather than an ovum. Assigning the harm to some ovum is utterly arbitrary, for no reason can be given for making an ovum the subject of harm rather than a sperm. One might attempt to avoid these problems by insisting that contraception deprives both the sperm and the ovum separately of a valuable future like ours. On this alternative, too many futures are lost. Contraception was supposed to be wrong, because it deprived us of one future of value, not two. One might attempt to avoid this problem by holding that contraception deprives the combination of sperm and ovum of a valuable future like ours. But here the definite article misleads. At the time of contraception, there are hundreds of millions of sperm, one (released) ovum and millions of possible combinations of all of these. There is no actual combination at all. Is the subject of the loss to be a merely possible combination? Which one? This alternative does not yield an actual subject of harm either. Accordingly, the immorality of contraception is not entailed by the loss of a future-like-ours argument

simply because there is no nonarbitrarily identifiable subject of the loss in the case of contraception.

## VI

The purpose of this essay has been to set out an argument for the serious presumptive wrongness of abortion subject to the assumption that the moral permissibility of abortion stands or falls on the moral status of the fetus. Since a fetus possesses a property, the possession of which in adult human beings is sufficient to make killing an adult human being wrong, abortion is wrong. This way of dealing with the problem of abortion seems superior to other approaches to the ethics of abortion, because it rests on an ethics of killing which is close to self-evident, because the crucial morally relevant property clearly applies to fetuses, and because the argument avoids the usual equivocations on "human life," "human being," or "person." The argument rests neither on religious claims nor on Papal dogma. It is not subject to the objection of "speciesism." Its soundness is compatible with the moral permissibility of euthanasia and contraception. It deals with our intuitions concerning young children.

Finally, this analysis can be viewed as resolving a standard problem—indeed, *the* standard problem—concerning the ethics of abortion. Clearly, it is wrong to kill adult human beings. Clearly, it is not wrong to end the life of some arbitrarily chosen single human cell. Fetuses seem to be like arbitrarily chosen human cells in some respects and like adult humans in other respects. The problem of the ethics of abortion is the problem of determining the fetal property that settles this moral controversy. The thesis of this essay is that the problem of the ethics of abortion, so understood, is solvable.

## NOTES

1. Feinberg, "Abortion," in *Matters of Life and Death: New Introductory Essays in Moral Philosophy*, Tom Regan, ed. (New York: Random House, 1986), pp. 256–93; Tooley, "Abortion and Infanticide," *Philosophy and Public Affairs*, II, 1 (1972): 37–65; Tooley, *Abortion and Infanticide* (New York: Oxford, 1984); Warren, "On the Moral and Legal Status of Abortion," *The Monist*, 1. VII, 1 (1973): 43–61; Engelhardt, "The Ontology of

- Abortion," *Ethics*, I, XXXIV, 3 (1974): 217–34; Sumner, *Abortion and Moral Theory* (Princeton: University Press, 1981); Noonan, "An Almost Absolute Value in History," in *The Morality of Abortion: Legal and Historical Perspectives*, Noonan, ed. (Cambridge: Harvard, 1970); and Devine, *The Ethics of Homicide* (Ithaca: Cornell, 1978).
2. For interesting discussions of this issue, see Warren Quinn, "Abortion: Identity and Loss," *Philosophy and Public Affairs*, XIII, 1 (1984): 24–54; and Lawrence C. Becker, "Human Being: The Boundaries of the Concept," *Philosophy and Public Affairs*, IV, 4 (1975): 334–59.
  3. For example, see my "Ethics and the Elderly: Some Problems," in Stuart Spicker, Kathleen Woodward, and David Van Tassel, eds., *Aging and the Elderly: Humanistic Perspectives in Gerontology* (Atlantic Highlands, NJ: Humanities, 1978), pp. 341–55.
  4. See Warren, "On the Moral and Legal Status of Abortion," and Tooley, "Abortion and Infanticide."
  5. This seems to be the fatal flaw in Warren's treatment of this issue.
  6. I have been most influenced on this matter by Jonathan Glover, *Causing Death and Saving Lives* (New York: Penguin, 1977), ch. 3; and Robert Young, "What Is So Wrong with Killing People?" *Philosophy*, LIV, 210 (1979): 515–28.
  7. Feinberg, Tooley, Warren, and Engelhardt have all dealt with this problem.
  8. Kant, "Duties to Animals and Spirits," in *Lectures on Ethics*, trans. Louis Infeld (New York: Harper, 1963), p. 239.
  9. I am indebted to Jack Brickle for raising this objection.
  10. Presumably a preference utilitarian would press such an objection. Tooley once suggested that his account has such a theoretical underpinning. See his "Abortion and Infanticide," pp. 44–5.
  11. Donald VanDeVeer seems to think this is self-evident. See his "Whither Baby Doe?" in *Matters of Life and Death*, p. 233.
  12. "Must the Bearer of a Right Have the Concept of That to Which He Has a Right?" *Ethics*, XCV, 1 (1984): 68–74.
  13. See Tooley again in "Abortion and Infanticide," pp. 47–9.
  14. "Present Sakes and Future Prospects: The Status of Early Abortion," *Philosophy and Public Affairs*, XI, 4 (1982): 322–6.
  15. Note carefully the reasons he gives on the bottom of p. 316.

## On the Moral and Legal Status of Abortion

MARY ANNE WARREN

In this famous essay, Warren defends the view that abortion is always morally permissible. It is permissible, she says, because the unborn is not a person. Merely being human—a creature with human DNA—is not sufficient for personhood. To qualify as a person, an entity must possess certain intrinsically valuable traits. She identifies several traits that seem "most central" to personhood: (1) consciousness and the capacity to feel pain, (2) reasoning, (3) self-motivated activity, (4) the capacity to communicate, and (5) "the presence of self-concepts, and self-awareness, either individual or racial or both." Warren argues that any being that has none of these traits is surely not a person; a fetus has none of them and is therefore not yet a person and "cannot coherently be said to have full moral rights."

We will be concerned with both the moral status of abortion, which for our purposes we may define as the act which a woman performs in voluntarily

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terminating, or allowing another person to terminate, her pregnancy, and the legal status which is appropriate for this act. I will argue that, while it is not possible to produce a satisfactory defense of a woman's right to obtain an abortion without showing that a fetus is not a human being, in the morally

relevant sense of that term, we ought not to conclude that the difficulties involved in determining whether or not a fetus is human make it impossible to produce any satisfactory solution to the problem of the moral status of abortion. For it is possible to show that, on the basis of intuitions which we may expect even the opponents of abortion to share, a fetus is not a person, and hence not the sort of entity to which it is proper to ascribe full moral rights.

Of course, while some philosophers would deny the possibility of any such proof,<sup>1</sup> others will deny that there is any need for it, since the moral permissibility of abortion appears to them to be too obvious to require proof. But the inadequacy of this attitude should be evident from the fact that both the friends and the foes of abortion consider their position to be morally self-evident. Because pro-abortionists have never adequately come to grips with the conceptual issues surrounding abortion, most if not all, of the arguments which they advance in opposition to laws restricting access to abortion fail to refute or even weaken the traditional antiabortion argument, i.e., that a fetus is a human being, and therefore abortion is murder.

These arguments are typically of one of two sorts. Either they point to the terrible side effects of the restrictive laws, e.g., the deaths due to illegal abortions, and the fact that it is poor women who suffer the most as a result of these laws, or else they state that to deny a woman access to abortion is to deprive her of her right to control her own body. Unfortunately, however, the fact that restricting access to abortion has tragic side effects does not, in itself, show that the restrictions are unjustified, since murder is wrong regardless of the consequences of prohibiting it; and the appeal to the right to control one's body, which is generally construed as a property right, is at best a rather feeble argument for the permissibility of abortion. Mere ownership does not give me the right to kill innocent people whom I find on my property, and indeed I am apt to be held responsible if such people injure themselves while on my property. It is equally unclear that I have any moral right to expel an innocent person from my property when I know that doing so will result in his or her death.

Furthermore, it is probably inappropriate to describe a woman's body as her property, since it seems natural to hold that a person is something distinct from her property, but not from her body. Even those who would object to the identification of a person with her body, or with the conjunction of her body and her mind, must admit that it would be very odd to describe, say, breaking a leg, as damaging one's property, and much more appropriate to describe it as injuring oneself. Thus it is probably a mistake to argue that the right to obtain an abortion is in any way derived from the right to own and regulate property.

But however we wish to construe the right to abortion, we cannot hope to convince those who consider abortion a form of murder of the existence of any such right unless we are able to produce a clear and convincing refutation of the traditional antiabortion argument, and this has not, to my knowledge, been done. With respect to the two most vital issues which that argument involves, i.e., the humanity of the fetus and its implication for the moral status of abortion, confusion has prevailed on both sides of the dispute. Thus, both proabortionists and antiabortionists have tended to abstract the question of whether abortion is wrong to that of whether it is wrong to destroy a fetus, just as though the rights of another person were not necessarily involved. This mistaken abstraction has led to the almost universal assumption that if a fetus is a human being, with a right to life, then it follows immediately that abortion is wrong (except perhaps when necessary to save the woman's life), and that it ought to be prohibited. It has also been generally assumed that unless the question about the status of the fetus is answered, the moral status of abortion cannot possibly be determined.

Two recent papers, one by B. A. Brody,<sup>2</sup> and one by Judith Thomson,<sup>3</sup> have attempted to settle the question of whether abortion ought to be prohibited apart from the question of whether or not the fetus is human. Brody examines the possibility that the following two statements are compatible: (1) that abortion is the taking of innocent human life, and therefore wrong; and (2) that nevertheless it ought not to be prohibited by law, at least under the present circumstances.<sup>4</sup> Not surprisingly, Brody finds it impossible to

reconcile these two statements, since, as he rightly argues, none of the unfortunate side effects of the prohibition of abortion is bad enough to justify legalizing the *wrongful* taking of human life. He is mistaken, however, in concluding that the incompatibility of (1) and (2), in itself, shows that “the legal problem about abortion cannot be resolved independently of the status of the fetus problem” (p. 369).

What Brody fails to realize is that (1) embodies the questionable assumption that if a fetus is a human being, then of course abortion is morally wrong, and that an attack on *this* assumption is more promising, as a way of reconciling the humanity of the fetus with the claim that laws prohibiting abortion are unjustified, than is an attack on the assumption that if abortion is the wrongful killing of innocent human beings then it ought to be prohibited. He thus overlooks the possibility that a fetus may have a right to life and abortion still be morally permissible, in that the right of a woman to terminate an unwanted pregnancy might override the right of the fetus to be kept alive. The immorality of abortion is no more demonstrated by the humanity of the fetus, in itself, than the immorality of killing in self-defense is demonstrated by the fact that the assailant is a human being. Neither is it demonstrated by the *innocence* of the fetus, since there may be situations in which the killing of innocent human beings is justified.

It is perhaps not surprising that Brody fails to spot this assumption, since it has been accepted with little or no argument by nearly everyone who has written on the morality of abortion. John Noonan is correct in saying that “the fundamental question in the long history of abortion is, How do you determine the humanity of a being?”<sup>5</sup> He summarizes his own antiabortion argument, which is a version of the official position of the Catholic Church, as follows:

it is wrong to kill humans, however poor, weak, defenseless, and lacking in opportunity to develop their potential they may be. It is therefore morally wrong to kill Biafrans. Similarly, it is morally wrong to kill embryos.<sup>6</sup>

Noonan bases his claim that fetuses are human upon what he calls the theologians’ criterion of

humanity: that whoever is conceived of human beings is human. But although he argues at length for the appropriateness of this criterion, he never questions the assumption that if a fetus is human then abortion is wrong for exactly the same reason that murder is wrong.

Judith Thomson is, in fact, the only writer I am aware of who has seriously questioned this assumption; she has argued that, even if we grant the anti-abortionist his claim that a fetus is a human being, with the same right to life as any other human being, we can still demonstrate that, in at least some and perhaps most cases, a woman is under no moral obligation to complete an unwanted pregnancy.<sup>7</sup> Her argument is worth examining, since if it holds up it may enable us to establish the moral permissibility of abortion without becoming involved in problems about what entitles an entity to be considered human, and accorded full moral rights. To be able to do this would be a great gain in the power and simplicity of the proabortion position, since, although I will argue that these problems can be solved at least as decisively as can any other moral problem, we should certainly be pleased to be able to avoid having to solve them as part of the justification of abortion.

On the other hand, even if Thomson’s argument does not hold up, her insight, i.e., that it requires *argument* to show that if fetuses are human then abortion is properly classified as murder, is an extremely valuable one. The assumption she attacks is particularly invidious, for it amounts to the decision that it is appropriate, in deciding the moral status of abortion, to leave the rights of the pregnant woman out of consideration entirely, except possibly when her life is threatened. Obviously, this will not do; determining what moral rights, if any, a fetus possesses is only the first step in determining the moral status of abortion. Step two, which is at least equally essential, is finding a just solution to the conflict between whatever rights the fetus may have, and the rights of the woman who is unwillingly pregnant. While the historical error has been to pay far too little attention to the second step, Ms. Thomson’s suggestion is that if we look at the second step first we may find that a woman has a right to obtain an abortion *regardless* of what rights the fetus has.

Our own inquiry will also have two stages. In Section I, we will consider whether or not it is possible to establish that abortion is morally permissible even on the assumption that a fetus is an entity with a full-fledged right to life. I will argue that in fact this cannot be established, at least not with the conclusiveness which is essential to our hopes of convincing those who are skeptical about the morality of abortion, and that we therefore cannot avoid dealing with the question of whether or not a fetus really does have the same right to life as a (more fully developed) human being.

In Section II, I will propose an answer to this question, namely, that a fetus cannot be considered a member of the moral community, the set of beings with full and equal moral rights, for the simple reason that it is not a person, and that it is personhood, and not genetic humanity, i.e., humanity as defined by Noonan, which is the basis for membership in this community. I will argue that a fetus, whatever its stage of development, satisfies none of the basic criteria of personhood, and is not even enough *like* a person to be accorded even some of the same rights on the basis of this resemblance. Nor, as we will see, is a fetus's *potential* personhood a threat to the morality of abortion, since, whatever the rights of potential people may be, they are invariably overridden in any conflict with the moral rights of actual people.

## I

We turn now to Professor Thomson's case for the claim that even if a fetus has full moral rights, abortion is still morally permissible, at least sometimes, and for some reasons other than to save the woman's life. Her argument is based upon a clever, but I think faulty, analogy. She asks us to picture ourselves waking up one day, in bed with a famous violinist. Imagine that you have been kidnapped, and your bloodstream hooked up to that of the violinist, who happens to have an ailment which will certainly kill him unless he is permitted to share your kidneys for a period of nine months. No one else can save him, since you alone have the right type of blood. He will be unconscious all that time, and you will have to stay in bed with him, but after the nine

months are over he may be unplugged, completely cured, that is provided that you have cooperated.

Now then, she continues, what are your obligations in this situation? The antiabortionist, if he is consistent, will have to say that you are obligated to stay in bed with the violinist: for all people have a right to life, and violinists are people, and therefore it would be murder for you to disconnect yourself from him and let him die. But this is outrageous, and so there must be something wrong with the same argument when it is applied to abortion. It would certainly be commendable of you to agree to save the violinist, but it is absurd to suggest that your refusal to do so would be murder. His right to life does not obligate you to do whatever is required to keep him alive; nor does it justify anyone else in forcing you to do so. A law which required you to stay in bed with the violinist would clearly be an unjust law, since it is no proper function of the law to force unwilling people to make huge sacrifices for the sake of other people toward whom they have no such prior obligation.

Thomson concludes that, if this analogy be an apt one, then we can grant the antiabortionist his claim that a fetus is a human being, and still hold that it is at least sometimes the case that a pregnant woman has the right to refuse to be a Good Samaritan towards the fetus, i.e., to obtain an abortion. For there is a great gap between the claim that *x* has a right to life, and the claim that *y* is obligated to do whatever is necessary to keep *x* alive, let alone that she ought to be forced to do so. It is *y*'s duty to keep *x* alive only if she has somehow contracted a *special* obligation to do so; and a woman who is unwillingly pregnant, e.g., who was raped, has done nothing which obligates her to make the enormous sacrifice which is necessary to preserve the conceptus.

This argument is initially quite plausible, and in the extreme case of pregnancy due to rape it is probably conclusive. Difficulties arise, however, when we try to specify more exactly the range of cases in which abortion is clearly justifiable even on the assumption that the fetus is human. Professor Thomson considers it a virtue of her argument that it does not enable us to conclude that abortion is *always* permissible. It would, she says, be

"indecent" for a woman in her seventh month to obtain an abortion just to avoid having to postpone a trip to Europe. On the other hand, her argument enables us to see that "a sick and desperately frightened schoolgirl pregnant due to rape may *of course* choose abortion, and that any law which rules this out is an insane law." So far, so good; but what are we to say about the woman who becomes pregnant not through rape but as a result of her own carelessness, or because of contraceptive failure, or who gets pregnant intentionally and then changes her mind about wanting a child? With respect to such cases, the violinist analogy is of much less use to the defender of the woman's right to obtain an abortion.

Indeed, the choice of a pregnancy due to rape, as an example of a case in which abortion is permissible even if a fetus is considered a human being, is extremely significant; for it is only in the case of pregnancy due to rape that the woman's situation is adequately analogous to the violinist case for our intuitions about the latter to transfer convincingly. The crucial difference between a pregnancy due to rape and the normal case of an unwanted pregnancy is that in the *normal* case we cannot claim that the woman is in no way responsible for her predicament; she could have remained chaste, or taken her pills more faithfully, or abstained on dangerous days, and so on. If, on the other hand, you are kidnapped by strangers, and hooked up to a strange violinist, then you are free of any shred of responsibility for the situation, on the basis of which it could be argued that you are obligated to keep the violinist alive. Only when her pregnancy is due to rape is a woman clearly just as nonresponsible.<sup>8</sup>

Consequently, there is room for the antiabortionist to argue that in the normal case of unwanted pregnancy a woman has, by her own actions, assumed responsibility for the fetus. For if  $x$  behaves in a way which she could have avoided, and which she knows involves, let us say, a 1 percent chance of bringing into existence a human being, with a right to life, and does so knowing that if this should happen then that human being will perish unless  $x$  does certain things to keep it alive, then it is by no means clear that when it does happen  $x$  is free of

any obligation to what she knew in advance would be required to keep that human being alive.

The plausibility of such an argument is enough to show that the Thomson analogy can provide a clear and persuasive defense of a woman's right to obtain an abortion only with respect to those cases in which the woman is in no way responsible for her pregnancy, e.g., where it is due to rape. In all other cases, we would almost certainly conclude that it was necessary to look carefully at the particular circumstances in order to determine the extent of the woman's responsibility, and hence the extent of her obligation. This is an extremely unsatisfactory outcome, from the viewpoint of the opponents of restrictive abortion laws, most of whom are convinced that a woman has a right to obtain an abortion regardless of how and why she got pregnant.

Of course a supporter of the violinist analogy might point out that it is absurd to suggest that forgetting her pill one day might be sufficient to oblige a woman to complete an unwanted pregnancy. And indeed it *is* absurd to suggest this. As we will see, the moral right to obtain an abortion is not in the least dependent upon the extent to which the woman is responsible for her pregnancy. But unfortunately, once we allow the assumption that a fetus has full moral rights, we cannot avoid taking this absurd suggestion seriously. Perhaps we can make this point more clear by altering the violinist story just enough to make it more analogous to a normal unwanted pregnancy and less to a pregnancy due to rape, and then seeing whether it is still obvious that you are not obligated to stay in bed with the fellow.

Suppose, then, that violinists are peculiarly prone to the sort of illness the only cure for which is the use of someone else's bloodstream for nine months, and that because of this there has been formed a society of music lovers who agree that whenever a violinist is stricken they will draw lots and the loser will, by some means, be made the one and only person capable of saving him or her. Now then, would you be obligated to cooperate in curing the violinist if you had voluntarily joined this society, knowing the possible consequences, and then your name had been drawn and you had been kidnapped? Admittedly, you did not promise ahead of time that you would, but you did deliberately place

yourself in a position in which it might happen that a human life would be lost if you did not. Surely this is at least a *prima facie* reason for supposing that you have an obligation to stay in bed with the violinist. Suppose that you had gotten your name drawn deliberately; surely that would be quite a strong reason for thinking that you have such an obligation.

It might be suggested that there is one important disanalogy between the modified violinist case and the case of an unwanted pregnancy, which makes the woman's responsibility significantly less, namely, the fact that the fetus *comes into existence* as the result of the woman's actions. This fact might give her a right to refuse to keep it alive, whereas she would not have had this right had it existed previously, independently, and then as a result of her actions become dependent upon her for its survival.

My own intuition, however, is that *x* has no more right to bring into existence, either deliberately or as a foreseeable result of actions she could have avoided, a being with full moral rights (*y*), and then refuse to do what she knew beforehand would be required to keep that being alive, than she has to enter into an agreement with an existing person, whereby she may be called upon to save that person's life, and then refuse to do so when so called upon. Thus, *x*'s responsibility for *y*'s existence does not seem to lessen her obligation to keep *y* alive, if she is also responsible for *y*'s being in a situation in which only she can save him or her.

Whether or not this intuition is entirely correct, it brings us back once again to the conclusion that once we allow the assumption that a fetus has full moral rights it becomes an extremely complex and difficult question whether and when abortion is justifiable. Thus the Thomson analogy cannot help us produce a clear and persuasive proof of the moral permissibility of abortion. Nor will the opponents of the restrictive laws thank us for anything less; for their conviction (for the most part) is that abortion is obviously *not* a morally serious and extremely unfortunate, even though sometimes justified act, comparable to killing in self-defense or to letting the violinist die, but rather is closer to being a morally neutral act, like cutting one's hair.

The basis of this conviction, I believe, is the realization that a fetus is not a person, and thus does not have a full-fledged right to life. Perhaps the reason why this claim has been so inadequately defended is that it seems self-evident to those who accept it. And so it is, insofar as it follows from what I take to be perfectly obvious claims about the nature of personhood, and about the proper grounds for ascribing moral rights, claims which ought, indeed, to be obvious to both the friends and foes of abortion. Nevertheless, it is worth examining these claims, and showing how they demonstrate the moral innocuousness of abortion, since this apparently has not been adequately done before.

## II

The question which we must answer in order to produce a satisfactory solution to the problem of the moral status of abortion is this: How are we to define the moral community, the set of beings with full and equal moral rights, such that we can decide whether a human fetus is a member of this community or not? What sort of entity, exactly, has the inalienable rights to life, liberty, and the pursuit of happiness? Jefferson attributed these rights to all *men*, and it may or may not be fair to suggest that he intended to attribute them *only* to men. Perhaps he ought to have attributed them to all human beings. If so, then we arrive, first, at Noonan's problem of defining what makes a being human, and, second, at the equally vital question which Noonan does not consider, namely, What reason is there for identifying the moral community with the set of all human beings, in whatever way we have chosen to define that term?

### I. On the Definition of "Human"

One reason why this vital second question is so frequently overlooked in the debate over the moral status of abortion is that the term "human" has two distinct, but not often distinguished, senses. This fact results in a slide of meaning, which serves to conceal the fallaciousness of the traditional argument that since (1) it is wrong to kill innocent human beings, and (2) fetuses are innocent human beings, then (3) it is wrong to kill fetuses. For if

"human" is used in the same sense in both (1) and (2) then, whichever of the two senses is meant, one of these premises is question-begging. And if it is used in two different senses then of course the conclusion doesn't follow.

Thus, (1) is a self-evident moral truth,<sup>9</sup> and avoids begging the question about abortion, only if "human being" is used to mean something like "a full-fledged member of the moral community." (It may or may not also be meant to refer exclusively to members of the species *Homo sapiens*.) We may call this the *moral* sense of "human." It is not to be confused with what we will call the *genetic* sense, i.e., the sense in which *any* member of the species is a human being, and no member of any other species could be. If (1) is acceptable only if the moral sense is intended, (2) is non-question-begging only if what is intended is the genetic sense.

In "Deciding Who Is Human," Noonan argues for the classification of fetuses with human beings by pointing to the presence of the full genetic code, and the potential capacity for rational thought (p. 35). It is clear that what he needs to show, for his version of the traditional argument to be valid, is that fetuses are human in the moral sense, the sense in which it is analytically true that all human beings have full moral rights. But, in the absence of any argument showing that whatever is genetically human is also morally human, and he gives none, nothing more than genetic humanity can be demonstrated by the presence of the human genetic code. And, as we will see, the *potential* capacity for rational thought can at most show that an entity has the potential for *becoming* human in the moral sense.

## 2. Defining the Moral Community

Can it be established that genetic humanity is sufficient for moral humanity? I think that there are very good reasons for not defining the moral community in this way. I would like to suggest an alternative way of defining the moral community, which I will argue for only to the extent of explaining why it is, or should be, self-evident. The suggestion is simply that the moral community consists of all and only *people*, rather than all and

only human beings;<sup>10</sup> and probably the best way of demonstrating its self-evidence is by considering the concept of personhood, to see what sorts of entities are and are not persons, and what the decision that a being is or is not a person implies about its moral rights.

What characteristics entitle an entity to be considered a person? This is obviously not the place to attempt a complete analysis of the concept of personhood, but we do not need such a fully adequate analysis just to determine whether and why a fetus is or isn't a person. All we need is a rough and approximate list of the most basic criteria of personhood, and some idea of which, or how many, of these an entity must satisfy in order to properly be considered a person.

In searching for such criteria, it is useful to look beyond the set of people with whom we are acquainted, and ask how we would decide whether a totally alien being was a person or not. (For we have no right to assume that genetic humanity is necessary for personhood.) Imagine a space traveler who lands on an unknown planet and encounters a race of beings utterly unlike any she has ever seen or heard of. If she wants to be sure of behaving morally toward these beings, she has to somehow decide whether they are people, and hence have full moral rights, or whether they are the sort of thing which she need not feel guilty about treating as, for example, a source of food.

How should she go about making this decision? If she has some anthropological background, she might look for such things as religion, art, and the manufacturing of tools, weapons, or shelters, since these factors have been used to distinguish our human from our prehuman ancestors, in what seems to be closer to the moral than the genetic sense of "human." And no doubt she would be right to consider the presence of such factors as good evidence that the alien beings were people, and morally human. It would, however, be overly anthropocentric of her to take the absence of these things as adequate evidence that they were not, since we can imagine people who have progressed beyond, or evolved without ever developing, these cultural characteristics.

I suggest that the traits which are most central to the concept of personhood, or humanity in the moral sense, are, very roughly, the following:

1. Consciousness (of objects and events external and/or internal to the being), and in particular the capacity to feel pain;
2. Reasoning (the *developed* capacity to solve new and relatively complex problems);
3. Self-motivated activity (activity which is relatively independent of either genetic or direct external control);
4. The capacity to communicate, by whatever means, messages of an indefinite variety of types, that is, not just with an indefinite number of possible contents, but on indefinitely many possible topics;
5. The presence of self-concepts, and self-awareness, either individual or racial, or both.

Admittedly, there are apt to be a great many problems involved in formulating precise definitions of these criteria, let alone in developing universally valid behavior criteria for deciding when they apply. But I will assume that both we and our explorer know approximately what (1)–(5) mean, and that she is also able to determine whether or not they apply. How, then, should she use her findings to decide whether or not the alien beings are people? We needn't suppose that an entity must have *all* of these attributes to be properly considered a person; (1) and (2) alone may well be sufficient for personhood, and quite probably (1)–(3) are sufficient. Neither do we need to insist that any one of these criteria is *necessary* for personhood, although once again (1) and (2) look like fairly good candidates for necessary conditions, as does (3), if “activity” is construed so as to include the activity of reasoning.

All we need to claim, to demonstrate that a fetus is not a person, is that any being which satisfies *none* of (1)–(5) is certainly not a person. I consider this claim to be so obvious that I think anyone who denied it, and claimed that a being which satisfied none of (1)–(5) was a person all the same, would thereby demonstrate that she had no notion at all of what a person is—perhaps because she had confused the concept of a person with that of genetic

humanity. If the opponents of abortion were to deny the appropriateness of these five criteria, I do not know what further arguments would convince them. We would probably have to admit that our conceptual schemes were indeed irreconcilably different, and that our dispute could not be settled objectively.

I do not expect this to happen, however, since I think that the concept of a person is one which is very nearly universal (to people), and that it is common to both proabortionists and antiabortionists, even though neither group has fully realized the relevance of this concept to the resolution of their dispute. Furthermore, I think that on reflection even the antiabortionists ought to agree not only that (1)–(5) are central to the concept of personhood, but also that it is a part of this concept that all and only people have full moral rights. The concept of a person is in part a moral concept; once we have admitted that *x* is a person we have recognized, even if we have not agreed to respect, *x*'s right to be treated as a member of the moral community. It is true that the claim that *x* is a *human being* is more commonly voiced as part of an appeal to treat *x* decently than is the claim that *x* is a person, but this is either because “human being” is here used in the sense which implies personhood, or because the genetic and moral senses of “human” have been confused.

Now if (1)–(5) are indeed the primary criteria of personhood, then it is clear that genetic humanity is neither necessary nor sufficient for establishing that an entity is a person. Some human beings are not people, and there may well be people who are not human beings. A man or woman whose consciousness has been permanently obliterated but who remains alive is a human being which is no longer a person; defective human beings, with no appreciable mental capacity, are not and presumably never will be people; and a fetus is a human being which is not yet a person, and which therefore cannot coherently be said to have full moral rights. Citizens of the next century should be prepared to recognize highly advanced, self-aware robots or computers, should such be developed, and intelligent inhabitants of other worlds, should such be found, as people in the fullest sense, and to respect their

moral rights. But to ascribe full moral rights to an entity which is not a person is as absurd as to ascribe moral obligations and responsibilities to such an entity.

### 3. Fetal Development and the Right to Life

Two problems arise in the application of these suggestions for the definition of the moral community to the determination of the precise moral status of a human fetus. Given that the paradigm example of a person is a normal adult human being, then (1) How like this paradigm, in particular how far advanced since conception, does a human being need to be before it begins to have a right to life by virtue, not of being fully a person as of yet, but of being *like* a person? and (2) To what extent, if any, does the fact that a fetus has the *potential* for becoming a person endow it with some of the same rights? Each of these questions requires some comment.

In answering the first question, we need not attempt a detailed consideration of the moral rights of organisms which are not developed enough, aware enough, intelligent enough, etc., to be considered people, but which resemble people in some respects. It does seem reasonable to suggest that the more like a person, in the relevant respects, a being is, the stronger is the case for regarding it as having a right to life, and indeed the stronger its right to life is. Thus we ought to take seriously the suggestion that, insofar as "the human individual develops biologically in a continuous fashion the rights of a human person might develop in the same way."<sup>11</sup> But we must keep in mind that the attributes which are relevant in determining whether or not an entity is enough like a person to be regarded as having some moral rights are no different from those which are relevant to determining whether or not it is fully a person—i.e., are no different from (1)–(5)—and that being genetically human, or having recognizably human facial and other physical features, or detectable brain activity, or the capacity to survive outside the uterus, are simply not among these relevant attributes.

Thus it is clear that even though a seven- or eight-month fetus has features which make it apt to arouse in us almost the same powerful protective instinct as is commonly aroused by a small infant,

nevertheless it is not significantly more personlike than is a very small embryo. It is *somewhat* more personlike; it can apparently feel and respond to pain, and it may even have a rudimentary form of consciousness, insofar as its brain is quite active. Nevertheless, it seems safe to say that it is not fully conscious, in the way that an infant of a few months is, and that it cannot reason, or communicate messages of indefinitely many sorts, does not engage in self-motivated activity, and has no self-awareness. Thus, in the *relevant* respects, a fetus, even a fully developed one, is considerably less personlike than is the average mature mammal, indeed the average fish. And I think that a rational person must conclude that if the right to life of a fetus is to be based upon its resemblance to a person, then it cannot be said to have any more right to life than, let us say, a newborn guppy (which also seems to be capable of feeling pain), and that a right of that magnitude could never override a woman's right to obtain an abortion, at any stage of her pregnancy.

There may, of course, be other arguments in favor of placing legal limits upon the stage of pregnancy in which an abortion may be performed. Given the relative safety of the new techniques of artificially inducing labor during the third trimester, the danger to the woman's life or health is no longer such an argument. Neither is the fact that people tend to respond to the thought of abortion in the later stages of pregnancy with emotional repulsion, since mere emotional responses cannot take the place of moral reasoning in determining what ought to be permitted. Nor, finally, is the frequently heard argument that legalizing abortion, especially late in the pregnancy, may erode the level of respect for human life, leading, perhaps, to an increase in unjustified euthanasia and other crimes. For this threat, if it is a threat, can be better met by educating people to the kinds of moral distinctions which we are making here than by limiting access to abortion (which limitation may, in its disregard for the rights of women, be just as damaging to the level of respect for human rights).

Thus, since the fact that even a fully developed fetus is not personlike enough to have any significant right to life on the basis of its personlikeness shows that no legal restrictions upon the stage of

pregnancy in which an abortion may be performed can be justified on the grounds that we should protect the rights of the older fetus; and since there is no other apparent justification for such restrictions, we may conclude that they are entirely unjustified. Whether or not it would be *indecent* (whatever that means) for a woman in her seventh month to obtain an abortion just to avoid having to postpone a trip to Europe, it would not, in itself, be *immoral*, and therefore it ought to be permitted.

#### 4. Potential Personhood and the Right to Life

We have seen that a fetus does not resemble a person in any way which can support the claim that it has even some of the same rights. But what about its *potential*, the fact that if nurtured and allowed to develop naturally it will very probably become a person? Doesn't that alone give it at least some right to life? It is hard to deny that the fact that an entity is a potential person is a strong *prima facie* reason for not destroying it; but we need not conclude from this that a potential person has a right to life, by virtue of that potential. It may be that our feeling that it is better, other things being equal, not to destroy a potential person is better explained by the fact that potential people are still (felt to be) an invaluable resource, not to be lightly squandered. Surely, if every speck of dust were a potential person, we would be much less apt to conclude that every potential person has a right to become actual.

Still, we do not need to insist that a potential person has no right to life whatever. There may well be something immoral, and not just imprudent, about wantonly destroying potential people, when doing so isn't necessary to protect anyone's rights. But even if a potential person does have some *prima facie* right to life, such a right could not possibly outweigh the right of a woman to obtain an abortion, since the rights of any actual person invariably outweigh those of any potential person, whenever the two conflict. Since this may not be immediately obvious in the case of a human fetus, let us look at another case.

Suppose that our space explorer falls into the hands of an alien culture, whose scientists decide to create a few hundred thousand or more human

beings, by breaking her body into its component cells, and using these to create fully developed human beings, with, of course, her genetic code. We may imagine that each of these newly created individuals will have all of the original individual's abilities, skills, knowledge, and so on, and also have an individual self-concept, in short that each of them will be a bona fide (though hardly unique) person. Imagine that the whole project will take only seconds, and that its chances of success are extremely high, and that our explorer knows all of this, and also knows that these people will be treated fairly. I maintain that in such a situation she would have every right to escape if she could, and thus to deprive all of these potential people of their potential lives; for her right to life outweighs all of theirs together, in spite of the fact that they are all genetically human, all innocent, and all have a very high probability of becoming people very soon, if only she refrains from acting.

Indeed, I think she would have a right to escape even if it were not her life which the alien scientists planned to take, but only a year of her freedom, or, indeed, only a day. Nor would she be obligated to stay if she had gotten captured (thus bringing all these people-potentials into existence) because of her own carelessness, or even if she had done so deliberately, knowing the consequences. Regardless of how she got captured, she is not morally obligated to remain in captivity for *any* period of time for the sake of permitting any number of potential people to come into actuality, so great is the margin by which one actual person's right to liberty outweighs whatever right to life even a hundred thousand potential people have. And it seems reasonable to conclude that the rights of a woman will outweigh by a similar margin whatever right to life a fetus may have by virtue of its potential personhood.

Thus, neither a fetus's resemblance to a person, nor its potential for becoming a person provides any basis whatever for the claim that it has any significant right to life. Consequently, a woman's right to protect her health, happiness, freedom, and even her life,<sup>12</sup> by terminating an unwanted pregnancy, will always override whatever right to life it may be appropriate to ascribe to a fetus, even a fully developed one. And thus, in the absence of any

overwhelming social need for every possible child, the laws which restrict the right to obtain an abortion, or limit the period of pregnancy during which an abortion may be performed, are a wholly unjustified violation of a woman's most basic moral and constitutional rights.<sup>13</sup>

#### **Postscript on Infanticide**

Since the publication of this article, many people have written to point out that my argument appears to justify not only abortion, but infanticide as well. For a new-born infant is not significantly more personlike than an advanced fetus, and consequently it would seem that if the destruction of the latter is permissible so too must be that of the former. Inasmuch as most people, regardless of how they feel about the morality of abortion, consider infanticide a form of murder, this might appear to represent a serious flaw in my argument.

Now, if I am right in holding that it is only people who have a full-fledged right to life, and who can be murdered, and if the criteria of personhood are as I have described them, then it obviously follows that killing a new-born infant isn't murder. It does *not* follow, however, that infanticide is permissible, for two reasons. In the first place, it would be wrong, at least in this country and in this period of history, and other things being equal, to kill a new-born infant, because even if its parents do not want it and would not suffer from its destruction, there are other people who would like to have it, and would, in all probability, be deprived of a great deal of pleasure by its destruction. Thus, infanticide is wrong for reasons analogous to those which make it wrong to wantonly destroy natural resources, or great works of art.

Secondly, most people, at least in this country, value infants and would much prefer that they be preserved, even if foster parents are not immediately available. Most of us would rather be taxed to support orphanages than allow unwanted infants to be destroyed. So long as there are people who want an infant preserved, and who are willing and able to provide the means of caring for it, under reasonably humane conditions, it is, *ceteris paribus*, wrong to destroy it.

But, it might be replied, if this argument shows that infanticide is wrong, at least at this time and in this country, doesn't it also show that abortion is wrong? After all, many people value fetuses, and are disturbed by their destruction, and would much prefer that they be preserved, even at some cost to themselves. Furthermore, as a potential source of pleasure to some foster family, a fetus is just as valuable as an infant. There is, however, a crucial difference between the two cases: so long as the fetus is unborn, its preservation, contrary to the wishes of the pregnant woman, violates her rights to freedom, happiness, and self-determination. Her rights override the rights of those who would like the fetus preserved, just as if someone's life or limb is threatened by a wild animal, his right to protect himself by destroying the animal overrides the rights of those who would prefer that the animal not be harmed.

The minute the infant is born, however, its preservation no longer violates any of its mother's rights, even if she wants it destroyed, because she is free to put it up for adoption. Consequently, while the moment of birth does not mark any sharp discontinuity in the degree to which an infant possesses the right to life, it does mark the end of its mother's right to determine its fate. Indeed, if abortion could be performed without killing the fetus, she would never possess the right to have the fetus destroyed, for the same reasons that she has no right to have an infant destroyed.

On the other hand, it follows from my argument that when an unwanted or defective infant is born into a society which cannot afford and/or is not willing to care for it, then its destruction is permissible. This conclusion will, no doubt, strike many people as heartless and immoral; but remember that the very existence of people who feel this way, and who are willing and able to provide care for unwanted infants, is reason enough to conclude that they should be preserved.

#### **NOTES**

1. For example, Roger Wertheimer, who in "Understanding the Abortion Argument" (*Philosophy and Public Affairs*, 1, No. 1 [Fall, 1971], 67–95), argues that the problem of the moral status of abortion is

insoluble, in that the dispute over the status of the fetus is not a question of fact at all, but only a question of how one responds to the facts.

2. B. A. Brody, "Abortion and the Law," *The Journal of Philosophy*, 68, No. 12 (June 17, 1971), 357–369.
3. Judith Thomson, "A Defense of Abortion," *Philosophy and Public Affairs*, 1, No. 1 (Fall, 1971), 47–66.
4. I have abbreviated these standards somewhat, but not in a way which affects the argument.
5. John Noonan, "Abortion and the Catholic Church: A Summary History," *Natural Law Forum*, 12 (1967), 125.
6. John Noonan, "Deciding Who Is Human," *Natural Law Forum*, 13 (1968), 134.
7. "A Defense of Abortion."
8. We may safely ignore the fact that she might have avoided getting raped, e.g., by carrying a gun, since by similar means you might likewise have avoided getting kidnapped, and in neither case does the victim's failure to take all possible precautions against a highly unlikely event (as opposed to reasonable precautions against a rather likely event) mean that she is morally responsible for what happens.

9. Of course, the principle that it is (always) wrong to kill innocent human beings is in need of many other modifications, e.g., that it may be permissible to do so to save a greater number of other innocent human beings, but we may safely ignore these complications here.

10. From here on, we will use "human" to mean genetically human, since the moral sense seems closely connected to, and perhaps derived from, the assumption that genetic humanity is sufficient for membership in the moral community.

11. Thomas L. Hayes, "A Biological View," *Commonwealth* 85 (March 17, 1967), 677–78; quoted by Daniel Callahan, in *Abortion, Law, Choice, and Morality* (London: Macmillan & Co., 1970).

12. That is, insofar as the death rate, for the woman, is higher for childbirth than for early abortion.

13. My thanks to the following people, who were kind enough to read and criticize an earlier version of this paper: Herbert Gold, Gene Glass, Anne Lauterbach, Judith Thomson, Mary Mothersill, and Timothy Binkley.

## Abortion and the Concept of a Person

JANE ENGLISH

English stakes out some middle ground in the abortion debate. Echoing points made by Judith Jarvis Thomson, she argues that whether or not a fetus is a person, a woman may be justified in some instances (most notably in early pregnancy) in having an abortion as a form of self-defense. But an abortion is not always permissible, for even if a fetus is not a person, it still has at least partial moral status—a status that increases the more the fetus resembles a person. So in the late months of pregnancy, abortion seems wrong except to spare a woman from great injury or death.

The abortion debate rages on. Yet the two most popular positions seem to be clearly mistaken. Conservatives maintain that a human life begins at conception and that therefore abortion must be wrong because it is murder. But not all killings of humans are murders. Most notably, self defense may justify even the killing of an innocent person.

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Liberals, on the other hand, are just as mistaken in their argument that since a fetus does not become a person until birth, a woman may do whatever she pleases in and to her own body. First, you cannot do as you please with your own body if it affects other people adversely.<sup>1</sup> Second, if a fetus is not a person, that does not imply that you can do to it anything you wish. Animals, for example, are not persons, yet to kill or torture them for no reason at all is wrong.

At the center of the storm has been the issue of just when it is between ovulation and adulthood

that a person appears on the scene. Conservatives draw the line at conception, liberals at birth. In this paper I first examine our concept of a person and conclude that no single criterion can capture the concept of a person and no sharp line can be drawn. Next I argue that if a fetus is a person, abortion is still justifiable in many cases; and if a fetus is not a person, killing it is still wrong in many cases. To a large extent, these two solutions are in agreement. I conclude that our concept of a person cannot and need not bear the weight that the abortion controversy has thrust upon it.

## I

The several factions in the abortion argument have drawn battle lines around various proposed criteria for determining what is and what is not a person. For example, Mary Anne Warren<sup>2</sup> lists five features (capacities for reasoning, self-awareness, complex communication, etc.) as her criteria for personhood and argues for the permissibility of abortion because a fetus falls outside this concept. Baruch Brody<sup>3</sup> uses brain waves. Michael Tooley<sup>4</sup> picks having-a-concept-of-self as his criterion and concludes that infanticide and abortion are justifiable, while the killing of adult animals is not. On the other side, Paul Ramsey<sup>5</sup> claims a certain gene structure is the defining characteristic. John Noonan<sup>6</sup> prefers conceived-of-humans and presents counterexamples to various other candidate criteria. For instance, he argues against viability as the criterion because the newborn and infirm would then be non-persons, since they cannot live without the aid of others. He rejects any criterion that calls upon the sorts of sentiments a being can evoke in adults on the grounds that this would allow us to exclude other races as non-persons if we could just view them sufficiently unsentimentally.

These approaches are typical: foes of abortion propose sufficient conditions for personhood which fetuses satisfy, while friends of abortion counter with necessary conditions for personhood which fetuses lack. But these both presuppose that the concept of a person can be captured in a strait jacket of necessary and/or sufficient conditions.<sup>7</sup> Rather, “person” is a cluster of features, of which rationality, having a self concept and being conceived of humans are only part.

What is typical of persons? Within our concept of a person we include, first, certain biological factors: descended from humans, having a certain genetic make-up, having a head, hands, arms, eyes, capable of locomotion, breathing, eating, sleeping. There are psychological factors: sentience, perception, having a concept of self and of one's own interests and desires, the ability to use tools, the ability to use language or symbol systems, the ability to joke, to be angry, to doubt. There are rationality factors: the ability to reason and draw conclusions, the ability to generalize and to learn from past experience, the ability to sacrifice present interests for greater gains in the future. There are social factors: the ability to work in groups and respond to peer pressures, the ability to recognize and consider as valuable the interests of others, seeing oneself as one among “other minds,” the ability to sympathize, encourage, love, the ability to evoke from others the responses of sympathy, encouragement, love, the ability to work with others for mutual advantage. Then there are legal factors: being subject to the law and protected by it, having the ability to sue and enter contracts, being counted in the census, having a name and citizenship, the ability to own property, inherit, and so forth.

Now the point is not that this list is incomplete, or that you can find counterinstances to each of its points. People typically exhibit rationality, for instance, but someone who was irrational would not thereby fail to qualify as a person. On the other hand, something could exhibit the majority of these features and still fail to be a person, as an advanced robot might. There is no single core of necessary and sufficient features which we can draw upon with the assurance that they constitute what really makes a person; there are only features that are more or less typical.

This is not to say that no necessary or sufficient conditions can be given. Being alive is a necessary condition for being a person, and being a U.S. Senator is sufficient. But rather than falling inside a sufficient condition or outside a necessary one, a fetus lies in the penumbra region where our concept of a person is not so simple. For this reason I think a conclusive answer to the question whether a fetus is a person is unattainable.

Here we might note a family of simple fallacies that proceed by stating a necessary condition for personhood and showing that a fetus has that characteristic. This is a form of the fallacy of affirming the consequent. For example, some have mistakenly reasoned from the premise that a fetus is human (after all, it is a human fetus rather than, say, a canine fetus), to the conclusion that it is a human. Adding an equivocation on “being,” we get the fallacious argument that since a fetus is something both living and human, it is a human being.

Nonetheless, it does seem clear that a fetus has very few of the above family of characteristics, whereas a newborn baby exhibits a much larger proportion of them—and a two-year-old has even more. Note that one traditional anti-abortion argument has centered on pointing out the many ways in which a fetus resembles a baby. They emphasize its development (“It already has ten fingers”) without mentioning its dissimilarities to adults (it still has gills and a tail). They also try to evoke the sort of sympathy on our part that we only feel toward other persons (“Never to laugh or feel the sunshine?”). This all seems to be a relevant way to argue, since its purpose is to persuade us that a fetus satisfies so many of the important features on the list that it ought to be treated as a person. Also note that a fetus near the time of birth satisfies many more of these factors than a fetus in the early months of development. This could provide reason for making distinctions among the different stages of pregnancy, as the U.S. Supreme Court has done.<sup>8</sup>

Historically, the time at which a person has been said to come into existence has varied widely. Muslims date personhood from fourteen days after conception. Some medievals followed Aristotle in placing ensoulment at forty days after conception for a male fetus and eighty days for a female fetus.<sup>9</sup> In European common law since the Seventeenth Century, abortion was considered the killing of a person only after quickening, the time when a pregnant woman first feels the fetus move on its own. Nor is this variety of opinions surprising. Biologically, a human being develops gradually. We shouldn’t expect there to be any specific time or sharp dividing point when a person appears on the scene.

For these reasons I believe our concept of a person is not sharp or decisive enough to bear the weight of a solution to the abortion controversy. To use it to solve that problem is to clarify *obscurum per obscurius*.

## II

Next let us consider what follows if a fetus is a person after all. Judith Jarvis Thomson’s landmark article, “A Defense of Abortion”<sup>10</sup> correctly points out that some additional argumentation is needed at this point in the conservative argument to bridge the gap between the premise that a fetus is an innocent person and the conclusion that killing it is always wrong. To arrive at this conclusion, we would need the additional premise that killing an innocent person is always wrong. But killing an innocent person is sometimes permissible, most notably in self defense. Some examples may help draw out our intuitions or ordinary judgments about self defense.

Suppose a mad scientist, for instance, hypnotized innocent people to jump out of the bushes and attack innocent passers-by with knives. If you are so attacked, we agree you have a right to kill the attacker in self defense, if killing him is the only way to protect your life or to save yourself from serious injury. It does not seem to matter here that the attacker is not malicious but himself an innocent pawn, for your killing of him is not done in a spirit of retribution but only in self defense.

How severe an injury may you inflict in self defense? In part this depends upon the severity of the injury to be avoided: you may not shoot someone merely to avoid having your clothes torn. This might lead one to the mistaken conclusion that the defense may only equal the threatened injury in severity; that to avoid death you may kill, but to avoid a black eye you may only inflict a black eye or the equivalent. Rather, our laws and customs seem to say that you may create an injury somewhat, but not enormously, greater than the injury to be avoided. To fend off an attack whose outcome would be as serious as rape, a severe beating or the loss of a finger, you may shoot; to avoid having your clothes torn, you may blacken an eye.

Aside from this, the injury you may inflict should only be the minimum necessary to deter or incapacitate the attacker. Even if you know he intends to kill you, you are not justified in shooting him if you could equally well save yourself by the simple expedient of running away. Self defense is for the purpose of avoiding harms rather than equalizing harms.

Some cases of pregnancy present a parallel situation. Though the fetus is itself innocent, it may pose a threat to the pregnant woman's well-being, life prospects or health, mental or physical. If the pregnancy presents a slight threat to her interests, it seems self defense cannot justify abortion. But if the threat is on a par with a serious beating or the loss of a finger, she may kill the fetus that poses such a threat, even if it is an innocent person. If a lesser harm to the fetus could have the same defensive effect, killing it would not be justified. It is unfortunate that the only way to free the woman from the pregnancy entails the death of the fetus (except in very late stages of pregnancy). Thus a self defense model supports Thomson's point that the woman has a right only to be freed from the fetus, not a right to demand its death.<sup>11</sup>

The self defense model is most helpful when we take the pregnant woman's point of view. In the pre-Thomson literature, abortion is often framed as a question for a third party: do you, a doctor, have a right to choose between the life of the woman and that of the fetus? Some have claimed that if you were a passer-by who witnessed a struggle between the innocent hypnotized attacker and his equally innocent victim, you would have no reason to kill either in defense of the other. They have concluded that the self defense model implies that a woman may attempt to abort herself, but that a doctor should not assist her. I think the position of the third party is somewhat more complex. We do feel some inclination to intervene on behalf of the victim rather than the attacker, other things equal. But if both parties are innocent, other factors come into consideration. You would rush to the aid of your husband whether he was attacker or attackee. If a hypnotized famous violinist were attacking a skid row bum, we would try to save the individual who is of more value to society. These

considerations would tend to support abortion in some cases.

But suppose you are a frail senior citizen who wishes to avoid being knifed by one of these innocent hypnotics, so you have hired a bodyguard to accompany you. If you are attacked, it is clear we believe that the bodyguard, acting as your agent, has a right to kill the attacker to save you from a serious beating. Your rights of self defense are transferred to your agent. I suggest that we should similarly view the doctor as the pregnant woman's agent in carrying out a defense she is physically incapable of accomplishing herself.

Thanks to modern technology, the cases are rare in which a pregnancy poses as clear a threat to a woman's bodily health as an attacker brandishing a switchblade. How does self defense fare when more subtle, complex and long-range harms are involved?

To consider a somewhat fanciful example, suppose you are a highly trained surgeon when you are kidnapped by the hypnotic attacker. He says he does not intend to harm you but to take you back to the mad scientist who, it turns out, plans to hypnotize you to have a permanent mental block against all your knowledge of medicine. This would automatically destroy your career which would in turn have a serious adverse impact on your family, your personal relationships and your happiness. It seems to me that if the only way you can avoid this outcome is to shoot the innocent attacker, you are justified in so doing. You are defending yourself from a drastic injury to your life prospects. I think it is no exaggeration to claim that unwanted pregnancies (most obviously among teenagers) often have such adverse lifelong consequences as the surgeon's loss of livelihood.

Several parallels arise between various views on abortion and the self defense model. Let's suppose further that these hypnotized attackers only operate at night, so that it is well known that they can be avoided completely by the considerable inconvenience of never leaving your house after dark. One view is that since you could stay home at night, therefore if you go out and are selected by one of these hypnotized people, you have no right to defend yourself. This parallels the view that

abstinence is the only acceptable way to avoid pregnancy. Others might hold that you ought to take along some defense such as Mace which will deter the hypnotized person without killing him, but that if this defense fails, you are obliged to submit to the resulting injury, no matter how severe it is. This parallels the view that contraception is all right but abortion is always wrong, even in cases of contraceptive failure.

A third view is that you may kill the hypnotized person only if he will actually kill you, but not if he will only injure you. This is like the position that abortion is permissible only if it is required to save a woman's life. Finally we have the view that it is all right to kill the attacker, even if only to avoid a very slight inconvenience to yourself and even if you knowingly walked down the very street where all these incidents have been taking place without taking along any Mace or protective escort. If we assume that a fetus is a person, this is the analogue of the view that abortion is always justifiable, "on demand."

The self defense model allows us to see an important difference that exists between abortion and infanticide, even if a fetus is a person from conception. Many have argued that the only way to justify abortion without justifying infanticide would be to find some characteristic of personhood that is acquired at birth. Michael Tooley, for one, claims infanticide is justifiable because the really significant characteristics of person are acquired some time after birth. But all such approaches look to characteristics of the developing human and ignore the relation between the fetus and the woman. What if, after birth, the presence of an infant or the need to support it posed a grave threat to the woman's sanity or life prospects? She could escape this threat by the simple expedient of running away. So a solution that does not entail the death of the infant is available. Before birth, such solutions are not available because of the biological dependence of the fetus on the woman. Birth is the crucial point not because of any characteristics the fetus gains, but because after birth the woman can defend herself by a means less drastic than killing the infant. Hence self defense can be used to justify abortion without necessarily thereby justifying infanticide.

### III

On the other hand, supposing a fetus is not after all a person, would abortion always be morally permissible? Some opponents of abortion seem worried that if a fetus is not a full-fledged person, then we are justified in treating it in any way at all. However, this does not follow. Non-persons do get some consideration in our moral code, though of course they do not have the same rights as persons have (and in general they do not have moral responsibilities), and though their interests may be overridden by the interests of persons. Still, we cannot just treat them in any way at all.

Treatment of animals is a case in point. It is wrong to torture dogs for fun or to kill wild birds for no reason at all. It is wrong Period, even though dogs and birds do not have the same rights persons do. However, few people think it is wrong to use dogs as experimental animals, causing them considerable suffering in some cases, provided that the resulting research will probably bring discoveries of great benefit to people. And most of us think it all right to kill birds for food or to protect our crops. People's rights are different from the consideration we give to animals, then, for it is wrong to experiment on people, even if others might later benefit a great deal as a result of their suffering. You might volunteer to be a subject, but this would be supererogatory; you certainly have a right to refuse to be a medical guinea pig.

But how do we decide what you may or may not do to non-persons? This is a difficult problem, one for which I believe no adequate account exists. You do not want to say, for instance, that torturing dogs is all right whenever the sum of its effects on people is good—when it doesn't warp the sensibilities of the torturer so much that he mistreats people. If that were the case, it would be all right to torture dogs if you did it in private, or if the torturer lived on a desert island or died soon afterward, so that his actions had no effect on people. This is an inadequate account, because whatever moral consideration animals get, it has to be indefeasible, too. It will have to be a general proscription of certain actions, not merely a weighing of the impact on people on a case-by-case basis.

Rather, we need to distinguish two levels on which consequences of actions can be taken into account in moral reasoning. The traditional objections to Utilitarianism focus on the fact that it operates solely on the first level, taking all the consequences into account in particular cases only. Thus Utilitarianism is open to “desert island” and “lifeboat” counterexamples because these cases are rigged to make the consequences of actions severely limited.

Rawls’ theory could be described as a teleological sort of theory, but with teleology operating on a higher level.<sup>12</sup> In choosing the principles to regulate society from the original position, his hypothetical choosers make their decision on the basis of the total consequences of various systems. Furthermore, they are constrained to choose a general set of rules which people can readily learn and apply. An ethical theory must operate by generating a set of sympathies and attitudes toward others which reinforces the functioning of that set of moral principles. Our prohibition against killing people operates by means of certain moral sentiments including sympathy, compassion and guilt. But if these attitudes are to form a coherent set, they carry us further: we tend to perform supererogatory actions, and we tend to feel similar compassion toward person-like non-persons.

It is crucial that psychological facts play a role here. Our psychological constitution makes it the case that for our ethical theory to work, it must prohibit certain treatment of non-persons which are significantly person-like. If our moral rules allowed people to treat some person-like non-persons in ways we do not want people to be treated, this would undermine the system of sympathies and attitudes that makes the ethical system work. For this reason, we would choose in the original position to make mistreatment of some sorts of animals wrong in general (not just wrong in the cases with public impact), even though animals are not themselves parties in the original position. Thus it makes sense that it is those animals whose appearance and behavior are most like those of people that get the most consideration in our moral scheme.

It is because of “coherence of attitudes,” I think, that the similarity of a fetus to a baby is very significant. A fetus one week before birth is so much like a newborn baby in our psychological space that we cannot allow any cavalier treatment of the former while expecting full sympathy and nurturative support for the latter. Thus, I think that anti-abortion forces are indeed giving their strongest arguments when they point to the similarities between a fetus and a baby, and when they try to evoke our emotional attachment to and sympathy for the fetus. An early horror story from New York about nurses who were expected to alternate between caring for six-week premature infants and disposing of viable 24-week aborted fetuses is just that—a horror story. These beings are so much alike that no one can be asked to draw a distinction and treat them so very differently.

Remember, however, that in the early weeks after conception, a fetus is not very much like a person. It is hard to develop these feelings for a set of genes which doesn’t yet have a head, hands, beating heart, response to touch or the ability to move by itself. Thus it seems to me that the alleged “slippery slope” between conception and birth is not so very slippery. In the early stages of pregnancy, abortion can hardly be compared to murder for psychological reasons, but in the latest stages it is psychologically akin to murder.

Another source of similarity is the bodily continuity between fetus and adult. Bodies play a surprisingly central role in our attitudes toward persons. One has only to think of the philosophical literature on how far physical identity suffices for personal identity or Wittgenstein’s remark that the best picture of the human soul is the human body. Even after death, when all agree the body is no longer a person, we still observe elaborate customs of respect for the human body; like people who torture dogs, necrophiliacs are not to be trusted with people.<sup>13</sup> So it is appropriate that we show respect to a fetus as the body continuous with the body of a person. This is a degree of resemblance to persons that animals cannot rival.

Michael Tooley also utilizes a parallel with animals. He claims that it is always permissible to

drown newborn kittens and draws conclusions about infanticide.<sup>14</sup> But it is only permissible to drown kittens when their survival would cause some hardship. Perhaps it would be a burden to feed and house six more cats or to find other homes for them. The alternative of letting them starve produces even more suffering than the drowning. Since the kittens get their rights secondhand, so to speak, *via* the need for coherence in our attitudes, their interests are often overridden by the interests of full-fledged persons. But if their survival would be no inconvenience of people at all, then it is wrong to drown them, *contra* Tooley.

Tooley's conclusions about abortion are wrong for the same reason. Even if a fetus is not a person, abortion is not always permissible, because of the resemblance of a fetus to a person. I agree with Thomson that it would be wrong for a woman who is seven months pregnant to have an abortion just to avoid having to postpone a trip to Europe. In the early months of pregnancy when the fetus hardly resembles a baby at all, then, abortion is permissible whenever it is in the interests of the pregnant woman or her family. The reasons would only need to outweigh the pain and inconvenience of the abortion itself. In the middle months, when the fetus comes to resemble a person, abortion would be justifiable only when the continuation of the pregnancy or the birth of the child would cause harms—physical, psychological, economic or social—to the woman. In the late months of pregnancy, even on our current assumption that a fetus is not a person, abortion seems to be wrong except to save a woman from significant injury or death.

The Supreme Court has recognized similar gradations in the alleged slippery slope stretching between conception and birth. To this point, the present paper has been a discussion of the moral status of abortion only, not its legal status. In view of the great physical, financial and sometimes psychological costs of abortion, perhaps the legal arrangement most compatible with the proposed moral solution would be the absence of restrictions, that is, so-called abortion “on demand.”

So I conclude, first, that application of our concept of a person will not suffice to settle the abortion issue. After all, the biological development of a human being is gradual. Second, whether a fetus is a person or not, abortion is justifiable early in pregnancy to avoid modest harms and seldom justifiable late in pregnancy except to avoid significant injury or death.<sup>15</sup>

#### NOTES

1. We also have paternalistic laws which keep us from harming our own bodies even when no one else is affected. Ironically, anti-abortion laws were originally designed to protect pregnant women from a dangerous but tempting procedure.
2. Mary Anne Warren, “On the Moral and Legal Status of Abortion,” *Monist* 57 (1973), p. 55.
3. Baruch Brody, “Fetal Humanity and the Theory of Essentialism,” in Robert Baker and Frederick Elliston (eds.), *Philosophy and Sex* (Buffalo, N.Y., 1975).
4. Michael Tooley, “Abortion and Infanticide,” *Philosophy and Public Affairs* 2 (1971).
5. Paul Ramsey, “The Morality of Abortion,” in James Rachels, ed., *Moral Problems* (New York, 1971).
6. John Noonan, “Abortion and the Catholic Church: A Summary History,” *Natural Law Forum* 12 (1967), pp. 125–131.
7. Wittgenstein has argued against the possibility of so capturing the concept of a game, *Philosophical Investigations* (New York, 1958), §66–71.
8. Not because the fetus is partly a person and so has some of the rights of persons, but rather because of the rights of person-like non-persons.
9. Aristotle himself was concerned, however, with the different question of when the soul takes form. For historical data, see Jimmye Kimmey, “How the Abortion Laws Happened,” *Ms. 1* (April, 1973), pp. 48ff and John Noonan, *loc. cit.*
10. J. J. Thomson, “A Defense of Abortion,” *Philosophy and Public Affairs* 1 (1971).
11. *Ibid.*, p. 52.
12. John Rawls, *A Theory of Justice* (Cambridge, Mass., 1971), §§ 3–4.
13. On the other hand, if they can be trusted with people, then our moral customs are mistaken. It all depends on the facts of psychology.
14. *Op. cit.*, pp. 40, 60–61.
15. I am deeply indebted to Larry Crocker and Arthur Kuflik for their constructive comments.

## Abortion

MARGARET OLIVIA LITTLE

Margaret Olivia Little offers an analysis of the issue of abortion that is more nuanced than assessments based only on questions of whether a fetus is a person. She explores values that women often wrestle with when deciding whether to end a pregnancy. These include the responsibilities of motherhood, respect for creation, the sanctity of developing human life, and the demands of kinship. Based on how they weigh these ideals, women might ultimately choose to continue a pregnancy or to end it.

Just as we cannot assume that abortion is monstrous if fetuses are persons, so too we cannot assume that abortion is empty of moral import if they are not. Given all the ink that has been spilt on arbitrating the question of fetal personhood, one might be forgiven for having thought so: on some accounts, decisions about whether to continue or end a pregnancy really are, from a moral point of view, just like decisions about whether to cut one's hair.

But as Ronald Dworkin (1993) has urged, to think abortion morally weighty does not require supposition that the fetus is a person, or even a creature with interests in continued life. Destruction of a Da Vinci painting, he points out, is not bad *for the painting*—the painting has no interests. Instead, it is regrettable because of the deep value it has. So, too, one of the reasons we might regard abortion as morally weighty does not have to do with its being bad *for the fetus*—a setback to its interests—for it may not satisfy the criteria of having interests. Abortion may be weighty, instead, because there is something precious and significant about germinating human life that deserves our deep respect. This, as Dworkin puts it, locates issues of abortion in a different neighborhood of our moral commitments: namely, the accommodation we owe to things of value. That an organism is a potential person may not make it a claims-bearer, but it

does mean it has a kind of stature that is worthy of respect.

This intuition, dismissed by some as mere sentimentality, is, I think, both important and broadly held. Very few people regard abortion as the moral equivalent of contraception. Most think a society better morally—not just by public health measures—if it regards abortion as a back-up to failed contraception rather than as routine birth control. Reasons adequate for contraception do not translate transparently as reasons adequate for abortion. Indeed, there is a telling shift in presumption: for most people, it takes no reason at all to justify contracepting; it takes *some* reason to justify ending a pregnancy. That a human life has now begun matters morally.

Burgeoning human life, we might put it, is *respect-worthy*. This is why we care not just whether, but how, abortion is done—while crass jokes are made or with solemnity—and why we care how the fetal remains are treated. It is why the thought of someone aborting for genuinely trivial reasons—to fit into a favorite party dress, say—makes us morally queasy. Perhaps, most basically, it is why the thought of someone aborting with casual indifference fills us with misgiving. Abortion involves loss. Not just loss of the hope that various parties might have invested, but loss of something valuable in its own right. To respect something is to appreciate fully the value it has and the claims it presents to us; someone who aborts but never gives it a second thought has not exhibited genuine appreciation of

From Margaret Olivia Little, "Abortion," in *A Companion to Applied Ethics*, ed. R. G. Frey and Christopher Heath Wellman (Oxford: Blackwell, 2003), 319–24.

the value and moral status of that which is now gone.

But if many share the intuition that early human life has a value deserving of respect, there is considerable disagreement about what that respect looks like. There is considerable conflict, that is, over what accommodation we owe to burgeoning human life. In part, of course, this is due to disagreement over the *degree* of value such life should be accorded: those for whom it is thoroughly modest will have very different views on issues, from abortion to stem-cell research, from those for whom it is transcendent. But this is only part of the story. Obscured by analogies to Da Vinci paintings, some of the most important sources of conflict, especially for the vast middle rank of moderates, ride atop rough agreement on “degree” of fetal value. If we listen to women’s own struggles about when it is morally decent to end pregnancy, what we hear are themes about *motherhood* and *respect for creation*. These themes are enormously complex, I want to argue, for they enter stories on both sides of the ledger: for some women, as reasons to continue pregnancy, and, for others, as reasons to end it. Let me start with motherhood.

For many women who contemplate abortion, the desire to end pregnancy is not, or not centrally, a desire to avoid the nine months of pregnancy; it is to avoid what lies on the far side of those months—namely, motherhood. If gestation were simply a matter of rendering, say, somewhat risky assistance to help a burgeoning human life they have come across—if they could somehow render that assistance without thereby adding a member to their family—the decision faced would be a far different one. But gestation does not just allow cells to become a person; it turns one into a mother.

One of the most common reasons women give for wanting to abort is that they do not want to become a mother—now, ever, again, with this partner, or no reliable partner, with these few resources, or these many that are now, after so many years of mothering, slated finally to another cause

(Hursthouse, 1987: ch. 8.4). Nor does adoption represent a universal solution. To give up a child would be for some a life-long trauma; others occupy fortunate circumstances that would, by their own lights, make it unjustified to give over a child for others to rear. Or again—and most frequently—she does not *want* to raise a child just now but knows that if she *does* carry the pregnancy to term, she will not *want* to give up the child for adoption. Gestation, she knows, is likely to reshape her heart and soul, transforming her into a mother emotionally, not just officially; and it is precisely that transformation she does not want to undergo. It is because continuing pregnancy brings with it this new identity and, likely, relationship, then, that many feel it legitimate to decline.

But pregnancy’s connection to motherhood also enters the phenomenology of abortion in just the opposite direction. For some women, that it would be her child is precisely why she feels she must continue the pregnancy, even if motherhood is not what she desired. To be pregnant is to have one’s potential child knocking at one’s door; to abort is to turn one’s back on it, a decision, many women say, that would haunt them forever. On this view, the desire to avoid motherhood, so compelling as a reason to use contraception, is uneasy grounds to abort: for once an embryo is on the scene, it is not about rejecting motherhood, it is about rejecting one’s *child*. Not literally, of course, since there is no child yet extant to stand as the object of rejection. But the stance one should take to pregnancy, sought or not, is one of *acceptance*: when a potential family member is knocking at the door, one should move over, make room, and welcome her in.

These two intuitive stances represent just profoundly different ways of *gestalting* the situation of ending pregnancy. On the first view, abortion is closer to contraception: hardly equivalent, because it means the demise of something of value. But the desire to avoid the enterprise and identity of motherhood is an understandable and honorable basis for deciding to end a pregnancy. Given that there is no child yet on the scene, one does not

owe special openness to the relationship that stands at the end of pregnancy's trajectory. On the second view, abortion is closer to exiting a parental relationship: hardly equivalent, for one of the key relata is not yet fully present. But one's decision about whether to continue the pregnancy already feels specially constrained; that one would be related to the resulting person exerts now some moral force. It would take especially grave reasons to refuse assistance here, for the norms of parenthood already have toehold. Assessing the moral status of abortion, it turns out, then, is not just about assessing the contours of generic respect owed to burgeoning human life, it is about assessing the salience of *impending relationship*. And this is an issue that functions in different ways for different women—and, sometimes, in one and the same woman.

In my own view, until the fetus is a person, we should recognize a moral prerogative to decline parenthood and end the pregnancy. Not because motherhood is necessarily a burden (though it can be), but because it so thoroughly changes what we might call one's fundamental *practical identity*. The enterprise of mothering restructures the self—changing the shape of one's heart, the primary commitments by which one lives one's life, the terms by which one judges one's life a success or a failure. If the enterprise is eschewed and one decides to give the child over to another, the identity of mother still changes the normative facts that are true of one, as there is now someone by whom one does well or poorly (see Ross, 1982). And either way—whether one rears the child or lets it go—to continue a pregnancy means that a piece of one's heart, as the saying goes, will forever walk outside one's body. As profound as the respect we should have for burgeoning human life, we should acknowledge moral prerogatives over identity-constituting commitments and enterprises as profound as motherhood.

Whether one agrees with this view or not, there is at any rate another layer of the moral story here. If women find themselves with different ways of *gestalting* the prospective

relationship involved in pregnancy, it is in part because they have different identities, commitments, and ideals that such a prospect intersects with, commitments which, while permissibly idiosyncratic, are morally authoritative for *them*. If one woman feels already duty-bound by the norms of parenthood to nurture this creature, for example, it may be for the very good reason that, in an important personal sense, she already *is* its mother. She finds herself (perhaps to her surprise) with a maternal commitment to this creature. But taking on the identity of mother toward something just *is* to take on certain imperatives about its well-being as categorical. Her job is thus clear: it is to help this creature reach its fullest potential. For another woman, on the other hand, the identity of mother is yet to be taken on; it is tried on, perhaps accepted, but perhaps declined—in which case respect is owed, but love is saved, or confirmed, for others—other relationships, other projects, other passions.

And, again, if one woman feels she owes a stance of welcome to burgeoning human life that comes her way, it may be, not because she thinks such a stance authoritative for all, but because of the virtues around which her practical identity is now oriented: receptivity to life's agenda, for instance, or responsiveness to that which is most vulnerable. For another woman, the virtues to be exercised may tug in just the other direction: loyalty to treasured life plans, a commitment that it be she, not the chances of biology, that should determine her life's course, bolstering self-direction after a life too long ruled by serendipity and fate.

Deciding when it is morally decent to end a pregnancy, it turns out, is an admixture of settling impersonally or universally authoritative moral requirements, and of discovering and arbitrating—sometimes after agonizing deliberation, sometimes in a decision no less deep for its immediacy—one's own commitments, identity, and defining virtues.

A similarly complex story appears when we turn to the second theme. Another thread that

appears in many women's stories in the face of unsought pregnancy is respect for the weighty responsibility involved in creating human life. Once again, it is a theme that pulls and tugs in different directions.

In its most familiar direction, it shows up in many stories of why an unsought pregnancy is continued. Many people believe that one's responsibility to nurture new life is importantly amplified if one is responsible for bringing about its existence in the first place. Just what it takes to count as responsible here is a point on which individuals diverge (whether voluntary intercourse with contraception is different from intercourse without use of birth control, and again from intentionally deciding to become pregnant at the IVF clinic). But triggering the relevant standard of responsibility for creation, it is felt, brings with it a heightened responsibility to nurture: it is disrespectful to create human life only to allow it to wither. Put more rigorously, one who is responsible for bringing about a creature that has intrinsic value in virtue of its potential to become a person has a special responsibility to enable it to reach that end state.

But the idea of respect for creation is also, if less frequently acknowledged, sometimes the reason why women are moved to *end* pregnancies. As Barbara Katz Rothman (1989) puts it, decisions to abort often represent, not a decision to destroy, but a refusal to create. Many people have deeply felt convictions about the circumstances under which they feel it right for them to bring a child into the world. Can it be brought into a decent world, an intact family, a society that can minimally respect its agency? These considerations may persist even after conception has taken place; for while the *embryo* has already been created, a person has not. Some women decide to abort, that is, not because they do not *want* the resulting child—indeed, they may yearn for nothing more, and desperately wish that their circumstances were otherwise—but because they do not think bringing a child into the world the right thing for them to do.

These are abortions marked by moral language. A woman wants to abort because she

knows she could not give up a child for adoption but feels she could not give the child the sort of life, or be the sort of parent, she thinks a child *deserves*; a woman who would have to give up the child thinks it would be *unfair* to bring a child into existence already burdened by rejection, however well grounded its reasons; a woman living in a country marked by poverty and gender apartheid wants to abort because she decides it would be *wrong* for her to bear a daughter whose life, like hers, would be filled with so much injustice and hardship.

Some have thought that such decisions betray a simple fallacy: unless the child's life were literally going to be worse than non-existence, how can one abort out of concern for the future child? But the worry here is not that one would be imposing a *harm* on the child by bringing it into existence (as though children who are in the situations mentioned have lives that are not worth living). The claim is that bringing about a person's life in these circumstances would do violence to her ideals of creating and parenthood. She does not want to bring into existence a daughter she cannot love and care for, she does not want to bring into existence a person whose life will be marked by disrespect or rejection.

Nor does the claim imply judgment on women who *do* continue pregnancies in similar circumstances—as though there were here an obligation to abort. For the norms in question, once again, need not be impersonally authoritative moral claims. Like ideals of good parenting, they mark out considerations all should be sensitive to, perhaps, but equally reasonable people may adhere to different variations and weightings. Still, they are normative for those who do have them; far from expressing mere matters of taste, the ideals one does accept carry an important kind of categoricity, issuing imperatives whose authority is not reducible to mere desire. These are, at root, issues about *integrity*, and the importance of maintaining integrity over one's participation in this enterprise precisely because it is so normatively weighty.

What is usually emphasized in the morality of abortion is the ethics of destruction, but there is a

balancing ethics of creation. And for many people, conflict about abortion is a conflict *within* that ethics. On the one hand, we now have on hand an entity that has a measure of sanctity: that it has begun is reason to help it continue, perhaps especially if one has had a role in its procreation, which is why even early abortion is not normatively equivalent to contraception. On the other hand, not to end a pregnancy *is* to do something else, namely, to continue creating a person, and, for some women, pregnancy strikes in circumstances in which they cannot countenance that enterprise. For some, the sanctity of developing human life will be strong enough to tip the balance toward continuing the pregnancy; for others, their norms of respectful creation will hold sway. For those who believe that the norms governing creation of a person are mild relative to the normative telos of embryonic life, being a responsible creator means continuing to gestate, and doing the best one can to bring about the conditions under which that creation will be more respectful. For others, though, the normativity of fetal telos is mild and their standards of respectful creation high, and the lesson goes in just the other direction: it is a sign of respect not to continue creating when certain background conditions, such as a loving family or adequate resources, are not in place.

However one thinks these issues settle out, they will not be resolved by austere contemplation of the value of human life. They require wrestling with the rich meanings of creation, responsibility, and kinship. And these issues, I have suggested, are just as much issues about one's integrity as they are about what is impersonally obligatory. On many treatments of abortion, considerations about whether or not to continue a pregnancy are exhausted by preferences, on the one hand, and universally authoritative moral demands, on the other; but some of the most important terrain lies in between.

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## Abortion Through a Feminist Ethics Lens

SUSAN SHERWIN

Sherwin says that a central moral feature of pregnancy is that it takes place in women's bodies and has a tremendous impact on women's lives. Policies about abortion affect women uniquely. So we must evaluate how proposed abortion policies "fit into general patterns of oppression for women," and a decision to have or not to have an abortion must be left to the individual woman, the one who best understands the circumstances of the decision. A fetus has moral significance, but its moral standing depends on its relationship to the pregnant woman. Feminist views, says Sherwin, stress "the importance of protecting women's right to continue as well as to terminate pregnancies as each sees fit."

Abortion has long been a central issue in the arena of applied ethics, but, the distinctive analysis of feminist ethics is generally overlooked in most philosophic discussions. Authors and readers commonly presume a familiarity with the feminist position and equate it with liberal defences of women's right to choose abortion, but, in fact, feminist ethics yields a different analysis of the moral questions surrounding abortion than that usually offered by the more familiar liberal defenders of abortion rights. Most feminists can agree with some of the conclusions that arise from certain non-feminist arguments on abortion, but they often disagree about the way the issues are formulated and the sorts of reasons that are invoked in the mainstream literature.

Among the many differences found between feminist and non-feminist arguments about abortion, is the fact that most non-feminist discussions of abortion consider the questions of the moral or legal permissibility of abortion in isolation from other questions, ignoring (and thereby obscuring) relevant connections to other social practices that oppress women. They are generally grounded in masculinist conceptions of freedom (e.g., privacy, individual choice, individuals' property rights in their own bodies) that do not meet the needs,

interests, and intuitions of many of the women concerned. In contrast, feminists seek to couch their arguments in moral concepts that support their general campaign of overcoming injustice in all its dimensions, including those inherent in moral theory itself.<sup>1</sup> There is even disagreement about how best to understand the moral question at issue: non-feminist arguments focus exclusively on the morality and/or legality of performing abortions, whereas feminists insist that other questions, including ones about accessibility and delivery of abortion services must also be addressed.

Although feminists welcome the support of non-feminists in pursuing policies that will grant women control over abortion decisions, they generally envision very different sorts of policies for this purpose than those considered by non-feminist sympathizers. For example, Kathleen McDonnell (1984) urges feminists to develop an explicitly "feminist morality" of abortion. At its root it would be characterized by the deep appreciations of time complexities of life, the refusal to polarize and adopt simplistic formulas" (p. 52). Here, I propose one conception of the shape such an analysis should take.

### Women and Abortion

The most obvious difference between feminist and non-feminist approaches to abortion can be seen in the relative attention each gives to the interests and experiences of women in its analysis. Feminists

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consider it self-evident that the pregnant woman is a subject of principal concern in abortion decisions. In most non-feminist accounts, however, not only is she not perceived as central, she is rendered virtually invisible. Non-feminist theorists, whether they support or oppose women's right to choose abortion, focus almost all their attention on the moral status of the developing embryo or the fetus.

In pursuing a distinctively feminist ethics, it is appropriate to begin with a look at the role of abortion in women's lives. Clearly, the need for abortion can be very intense; women have pursued abortions under appalling and dangerous conditions, across widely diverse cultures and historical periods. No one denies that if abortion is not made legal, safe, and accessible, women will seek out illegal and life-threatening abortions to terminate pregnancies they cannot accept. Anti-abortion activists seem willing to accept this price, but feminists judge the inevitable loss of women's lives associated with restrictive abortion policies to be a matter of fundamental concern.

Although anti-abortion campaigners imagine that women often make frivolous and irresponsible decisions about abortion, feminists recognize that women have abortions for a wide variety of reasons. Some women, for instance, find themselves seriously ill and incapacitated throughout pregnancy; they cannot continue in their jobs and may face enormous difficulties in fulfilling their responsibilities at home. Many employers and schools will not tolerate pregnancy in their employees or students, and not every woman is able to put her job, career, or studies on hold. Women of limited means may be unable to take adequate care of children they have already borne and they may know that another mouth to feed will reduce their ability to provide for their existing children. Women who suffer from chronic disease, or who feel too young, or too old, or who are unable to maintain lasting relationships may recognize that they will not be able to care properly for a child at this time. Some who are homeless, or addicted to drugs, or who are diagnosed as carrying the AIDS virus may be unwilling to allow a child to enter the world under such circumstances. If the pregnancy is a result of rape or incest, the psychological pain of carrying it

to term may be unbearable, and the woman may recognize that her attitude to the child after birth will always be tinged with bitterness. Some women have learned that the fetuses they carry have serious chromosomal anomalies and consider it best to prevent them from being born with a condition bound to cause suffering. Others, knowing the fathers to be brutal and violent, may be unwilling to subject a child to the beatings or incestuous attacks they anticipate; some may have no other realistic way to remove the child (or themselves) from the relationship.

Or a woman may simply believe that bearing a child is incompatible with her life plans at this time, since continuing a pregnancy is likely to have profound repercussions throughout a woman's entire life. If the woman is young, a pregnancy will very likely reduce her chances of education and hence limit her career and life opportunities: "The earlier a woman has a baby, it seems, the more likely she is to drop out of school; the less education she gets, the more likely she is to remain poorly paid, peripheral to the labour market, or unemployed, and the more children she will have—between one and three more than her working childless counterpart" (Petchesky 1984, p. 150). In many circumstances, having a child will exacerbate the social and economic forces already stacked against her by virtue of her sex (and her race, class, age, sexual orientation, or the effects of some disability, etc.). Access to abortion is a necessary option for many women if they are to escape the oppressive conditions of poverty.

Whatever the reason, most feminists believe that a pregnant woman is in the best position to judge whether abortion is the appropriate response to her circumstances. Since she is usually the only one able to weigh all the relevant factors, most feminists reject attempts to offer any general abstract rules for determining when abortion is morally justified. Women's personal deliberations about abortion include contextually defined considerations reflecting their commitment to the needs and interests of everyone concerned—including herself, the fetus she carries, other members of her household, etc. Because there is no single formula available for balancing these complex factors through all possible

cases, it is vital that feminists insist on protecting each woman's right to come to her own conclusions. Abortion decisions are, by their very nature, dependent on specific features of each woman's experience; theoretically dispassionate philosophers and other moralists should not expect to set the agenda for these considerations in any universal way. Women must be acknowledged as full moral agents with the responsibility for making moral decisions about their own pregnancies.<sup>2</sup> Although I think that it is possible for a woman to make a mistake in her moral judgment on this matter (i.e., it is possible that a woman may come to believe that she was wrong about her decision to continue or terminate a pregnancy), the intimate nature of this sort of decision makes it unlikely that anyone else is in a position to arrive at a more reliable conclusion; it is, therefore, improper to grant others the authority to interfere in women's decisions to seek abortions.

Feminist analysis regards the effects of unwanted pregnancies on the lives of women individually and collectively as a central element in the moral evaluation of abortion. Even without patriarchy, bearing a child would be a very important event in a woman's life. It involves significant physical, emotional, social, and (usually) economic changes for her. The ability to exert control over the incidence, timing, and frequency of childbearing is often tied to her ability to control most other things she values. Since we live in a patriarchal society, it is especially important to ensure that women have the authority to control their own reproduction.<sup>3</sup> Despite the diversity of opinion among feminists on most other matters, virtually all feminists seem to agree that women must gain full control over their own reproductive lives if they are to free themselves from male dominance.<sup>4</sup> Many perceive the commitment of the political right wing to opposing abortion as part of a general strategy to reassert patriarchal control over women in the face of significant feminist influence (Petchesky 1980, p. 112).

Women's freedom to choose abortion is also linked with their ability to control their own sexuality. Women's subordinate status often prevents them from refusing men sexual access to their bodies. If women cannot end the unwanted pregnancies that

result from male sexual dominance, their sexual vulnerability to particular men can increase, because caring for an(other) infant involves greater financial needs and reduced economic opportunities for women.<sup>5</sup> As a result, pregnancy often forces women to become dependent on men. Since a woman's dependence on a man is assumed to entail that she will remain sexually loyal to him, restriction of abortion serves to channel women's sexuality and further perpetuates the cycle of oppression.

In contrast to most non-feminist accounts, feminist analyses of abortion direct attention to the question of how women get pregnant. Those who reject abortion seem to believe that women can avoid unwanted pregnancies by avoiding sexual intercourse. Such views show little appreciation for the power of sexual politics in a culture that oppresses women. Existing patterns of sexual dominance mean that women often have little control over their sexual lives. They may be subject to rape by strangers, or by their husbands, boyfriends, colleagues, employers, customers, fathers, brothers, uncles, and dates. Often, the sexual coercion is not even recognized as such by the participants, but is the price of continued "good will"—popularity, economic survival, peace, or simple acceptance. Few women have not found themselves in circumstances where they do not feel free to refuse a man's demands for intercourse, either because he is holding a gun to her head or because he threatens to be emotionally hurt if she refuses (or both). Women are socialized to be compliant and accommodating, sensitive to the feelings of others, and frightened of physical power; men are socialized to take advantage of every opportunity to engage in sexual intercourse and to use sex to express dominance and power. Under such circumstances, it is difficult to argue that women could simply "choose" to avoid heterosexual activity if they wish to avoid pregnancy. Catherine MacKinnon neatly sums it up: "the logic by which women are supposed to consent to sex [is]: preclude the alternatives, then call the remaining option 'her choice'" (MacKinnon 1989, p. 192).

Nor can women rely on birth control alone to avoid pregnancy. There simply is no form of reversible contraception available that is fully safe and reliable. The pill and the IUD are the most effective means offered, but both involve significant health

hazards to women and are quite dangerous for some. No woman should spend the 30 to 40 years of her reproductive life on either form of birth control. Further, both have been associated with subsequent problems of involuntary infertility, so they are far from optimum for women who seek to control the timing of their pregnancies.

The safest form of birth control involves the use of barrier methods (condoms or diaphragms) in combination with spermicidal foams or jelly. But these methods also pose difficulties for women. They may be socially awkward to use: young women are discouraged from preparing for sexual activity that might never happen and are offered instead romantic models of spontaneous passion. (Few films or novels interrupt scenes of seduction for the fetching of contraceptives.) Many women find their male partners unwilling to use barrier methods of contraception and they do not have the power to insist. Further, cost is a limiting factor for many women. Condoms and spermicides are expensive and are not covered under most health care plans. There is only one contraceptive option which offers women safe and fully effective birth control: barrier methods with the back-up option of abortion.<sup>6</sup>

From a feminist perspective, a central moral feature of pregnancy is that it takes place in *women's bodies* and has profound effects on *women's lives*. Gender-neutral accounts of pregnancy are not available; pregnancy is explicitly a condition associated with the female body.<sup>7</sup> Because the need for abortion is experienced only by women, policies about abortion affect women uniquely. Thus, it is important to consider how proposed policies on abortion fit into general patterns of oppression for women. Unlike non-feminist accounts, feminist ethics demands that the effects on the oppression of women be a principal consideration when evaluating abortion policies.

### **The Fetus**

In contrast, most non-feminist analysts believe that the moral acceptability of abortion turns on the question of the moral status of the fetus. Even those who support women's right to choose abortion tend to accept the central premise of the anti-abortion proponents that abortion can only be tolerated if it

can be proved that the fetus is lacking some criterion of full personhood.<sup>8</sup> Opponents of abortion have structured the debate so that it is necessary to define the status of the fetus as either valued the same as other humans (and hence entitled not to be killed) or as lacking in all value. Rather than challenging the logic of this formulation, many defenders of abortion have concentrated on showing that the fetus is indeed without significant value (Tooley 1972, Warren 1973); others, such as Wayne Sumner (1981), offer a more subtle account that reflects the gradual development of fetuses whereby there is some specific criterion that determines the degree of protection to be afforded them which is lacking in the early stages of pregnancy but present in the later stages. Thus, the debate often rages between abortion opponents who describe the fetus as an "innocent," vulnerable, morally important, separate being whose life is threatened and who must be protected at all costs, and abortion supporters who try to establish some sort of deficiency inherent to fetuses which removes them from the scope of the moral community.

The woman on whom the fetus depends for survival is considered as secondary (if she is considered at all) in these debates. The actual experiences and responsibilities of real women are not perceived as morally relevant (unless they, too, can be proved innocent by establishing that their pregnancies are a result of rape or incest). It is a common assumption of both defenders and opponents of women's right to choose abortion that many women will be irresponsible in their choices. The important question, though, is whether fetuses have the sort of status that justifies interfering in women's choices at all. In some contexts, women's role in gestation is literally reduced to that of "fetal containers"; the individual women disappear or are perceived simply as mechanical life-support systems.<sup>9</sup>

The current rhetoric against abortion stresses the fact that the genetic make-up of the fetus is determined at conception and the genetic code is incontestably human. Lest there be any doubt about the humanity of the fetus, we are assailed with photographs of fetuses at various stages of development demonstrating the early appearance of recognizably human characteristics, e.g., eyes, fingers, and

toes. The fact that the fetus in its early stages is microscopic, virtually indistinguishable from other primate fetuses to the untrained eye, and lacking in the capacities that make human life meaningful and valuable is not deemed relevant by the self-appointed defenders of fetuses. The anti-abortion campaign is directed at evoking sympathetic attitudes towards this tiny, helpless being whose life is threatened by its own mother; it urges us to see the fetus as entangled in an adversarial relationship with the (presumably irresponsible) woman who carries it. We are encouraged to identify with the "unborn child" and not with the (selfish) woman whose life is also at issue.

Within the non-feminist literature, both defenders and opponents of women's right to choose abortion agree that the difference between a late term fetus and a newborn infant is "merely geographical" and cannot be considered morally significant. But a fetus inhabits a woman's body and is wholly dependent on her unique contribution to its maintenance while a newborn is physically separate though still in need of a lot of care. One can only view the distinction between being in or out of a woman's womb as morally irrelevant if one discounts the perspective of the pregnant woman; feminists seem to be alone in recognizing her perspective as morally important.<sup>10</sup>

Within anti-abortion arguments, fetuses are identified as individuals; in our culture which views the (abstract) individual as sacred, fetuses *qua* individuals should be honoured and preserved. Extraordinary claims are made to try to establish the individuality and moral agency of fetuses. At the same time, the women who carry these fetal individuals are viewed as passive hosts whose only significant role is to refrain from aborting or harming their fetuses. Since it is widely believed that the woman does not actually have to *do* anything to protect the life of the fetus, pregnancy is often considered (abstractly) to be a tolerable burden to protect the life of an individual so like us.<sup>11</sup>

Medicine has played its part in supporting these sorts of attitudes. Fetal medicine is a rapidly expanding specialty, and it is commonplace in professional medical journals to find references to

pregnant women as "fetal environments." Fetal surgeons now have at their disposal a repertory of sophisticated technology that can save the lives of dangerously ill fetuses; in light of such heroic successes, it is perhaps understandable that women have disappeared from their view. These specialists see fetuses as their patients, not the women who nurture them. Doctors perceive themselves as the *active* agents in saving fetal lives and, hence, believe that they are the ones in direct relationship with the fetuses they treat.

Perhaps even more distressing than the tendency to ignore the woman's agency altogether and view her as a purely passive participant in the medically controlled events of pregnancy and childbirth is the growing practice of viewing women as genuine threats to the well-being of the fetus. Increasingly, women are viewed as irresponsible or hostile towards their fetuses, and the relationship between them is characterized as adversarial (Overall 1987, p. 60). Concern for the well-being of the fetus is taken as licence for doctors to intervene to ensure that women comply with medical "advice." Courts are called upon to enforce the doctors' orders when moral pressure alone proves inadequate, and women are being coerced into undergoing unwanted Caesarean deliveries and technologically monitored hospital births. Some states have begun to imprison women for endangering their fetuses through drug abuse and other socially unacceptable behaviours. An Australian state recently introduced a bill that makes women liable to criminal prosecution "if they are found to have smoked during pregnancy, eaten unhealthful foods, or taken any other action which can be shown to have adversely affected the development of the fetus" (Warren 1989, p. 60).

In other words, physicians have joined with anti-abortionist activists in fostering a cultural acceptance of the view that fetuses are distinct individuals, who are physically, ontologically, and socially separate from the women whose bodies they inhabit, and who have their own distinct interests. In this picture, pregnant women are either ignored altogether or are viewed as deficient in some crucial respect and hence subject to coercion for the sake of their fetuses. In the former case, the interests of the

women concerned are assumed to be identical with those of the fetus; in the latter, the women's interests are irrelevant because they are perceived as immoral, unimportant, or unnatural. Focus on the fetus as an independent entity has led to presumptions which deny pregnant women their roles as active, independent, moral agents with a primary interest in what becomes of the fetuses they carry. Emphasis on the fetus's status has led to an assumed licence to interfere with women's reproductive freedom.

### A Feminist View of the Fetus

Because the public debate has been set up as a competition between the rights of women and those of fetuses, feminists have often felt pushed to reject claims of fetal value in order to protect women's claims. Yet, as Addelson (1987) has argued, viewing abortion in this way "tears [it] out of the context of women's lives" (p. 107). There are other accounts of fetal value that are more plausible and less oppressive to women.

On a feminist account, fetal development is examined in the context in which it occurs, within women's bodies rather than in the imagined isolation implicit in many theoretical accounts. Fetuses develop in specific pregnancies which occur in the lives of particular women. They are not individuals housed in generic female wombs, nor are they full persons at risk only because they are small and subject to the whims of women. Their very existence is relational, developing as they do within particular women's bodies, and their principal relationship is to the women who carry them.

On this view, fetuses are morally significant, but their status is relational rather than absolute. Unlike other human beings, fetuses do not have any independent existence; their existence is uniquely tied to the support of a specific other. Most non-feminist commentators have ignored the relational dimension of fetal development and have presumed that the moral status of fetuses could be resolved solely in terms of abstract metaphysical criteria of personhood. They imagine that there is some set of properties (such as genetic heritage, moral agency, self-consciousness, language use, or self-determination) which will

entitle all who possess them to be granted the moral status of persons (Warren 1973, Tooley 1972). They seek some particular feature by which we can neatly divide the world into the dichotomy of moral persons (who are to be valued and protected) and others (who are not entitled to the same group privileges); it follows that it is a merely empirical question whether or not fetuses possess the relevant properties.

But this vision misinterprets what is involved in personhood and what it is that is especially valued about persons. Personhood is a social category, not an isolated state. Persons are members of a community; they develop as concrete, discrete, and specific individuals. To be a morally significant category, personhood must involve personality as well as biological integrity.<sup>12</sup> It is not sufficient to consider persons simply as Kantian atoms of rationality; persons are all embodied, conscious beings with particular social histories. Annette Baier (1985) has developed a concept of persons as "second persons" which helps explain the sort of social dimension that seems fundamental to any moral notion of personhood:

A person, perhaps, is best seen as one who was long enough dependent upon other persons to acquire the essential arts of personhood. Persons essentially are *second persons*, who grow up with other persons. The fact that a person has a life *history*, and that a people collectively have a history depends upon the humbler fact that each person has a childhood in which a cultural heritage is transmitted, ready for adolescent rejection and adult discriminating selection and contribution. Persons come after and before other persons. (pp. 84–85; her emphasis)

Persons, in other words, are members of a social community which shapes and values them, and personhood is a relational concept that must be defined in terms of interactions and relationships with others.

A fetus is a unique sort of being in that it cannot form relationships freely with others, nor can others readily form relationships with it. A fetus has a primary and particularly intimate relationship with the woman in whose womb it develops; any other relationship it may have is indirect, and must be

mediated through the pregnant woman. The relationship that exists between a woman and her fetus is clearly asymmetrical, since she is the only party to the relationship who is capable of making a decision about whether the interaction should continue and since the fetus is wholly dependent on the woman who sustains it while she is quite capable of surviving without it.

However much some might prefer it to be otherwise, no one else can do anything to support or harm a fetus without doing something to the woman who nurtures it. Because of this inexorable biological reality, she bears a unique responsibility and privilege in determining her fetus's place in the social scheme of things. Clearly, many pregnancies occur to women who place very high value on the lives of the particular fetuses they carry, and choose to see their pregnancies through to term despite the possible risks and costs involved; hence, it would be wrong of anyone to force such a woman to terminate her pregnancy under these circumstances. Other women, or some of these same women at other times, value other things more highly (e.g., their freedom, their health, or previous responsibilities which conflict with those generated by the pregnancies), and choose not to continue their pregnancies. The value that women ascribe to individual fetuses varies dramatically from case to case, and may well change over the course of any particular pregnancy. There is no absolute value that attaches to fetuses apart from their relational status determined in the context of their particular development.

Since human beings are fundamentally relational beings, it is important to remember that fetuses are characteristically limited in the relationships in which they can participate; within those relationships, they can make only the most restricted "contributions."<sup>13</sup> After birth, human beings are capable of a much wider range of roles in relationships with an infinite variety of partners; it is that very diversity of possibility and experience that leads us to focus on the abstraction of the individual as a constant through all her/his relationships. But until birth, no such variety is possible, and the fetus is defined as an entity within a woman who will almost certainly be principally responsible for it for many years to come.

No human, and especially no fetus, can exist apart from relationships; feminist views of what is valuable about persons must reflect the social nature of their existence. Fetal lives can neither be sustained nor destroyed without affecting the women who support them. Because of a fetus's unique physical status—*within* and dependent on a particular woman—the responsibility and privilege of determining its specific social status and value must rest with the woman carrying it. Fetuses are not persons because they have not developed sufficiently in social relationships to be persons in any morally significant sense (i.e., they are not yet second persons). Newborns, although just beginning their development into persons, are immediately subject to social relationships, for they are capable of communication and response in interaction with a variety of other persons. Thus, feminist accounts of abortion stress the importance of protecting women's right to continue as well as to terminate pregnancies as each sees fit.

### Feminist Politics and Abortion

Feminists support abortion on demand because they know that women must have control over their reproduction. For the same reason, they actively oppose forced abortion and coerced sterilization, practices that are sometimes inflicted on the most powerless women, especially those in the Third World. Feminist ethics demands that access to voluntary, safe, effective birth control be part of any abortion discussion, so that women have access to other means of avoiding pregnancy.<sup>14</sup>

Feminist analysis addresses the context as well as the practice of abortion decisions. Thus, feminists also object to the conditions which lead women to abort wanted fetuses because there are not adequate financial and social supports available to care for a child. Because feminist accounts value fetuses that are wanted by the women who carry them, they oppose practices which force women to abort because of poverty or intimidation. Yet, the sorts of social changes necessary if we are to free women from having abortions out of economic necessity are vast; they include changes not only in legal and health-care policy, but also in housing, child care, employment, etc.

(Petchesky 1980, p. 112). Nonetheless, feminist ethics defines reproductive freedom as the condition under which women are able to make truly voluntary choices about their reproductive lives, and these many dimensions are implicit in the ideal.

Clearly, feminists are not “pro-abortion,” for they are concerned to ensure the safety of each pregnancy to the greatest degree possible; wanted fetuses should not be harmed or lost. Therefore, adequate pre- and post-natal care and nutrition are also important elements of any feminist position on reproductive freedom. Where anti-abortionists direct their energies to trying to prevent women from obtaining abortions, feminists seek to protect the health of wanted fetuses. They recognize that far more could be done to protect and care for fetuses if the state directed its resources at supporting women who continue their pregnancies, rather than draining away resources in order to police women who find that they must interrupt their pregnancies. Caring for the women who carry fetuses is not only a more legitimate policy than is regulating them; it is probably also more effective at ensuring the health and well-being of more fetuses.

Feminist ethics also explores how abortion policies fit within the politics of sexual domination. Most feminists are sensitive to the fact that many men support women’s right to abortion out of the belief that women will be more willing sexual partners if they believe that they can readily terminate an unwanted pregnancy. Some men coerce their partners into obtaining abortions the women may not want.<sup>15</sup> Feminists understand that many women oppose abortion for this very reason, being unwilling to support a practice that increases women’s sexual vulnerability (Luker 1984, pp. 209–15). Thus, it is important that feminists develop a coherent analysis of reproductive freedom that includes sexual freedom (as women choose to define it). That requires an analysis of sexual freedom that includes women’s right to refuse sex; such a right can only be assured if women have equal power to men and are not subject to domination by virtue of their sex.<sup>16</sup>

In sum, then, feminist ethics demands that moral discussions of abortion be more broadly

defined than they have been in most philosophic discussions. Only by reflecting on the meaning of ethical pronouncements on actual women’s lives and the connections between judgments on abortion and the conditions of domination and subordination can we come to an adequate understanding of the moral status of abortion in our society. As Rosalind Petchesky (1980) argues, feminist discussion of abortion “must be moved beyond the framework of a ‘woman’s right to choose’ and connected to a much broader revolutionary movement that addresses all of the conditions of women’s liberation” (p. 113).

#### NOTES

Earlier versions of this paper were read to the Department of Philosophy, Dalhousie University and to the Canadian Society for Women in Philosophy in Kingston. I am very grateful for the comments received from colleagues in both forums: particular thanks go to Lorraine Code, David Braybrooke, Richmond Campbell, Sandra Taylor, Terry Tomkow and Kadri Vihvelin for their patience and advice.

1. For some idea of the ways in which traditional moral theory oppresses women, see Morgan (1987) and Hoagland (1988).
2. Critics continue to want to structure the debate around the *possibility* of women making frivolous abortion decisions and hence want feminists to agree to setting boundaries on acceptable grounds for choosing abortion. Feminists ought to resist this injunction, though. There is no practical way of drawing a line fairly in the abstract; cases that may appear “frivolous” at a distance, often turn out to be substantive when the details are revealed, i.e., frivolity is in the eyes of the beholder. There is no evidence to suggest that women actually make the sorts of choices worried critics hypothesize about: e.g., a woman eight months pregnant who chooses to abort because she wants to take a trip or gets in “a tiff” with her partner. These sorts of fantasies, on which demands to distinguish between legitimate and illegitimate personal reasons for choosing abortion chiefly rest, reflect an offensive conception of women as irresponsible; they ought not to be perpetuated. Women, seeking moral guidance in their own deliberations about choosing abortion, do not find such hypothetical discussions of much use.
3. In her monumental historical analysis of the early roots of Western patriarchy, Gerda Lerner (1986) determined that patriarchy began in the period from

3100 to 600 b.c. when men appropriated women's sexual and reproductive capacity; the earliest states entrenched patriarchy by institutionalizing the sexual and procreative subordination of women to men.

4. There are some women who claim to be feminists against choice in abortion. See, for instance, Callahan (1987), though few spell out their full feminist program. For reasons I develop in this paper, I do not think this is a consistent position.

5. There is a lot the state could do to ameliorate this condition. If it provided women with adequate financial support, removed the inequities in the labour market, and provided affordable and reliable childcare, pregnancy need not so often lead to a woman's dependence on a particular man. The fact that it does not do so is evidence of the state's complicity in maintaining women's subordinate position with respect to men.

6. See Petchesky (1984), especially Chapter 5, "Considering the Alternatives: The Problems of Contraception," where she documents the risks and discomforts associated with pill use and IUD's and the increasing rate at which women are choosing the option of diaphragm or condom with the option of early legal abortions as backup.

7. See Zillah Eisenstein (1988) for a comprehensive theory of the role of the pregnant body as the central element in the cultural subordination of women.

8. Thomson (1971) is a notable exception to this trend.

9. This seems reminiscent of Aristotle's view of women as "flower pots" where men implant the seed with all the important genetic information and the movement necessary for development and women's job is that of passive gestation, like the flower pot. For exploration of the flower pot picture of pregnancy, see Whitbeck (1973) and Lange (1983).

10. Contrast Warren (1989) with Tooley (1972).

11. The definition of pregnancy as a purely passive activity reaches its ghoulish conclusion in the increasing acceptability of sustaining brain-dead women on life support systems to continue their functions as incubators until the fetus can be safely delivered. For a discussion of this new trend, see Murphy (1989).

12. This apt phrasing is taken from Petchesky (1986), p. 342.

13. Fetuses are almost wholly individuated by the women who bear them. The fetal "contributions" to the relationship are defined by the projections and interpretations of the pregnant woman in the latter stages of pregnancy if she chooses to perceive fetal movements in purposeful ways (e.g., it likes classical music, wine, exercise).

14. Therefore, the Soviet model, where women have access to multiple abortions but where there is no other birth control available, must also be opposed.

15. See CARAL/Halifax (1990), pp. 20–21, for examples of this sort of abuse.

16. It also requires that discussions of reproductive and sexual freedom not be confined to "the language of control and sexuality characteristic of a technology of sex" (Diamond and Quinby 1988, p. 197), for such language is alienating and constrains women's experiences of their own sexuality.

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## Roe v. Wade

UNITED STATES SUPREME COURT

In this decision, the Court ruled that no state can ban abortions performed before viability. The Court thought that the Constitution implied a guaranteed right of personal privacy that limits interference by the state in people's private lives and that the right encompassed a woman's decision to have an abortion. But the woman's right is not absolute and must be balanced against important state interests. Thus, the Court held that in the first trimester, the woman's right to an abortion cannot be restrained by the state. In the second trimester, the state may limit—but not entirely prohibit—the woman's right by regulating abortion for the sake of her health. After viability, the state may regulate and even ban abortion except when necessary to preserve her life or health.

### Majority Opinion (Delivered by Justice Blackmun)

Three reasons have been advanced to explain historically the enactment of criminal abortion laws in the 19th century and to justify their continued existence.

United States Supreme Court, 410 U.S. 113, 93 S. Ct. 705, January 22, 1973.

It has been argued occasionally that these laws were the product of a Victorian social concern to discourage illicit sexual conduct. Texas, however, does not advance this justification in the present case, and it appears that no court or commentator has taken the argument seriously. The appellants and *amici* contend, moreover, that this is not a proper state purpose at all and suggest that, if it

were, the Texas statutes are overbroad in protecting it since the law fails to distinguish between married and unwed mothers.

A second reason is concerned with abortion as a medical procedure. When most criminal abortion laws were first enacted, the procedure was a hazardous one for the woman. This was particularly true prior to the development of antisepsis. Antiseptic techniques, of course, were based on discoveries by Lister, Pasteur, and others first announced in 1867, but were not generally accepted and employed until about the turn of the century. Abortion mortality was high. Even after 1900, and perhaps until as late as the development of antibiotics in the 1940s, standard modern techniques such as dilation and curettage were not nearly so safe as they are today. Thus, it has been argued that a state's real concern in enacting a criminal abortion law was to protect the pregnant woman, that is, to restrain her from submitting to a procedure that placed her life in serious jeopardy.

Modern medical techniques have altered this situation. Appellants and various *amici* refer to medical data indicating that abortion in early pregnancy, that is, prior to the end of the first trimester, although not without its risk, is now relatively safe. Mortality rates for women undergoing early abortions, where the procedure is legal, appear to be as low as or lower than the rates for normal childbirth. Consequently, any interest of the state in protecting the woman from an inherently hazardous procedure except when it would be equally dangerous for her to forgo it, has largely disappeared. Of course, important state interests in the areas of health and medical standards do remain. The state has a legitimate interest in seeing to it that abortion, like any other medical procedure, is performed under circumstances that insure maximum safety for the patient. This interest obviously extends at least to the performing physician and his staff, to the facilities involved, to the availability of after-care, and to adequate provision for any complication or emergency that might arise. The prevalence of high mortality rates at illegal "abortion mills" strengthens, rather than weakens, the state's interest in regulating the conditions under which abortions are

performed. Moreover, the risk to the woman increases as her pregnancy continues. Thus, the state retains a definite interest in protecting the woman's own health and safety when an abortion is proposed at a late stage of pregnancy.

The third reason is the state's interest—some phrase it in terms of duty—in protecting prenatal life. Some of the argument for this justification rests on the theory that a new human life is present from the moment of conception. The state's interest and general obligation to protect life then extends, it is argued, to prenatal life. Only when the life of the pregnant mother herself is at stake, balanced against the life she carries within her, should the interest of the embryo or fetus not prevail. Logically, of course, a legitimate state interest in this area need not stand or fall on acceptance of the belief that life begins at conception or at some other point prior to live birth. In assessing the state's interest, recognition may be given to the less rigid claim that as long as at least potential life is involved, the state may assert interests beyond the protection of the pregnant woman alone.

Parties challenging state abortion laws have sharply disputed in some courts the contention that a purpose of these laws, when enacted, was to protect prenatal life. Pointing to the absence of legislative history to support the contention, they claim that most state laws were designed solely to protect the woman. Because medical advances have lessened this concern, at least with respect to abortion in early pregnancy, they argue that with respect to such abortions the laws can no longer be justified by any state interest. There is some scholarly support for this view of original purpose. The few state courts called upon to interpret their laws in the late 19th and early 20th centuries did focus on the state's interest in protecting the woman's health rather than in preserving the embryo and fetus. Proponents of this view point out that in many states, including Texas, by statute or judicial interpretation, the pregnant woman herself could not be prosecuted for self-abortion or for cooperating in an abortion performed upon her by another. They claim that adoption of the "quickening" distinction through received common law and state statutes

tacitly recognizes the greater health hazards inherent in late abortion and impliedly repudiates the theory that life begins at conception.

It is with these interests, and the weight to be attached to them, that this case is concerned.

The Constitution does not explicitly mention any right of privacy. In a line of decisions, however, going back perhaps as far as *Union Pacific R. Co. v. Botsford*, 141 U.S. 250, 251 (1891), the court has recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution. In varying contexts, the court or individual justices have, indeed, found at least the roots of that right in the first amendment, in the fourth and fifth amendments, in the penumbras of the Bill of Rights, in the ninth amendment, or in the concept of liberty guaranteed by the first section of the fourteenth amendment. These decisions make it clear that only personal rights that can be deemed "fundamental" or "implicit" in the concept of ordered liberty are included in this guarantee of personal privacy. They also make it clear that the right has some extension to activities relating to marriage, procreation, contraception, family relationships, and child rearing and education.

This right of privacy, whether it be founded in the fourteenth amendment's concept of personal liberty and restrictions upon state action, as we feel it is, or, as the district court determined, in the ninth amendment's reservation of rights to the people, is broad enough to encompass a woman's decision whether or not to terminate her pregnancy. The detriment that the state would impose upon the pregnant woman by denying this choice altogether is apparent. Specific and direct harm medically diagnosable even in early pregnancy may be involved. Maternity, or additional offspring, may force upon the woman a distressful life and future. Psychological harm may be imminent. Mental and physical health may be taxed by child care. There is also the distress, for all concerned, associated with the unwanted child, and there is the problem of bringing a child into a family already unable, psychologically and otherwise, to care for it. In other cases,

as in this one, the additional difficulties and continuing stigma factors the woman and her responsible physician necessarily will consider in consultation.

On the basis of elements such as these, appellant and some *amici* argue that the woman's right is absolute and that she is entitled to terminate her pregnancy at whatever time, in whatever way, and for whatever reason she alone chooses. With this we do not agree. Appellant's arguments that Texas either has no valid interest strong enough to support any limitation upon the woman's sole determination are unpersuasive. The court's decisions recognizing a right of privacy also acknowledge that some state regulation in areas protected by that right is appropriate. As noted above, a state may properly assert important interests in safeguarding health, in maintaining medical standards, and in protecting potential life. At some point in pregnancy, these respective interests become sufficiently compelling to sustain regulation of the factors that govern the abortion decision. The privacy right involved, therefore, cannot be said to be absolute. In fact, it is not clear to us that the claim asserted by some *amici* that one has an unlimited right to do with one's body as one pleases bears a close relationship to the right of privacy previously articulated in the court's decisions. The court has refused to recognize an unlimited right of this kind in the past.

We, therefore, conclude that the right of personal privacy includes the abortion decision, but that this right is not unqualified and must be considered against important state interests in regulation.

We note that those federal and state courts that have recently considered abortion law challenges have reached the same conclusion. A majority, in addition to the district court in the present case, have held state laws unconstitutional, at least in part, because of vagueness or because of overbreadth and abridgment of rights.

Although the results are divided, most of these courts have agreed that the right of privacy, however based, is broad enough to cover the abortion decision; that the right, nonetheless, is not absolute and is subject to some limitations; and that at some

point the state interests as to protection of health, medical standards, and prenatal life, become dominant. We agree with this approach.

Where certain "fundamental rights" are involved, the court has held that regulation limiting these rights may be justified only by a "compelling state interest," and that legislative enactments must be narrowly drawn to express only the legitimate state interests at stake.

In the recent abortion cases, cited above, courts have recognized these principles. Those striking down state laws have generally scrutinized the state's interests in protecting health and potential life, and have concluded that neither interest justified broad limitations on the reasons for which a physician and his pregnant patient might decide that she should have an abortion in the early stages of pregnancy. Courts sustaining state laws have held that the state's determinations to protect health or prenatal life are dominant and constitutionally justifiable.

The district court held that the appellee failed to meet his burden of demonstrating that the Texas statute's infringement upon Roe's rights was necessary to support a compelling state interest, and that, although the appellee presented "several compelling justifications for state presence in the area of abortions," the statutes outstripped these justifications and swept "far beyond any areas of compelling state interest." Appellant and appellee both contest that holding. Appellant, as has been indicated, claims an absolute right that bars any state imposition of criminal penalties in the area. Appellee argues that the state's determination to recognize and protect prenatal life from and after conception constitutes a compelling state interest. As noted above, we do not agree fully with either formulation.

A. The appellee and certain *amici* argue that the fetus is a "person" within the language and meaning of the fourteenth amendment. In support of this, they outline at length and in detail the well-known facts of fetal development. If this suggestion of personhood is established, the appellant's case, of course, collapses, for the fetus' right to life would then be guaranteed specifically by the amendment.

The appellant conceded as much on reargument. On the other hand, the appellee conceded on reargument that no case could be cited that holds that a fetus is a person within the meaning of the fourteenth amendment.

The Constitution does not define "person" in so many words. Section 1 of the fourteenth amendment contains three references to "person" but in nearly all these instances, the use of the word is such that it has application only postnatally. None indicates, with any assurance, that it has any possible prenatal application.

All this, together with our observation, *supra*, that throughout the major portion of the 19th century prevailing legal abortion practices were far freer than they are today, persuades us that the word "person," as used in the fourteenth amendment, does not include the unborn.

B. The pregnant woman cannot be isolated in her privacy. She carries an embryo and, later, a fetus, if one accepts the medical definitions of the developing young in the human uterus. See Dorland's *Illustrated Medical Dictionary* 478-479, 547 (7th ed. 1965). The situation therefore is inherently different from marital intimacy, or bedroom possession of obscene material, or marriage, or procreation, or education, with which *Eisenstadt*, *Griswold*, *Stanley*, *Loving*, *Skinner*, *Pierce*, and *Meyer* were respectively concerned. As we have intimated above, it is reasonable and appropriate for a state to decide that at some point in time another interest, that of health of the mother or that of potential human life, becomes significantly involved. The woman's privacy is no longer sole and any right of privacy she possesses must be measured accordingly.

Texas urges that, apart from the fourteenth amendment, life begins at conception and is present throughout pregnancy, and that, therefore, the state has a compelling interest in protecting that life from and after conception. We need not resolve the difficult question of when life begins. When those trained in the respective disciplines of medicine, philosophy, and theology are unable to arrive at any consensus, the judiciary, at this point in the development of man's knowledge, is not in a position to speculate as to the answer.

It should be sufficient to note briefly the wide divergence of thinking on this most sensitive and difficult question. There has always been strong support for the view that life does not begin until live birth. This was the belief of the Stoics. It appears to be the predominant, though not the unanimous, attitude of the Jewish faith. It may be taken to represent also the position of a large segment of the Protestant community, insofar as that can be ascertained; organized groups that have taken a formal position on the abortion issue have generally regarded abortion as a matter for the conscience of the individual and her family. As we have noted, the common law found greater significance in quickening. Physicians and their scientific colleagues have regarded that event with less interest and have tended to focus either upon conception, upon live birth, or upon the interim point at which the fetus becomes "viable," that is, potentially able to live outside the mother's womb, albeit with artificial aid. Viability is usually placed at about seven months (28 weeks) but may occur earlier, even at 24 weeks. The Aristotelian theory of "mediate animation," that held sway throughout the Middle Ages and the Renaissance in Europe, continued to be official Roman Catholic dogma until the 19th century, despite opposition to this "ensoulment" theory from those in the church who would recognize the existence of life from the moment of conception. The latter is now, of course, the official belief of the Catholic church. As one brief *amicus* discloses, this is a view strongly held by many non-Catholics as well, and by many physicians. Substantial problems for precise definition of this view are posed, however, by new embryological data that purport to indicate that conception is a "process" over time, rather than an event, and by new medical techniques: implantation of embryos, artificial insemination, and even artificial wombs.

In areas other than criminal abortion, the law has been reluctant to endorse any theory that life, as we recognize it, begins before live birth or to accord legal rights to the unborn except in narrowly defined situations and except when the rights are contingent upon live birth. For example, the traditional rule of tort law denied recovery for

prenatal injuries even though the child was born alive. That rule has been changed in almost every jurisdiction. In most states, recovery is said to be permitted only if the fetus was viable, or at least quick, when the injuries were sustained, though few courts have squarely so held. In a recent development, generally opposed by the commentators, some states permit the parents of a stillborn child to maintain an action for wrongful death because of prenatal injuries. Such an action, however, would appear to be one to vindicate the parents' interest and is thus consistent with the view that the fetus, at most, represents only the potentiality of life. Similarly, unborn children have been recognized as acquiring rights or interests by way of inheritance or other devolution of property, and have been represented by guardians ad litem. Perfection of the interests involved, again, has generally been contingent upon live birth. In short, the unborn have never been recognized in the law as persons in the whole sense.

In view of all this, we do not agree that, by adopting one theory of life, Texas may override the rights of the pregnant woman that are at stake. We repeat, however, that the state does have an important and legitimate interest in preserving and protecting the health of the pregnant woman, whether she be a resident of the state or a nonresident who seeks medical consultation and treatment there, and that it has still another important and legitimate interest in protecting the potentiality of human life. These interests are separate and distinct. Each grows in substantiality as the woman approaches term and, at a point during pregnancy, each becomes "compelling."

With respect to the state's important and legitimate interest in the health of the mother, the "compelling" point, in the light of present medical knowledge, is at approximately the end of the first trimester. This is so because of the now-established medical fact, referred to above at 149, that until the end of the first trimester mortality in abortion may be less than mortality in normal childbirth. It follows that, from and after this point, a state may regulate the abortion procedure to the extent that the regulation reasonably relates to the preservation

and protection of maternal health. Examples of permissible state regulation in this area are requirements as to the qualifications of the person who is to perform the abortion; as to the licensure of that person; as to the facility in which the procedure is to be performed, that is, whether it must be a hospital or may be a clinic or some other place of less-than-hospital status; as to the licensing of the facility; and the like.

This means, on the other hand, that, for the period of pregnancy prior to this "compelling" point, the attending physician, in consultation with his patient, is free to determine, without regulation by the state, that, in his medical judgment, the patient's pregnancy should be terminated. If that decision is reached, the judgment may be effectuated by an abortion free of interference by the state.

With respect to the state's important and legitimate interest in potential life, the "compelling" point is at viability. This is so because the fetus then presumably has the capability of meaningful life outside the mother's womb. State regulation protective of fetal life after viability thus has both logical and biological justifications. If the state is interested in protecting fetal life after viability, it may go so far as to proscribe abortion during that period, except when it is necessary to preserve the life or health of the mother.

Measured against these standards, art. 1196 of the Texas penal code, in restricting legal abortions to those "procured or attempted by medical advice for the purpose of saving the life of the mother," sweeps too broadly. The statute makes no distinction between abortions performed early in pregnancy and those performed later, and it limits to a single reason, "saving" the mother's life, the legal justification for the procedure. The statute, therefore, cannot survive the constitutional attack made upon it here.

To summarize and to repeat:

1. A state criminal abortion statute of the current Texas type, that excepts from criminality only a lifesaving procedure on behalf of the mother, without regard to pregnancy stage and without recognition of the other interests involved, is violative of

the due process clause of the fourteenth amendment.

a. For the stage prior to approximately the end of the first trimester, the abortion decision and its effectuation must be left to the medical judgment of the pregnant woman's attending physician.

b. For the stage subsequent to approximately the end of the first trimester, the state, in promoting its interest in the health of the mother, may, if it chooses, regulate the abortion procedure in ways that are reasonably related to maternal health.

c. For the stage subsequent to viability, the state in promoting its interest in the potentiality of human life may, if it chooses, regulate, and even proscribe, abortion except where it is necessary, in appropriate medical judgment, for the preservation of the life or health of the mother.

2. The state may define the term "physician," as it has been employed in the preceding paragraphs of this part XI of this opinion, to mean only a physician currently licensed by the state, and may proscribe any abortion by a person who is not a physician as so defined.

This holding, we feel, is consistent with the relative weights of the respective interests involved, with the lessons and examples of medical and legal history, with the lenity of the common law, and with the demands of the profound problems of the present day. The decision leaves the state free to place increasing restrictions on abortion as the period of pregnancy lengthens, so long as those restrictions are tailored to the recognized state interests. The decision vindicates the right of the physician to administer medical treatment according to his professional judgment up to the points where important state interests provide compelling justifications for intervention. Up to those points, the abortion decision in all its aspects is inherently, and primarily, a medical decision, and basic responsibility for it must rest with the physician. If an individual practitioner abuses the privilege of exercising proper medical judgment, the usual remedies, judicial and intra-professional, are available.

## **Planned Parenthood of Southeastern Pennsylvania v. Casey**

UNITED STATES SUPREME COURT

In this 1992 ruling, the Court found that “the essential holding of *Roe v. Wade* should be retained and once again reaffirmed.” But it rejected *Roe*’s trimester framework and established an “undue burden” test for assessing the restrictions that states put on abortion. Before viability, abortion can be restricted in many ways as long as the constraints do not amount to an undue burden on a woman wishing to obtain an abortion. The Court held that several restrictions do not impose such burdens, including the requirement that a woman give her written informed consent to abortion and that minors under age 18 who seek abortions obtain parental consent or a judge’s authorization. But a spousal notification provision does constitute an undue burden.

Liberty finds no refuge in a jurisprudence of doubt. Yet, 19 years after our holding that the Constitution protects a woman’s right to terminate her pregnancy in its early stages, *Roe v. Wade* (1973), that definition of liberty is still questioned. Joining the respondents as amicus curiae, the United States, as it has done in five other cases in the last decade, again asks us to overrule *Roe*.

At issue are five provisions of the Pennsylvania Abortion Control Act of 1982, as amended in 1988 and 1989. The Act requires that a woman seeking an abortion give her informed consent prior to the abortion procedure, and specifies that she be provided with certain information at least 24 hours before the abortion is performed. Section 3205. For a minor to obtain an abortion, the Act requires the informed consent of one of her parents, but provides for a judicial bypass option if the minor does not wish to or cannot obtain a parent’s consent. Section 3206. Another provision of the Act requires that, unless certain exceptions apply, a married woman seeking an abortion must sign a statement indicating that she has notified her husband of her intended abortion. Section 3209. The

Act exempts compliance with these three requirements in the event of a “medical emergency,” which is defined in Section 3 of the Act. See Section 3205(a), Section 3206(a), Section 3209(c). In addition to the above provisions regulating the performance of abortions, the Act imposes certain reporting requirements on facilities that provide abortion services.

Before any of these provisions took effect, the petitioners, who are five abortion clinics and one physician representing himself as well as a class of physicians who provide abortion services, brought this suit seeking declaratory and injunctive relief. Each provision was challenged as unconstitutional on its face. The District Court entered a preliminary injunction against the enforcement of the regulations, and, after a 3-day bench trial, held all the provisions at issue here unconstitutional, entering a permanent injunction against Pennsylvania’s enforcement of them. The Court of Appeals for the Third Circuit affirmed in part and reversed in part, upholding all of the regulations except for the husband notification requirement. [W]e find it imperative to review once more the principles that define the rights of the woman and the legitimate authority of the State respecting the termination of pregnancies by abortion procedures.

After considering the fundamental constitutional questions resolved by *Roe*, principles of institutional integrity, and the rule of stare decisis, we are led to conclude this: the essential holding of *Roe v. Wade* should be retained and once again reaffirmed.

It must be stated at the outset and with clarity that *Roe's* essential holding, the holding we reaffirm, has three parts. First is a recognition of the right of the woman to choose to have an abortion before viability and to obtain it without undue interference from the State. Before viability, the State's interests are not strong enough to support a prohibition of abortion or the imposition of a substantial obstacle to the woman's effective right to elect the procedure. Second is a confirmation of the State's power to restrict abortions after fetal viability if the law contains exceptions for pregnancies which endanger the woman's life or health. And third is the principle that the State has legitimate interests from the outset of the pregnancy in protecting the health of the woman and the life of the fetus that may become a child. These principles do not contradict one another; and we adhere to each.

## II

Constitutional protection of the woman's decision to terminate her pregnancy derives from the Due Process Clause of the Fourteenth Amendment. It declares that no State shall "deprive any person of life, liberty, or property, without due process of law." The controlling word in the cases before us is "liberty."

It is a promise of the Constitution that there is a realm of personal liberty which the government may not enter. We have vindicated this principle before. Marriage is mentioned nowhere in the Bill of Rights, and interracial marriage was illegal in most States in the 19th century, but the Court was no doubt correct in finding it to be an aspect of liberty protected against state interference by the substantive component of the Due Process Clause.

Neither the Bill of Rights nor the specific practices of States at the time of the adoption of the Fourteenth Amendment marks the outer limits of the substantive sphere of liberty which the

Fourteenth Amendment protects. It is settled now, as it was when the Court heard arguments in *Roe v. Wade*, that the Constitution places limits on a State's right to interfere with a person's most basic decisions about family and parenthood, as well as bodily integrity.

The inescapable fact is that adjudication of substantive due process claims may call upon the Court in interpreting the Constitution to exercise that same capacity which, by tradition, courts always have exercised: reasoned judgment. Its boundaries are not susceptible of expression as a simple rule. That does not mean we are free to invalidate state policy choices with which we disagree; yet neither does it permit us to shrink from the duties of our office.

## III

No evolution of legal principle has left *Roe's* doctrinal footings weaker than they were in 1973. No development of constitutional law since the case was decided has implicitly or explicitly left *Roe* behind as a mere survivor of obsolete constitutional thinking.

We have seen how time has overtaken some of *Roe's* factual assumptions: advances in maternal health care allow for abortions safe to the mother later in pregnancy than was true in 1973, and advances in neonatal care have advanced viability to a point somewhat earlier. But these facts go only to the scheme of time limits on the realization of competing interests, and the divergences from the factual premises of 1973 have no bearing on the validity of *Roe's* central holding, that viability marks the earliest point at which the State's interest in fetal life is constitutionally adequate to justify a legislative ban on nontherapeutic abortions. The soundness or unsoundness of that constitutional judgment in no sense turns on whether viability occurs at approximately 28 weeks, as was usual at the time of *Roe*, at 23 to 24 weeks, as it sometimes does today, or at some moment even slightly earlier in pregnancy, as it may if fetal respiratory capacity can somehow be enhanced in the future. Whenever it may occur, the attainment of viability may continue to serve as the critical fact, just as it has done since *Roe* was

decided; which is to say that no change in *Roe*'s factual underpinning has left its central holding obsolete, and none supports an argument for overruling it.

The sum of the precedential enquiry to this point shows *Roe*'s underpinnings unweakened in any way affecting its central holding. While it has engendered disapproval, it has not been unworkable.

The Court's duty in the present case is clear. In 1973, it confronted the already-divisive issue of governmental power to limit personal choice to undergo abortion, for which it provided a new resolution based on the due process guaranteed by the Fourteenth Amendment. Whether or not a new social consensus is developing on that issue, its divisiveness is no less today than in 1973, and pressure to overrule the decision, like pressure to retain it, has grown only more intense. A decision to overrule *Roe*'s essential holding under the existing circumstances would address error, if error there was, at the cost of both profound and unnecessary damage to the Court's legitimacy, and to the Nation's commitment to the rule of law. It is therefore imperative to adhere to the essence of *Roe*'s original decision, and we do so today.

#### IV

From what we have said so far, it follows that it is a constitutional liberty of the woman to have some freedom to terminate her pregnancy. We conclude that the basic decision in *Roe* was based on a constitutional analysis which we cannot now repudiate. The woman's liberty is not so unlimited, however, that from the outset the State cannot show its concern for the life of the unborn, and at a later point in fetal development the State's interest in life has sufficient force so that the right of the woman to terminate the pregnancy can be restricted.

We conclude the line should be drawn at viability, so that, before that time, the woman has a right to choose to terminate her pregnancy. We adhere to this principle for two reasons. First, as we have said, is the doctrine of *stare decisis*. Any judicial act of line-drawing may seem somewhat arbitrary, but *Roe* was a reasoned statement, elaborated with great care. We have twice reaffirmed it in the face of great opposition.

The second reason is that the concept of viability, as we noted in *Roe*, is the time at which there is a realistic possibility of maintaining and nourishing a life outside the womb, so that the independent existence of the second life can, in reason and all fairness, be the object of state protection that now overrides the rights of the woman. We must justify the lines we draw. And there is no line other than viability which is more workable. To be sure, as we have said, there may be some medical developments that affect the precise point of viability, see *supra*, but this is an imprecision within tolerable limits, given that the medical community and all those who must apply its discoveries will continue to explore the matter. The viability line also has, as a practical matter, an element of fairness. In some broad sense, it might be said that a woman who fails to act before viability has consented to the State's intervention on behalf of the developing child.

The woman's right to terminate her pregnancy before viability is the most central principle of *Roe v. Wade*. It is a rule of law and a component of liberty we cannot renounce.

Yet it must be remembered that *Roe v. Wade* speaks with clarity in establishing not only the woman's liberty but also the State's "important and legitimate interest in potential life." That portion of the decision in *Roe* has been given too little acknowledgment and implementation by the Court in its subsequent cases.

*Roe* established a trimester framework to govern abortion regulations. Under this elaborate but rigid construct, almost no regulation at all is permitted during the first trimester of pregnancy; regulations designed to protect the woman's health, but not to further the State's interest in potential life, are permitted during the second trimester; and, during the third trimester, when the fetus is viable, prohibitions are permitted provided the life or health of the mother is not at stake. Most of our cases since *Roe* have involved the application of rules derived from the trimester framework.

The trimester framework no doubt was erected to ensure that the woman's right to choose not become so subordinate to the State's interest in promoting fetal life that her choice exists in theory, but not in fact. We do not agree, however, that the

trimester approach is necessary to accomplish this objective. A framework of this rigidity was unnecessary, and, in its later interpretation, sometimes contradicted the State's permissible exercise of its powers.

Though the woman has a right to choose to terminate or continue her pregnancy before viability, it does not at all follow that the State is prohibited from taking steps to ensure that this choice is thoughtful and informed. Even in the earliest stages of pregnancy, the State may enact rules and regulations designed to encourage her to know that there are philosophic and social arguments of great weight that can be brought to bear in favor of continuing the pregnancy to full term, and that there are procedures and institutions to allow adoption of unwanted children as well as a certain degree of state assistance if the mother chooses to raise the child herself. It follows that the States are free to enact laws to provide a reasonable framework for a woman to make a decision that has such profound and lasting meaning. This, too, we find consistent with *Roe*'s central premises, and indeed the inevitable consequence of our holding that the State has an interest in protecting the life of the unborn.

Numerous forms of state regulation might have the incidental effect of increasing the cost or decreasing the availability of medical care, whether for abortion or any other medical procedure. The fact that a law which serves a valid purpose, one not designed to strike at the right itself, has the incidental effect of making it more difficult or more expensive to procure an abortion cannot be enough to invalidate it. Only where state regulation imposes an undue burden on a woman's ability to make this decision does the power of the State reach into the heart of the liberty protected by the Due Process Clause.

Before viability, *Roe* and subsequent cases treat all governmental attempts to influence a woman's decision on behalf of the potential life within her as unwarranted. This treatment is, in our judgment, incompatible with the recognition that there is a substantial state interest in potential life throughout pregnancy.

The very notion that the State has a substantial interest in potential life leads to the conclusion that

not all regulations must be deemed unwarranted. Not all burdens on the right to decide whether to terminate a pregnancy will be undue. In our view, the undue burden standard is the appropriate means of reconciling the State's interest with the woman's constitutionally protected liberty.

We give this summary:

- a. To protect the central right recognized by *Roe v. Wade* while at the same time accommodating the State's profound interest in potential life, we will employ the undue burden analysis as explained in this opinion. An undue burden exists, and therefore a provision of law is invalid, if its purpose or effect is to place a substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability.
- b. We reject the rigid trimester framework of *Roe v. Wade*. To promote the State's profound interest in potential life, throughout pregnancy, the State may take measures to ensure that the woman's choice is informed, and measures designed to advance this interest will not be invalidated as long as their purpose is to persuade the woman to choose childbirth over abortion. These measures must not be an undue burden on the right.
- c. As with any medical procedure, the State may enact regulations to further the health or safety of a woman seeking an abortion. Unnecessary health regulations that have the purpose or effect of presenting a substantial obstacle to a woman seeking an abortion impose an undue burden on the right.
- d. Our adoption of the undue burden analysis does not disturb the central holding of *Roe v. Wade*, and we reaffirm that holding. Regardless of whether exceptions are made for particular circumstances, a State may not prohibit any woman from making the ultimate decision to terminate her pregnancy before viability.
- e. We also reaffirm *Roe*'s holding that, "subsequent to viability, the State, in promoting its interest in the potentiality of human life, may, if it chooses, regulate, and even proscribe,

abortion except where it is necessary, in appropriate medical judgment, for the preservation of the life or health of the mother.”

These principles control our assessment of the Pennsylvania statute, and we now turn to the issue of the validity of its challenged provisions.

## V

The Court of Appeals applied what it believed to be the undue burden standard, and upheld each of the provisions except for the husband notification requirement. We agree generally with this conclusion, but refine the undue burden analysis in accordance with the principles articulated above. We now consider the separate statutory sections at issue.

### (B)

We next consider the informed consent requirement. Section 3205. Except in a medical emergency, the statute requires that at least 24 hours before performing an abortion a physician inform the woman of the nature of the procedure, the health risks of the abortion and of childbirth, and the “probable gestational age of the unborn child.” The physician or a qualified nonphysician must inform the woman of the availability of printed materials published by the State describing the fetus and providing information about medical assistance for childbirth, information about child support from the father, and a list of agencies which provide adoption and other services as alternatives to abortion. An abortion may not be performed unless the woman certifies in writing that she has been informed of the availability of these printed materials and has been provided them if she chooses to view them.

Our prior decisions establish that, as with any medical procedure, the State may require a woman to give her written informed consent to an abortion.

In *Akron v. Akron Center for Reproductive Health, Inc.* (1983) (*Akron I*) we invalidated an ordinance which required that a woman seeking an abortion be provided by her physician with specific information “designed to influence the woman’s informed choice between abortion or childbirth.” As we later

described the *Akron I* holding in *Thornburgh v. American College of Obstetricians and Gynecologists*, there were two purported flaws in the Akron ordinance: the information was designed to dissuade the woman from having an abortion, and the ordinance imposed “a rigid requirement that a specific body of information be given in all cases, irrespective of the particular needs of the patient.”

It cannot be questioned that psychological well-being is a facet of health. Nor can it be doubted that most women considering an abortion would deem the impact on the fetus relevant, if not dispositive, to the decision. In attempting to ensure that a woman apprehend the full consequences of her decision, the State furthers the legitimate purpose of reducing the risk that a woman may elect an abortion, only to discover later, with devastating psychological consequences, that her decision was not fully informed. If the information the State requires to be made available to the woman is truthful and not misleading, the requirement may be permissible.

We also see no reason why the State may not require doctors to inform a woman seeking an abortion of the availability of materials relating to the consequences to the fetus, even when those consequences have no direct relation to her health. An example illustrates the point. We would think it constitutional for the State to require that, in order for there to be informed consent to a kidney transplant operation, the recipient must be supplied with information about risks to the donor as well as risks to himself or herself. A requirement that the physician make available information similar to that mandated by the statute here was described in *Thornburgh* as an outright attempt to wedge the Commonwealth’s message discouraging abortion into the privacy of the informed consent dialogue between the woman and her physician. We conclude, however, that informed choice need not be defined in such narrow terms that all considerations of the effect on the fetus are made irrelevant. As we have made clear, we depart from the holdings of *Akron I* and *Thornburgh* to the extent that we permit a State to further its legitimate goal of protecting the life of the unborn by enacting legislation

aimed at ensuring a decision that is mature and informed, even when, in so doing, the State expresses a preference for childbirth over abortion. In short, requiring that the woman be informed of the availability of information relating to fetal development and the assistance available should she decide to carry the pregnancy to full term is a reasonable measure to ensure an informed choice, one which might cause the woman to choose childbirth over abortion. This requirement cannot be considered a substantial obstacle to obtaining an abortion, and, it follows, there is no undue burden.

The Pennsylvania statute also requires us to reconsider the holding in *Akron I* that the State may not require that a physician, as opposed to a qualified assistant, provide information relevant to a woman's informed consent. Since there is no evidence on this record that requiring a doctor to give the information as provided by the statute would amount, in practical terms, to a substantial obstacle to a woman seeking an abortion, we conclude that it is not an undue burden. Our cases reflect the fact that the Constitution gives the States broad latitude to decide that particular functions may be performed only by licensed professionals, even if an objective assessment might suggest that those same tasks could be performed by others. Thus, we uphold the provision as a reasonable means to ensure that the woman's consent is informed.

Our analysis of Pennsylvania's 24-hour waiting period between the provision of the information deemed necessary to informed consent and the performance of an abortion under the undue burden standard requires us to reconsider the premise behind the decision in *Akron I* invalidating a parallel requirement. In *Akron I* we said: Nor are we convinced that the State's legitimate concern that the woman's decision be informed is reasonably served by requiring a 24-hour delay as a matter of course. We consider that conclusion to be wrong. The idea that important decisions will be more informed and deliberate if they follow some period of reflection does not strike us as unreasonable, particularly where the statute directs that important information become part of the background of the decision. The statute, as construed by the Court of Appeals,

permits avoidance of the waiting period in the event of a medical emergency, and the record evidence shows that, in the vast majority of cases, a 24-hour delay does not create any appreciable health risk. In theory, at least, the waiting period is a reasonable measure to implement the State's interest in protecting the life of the unborn, a measure that does not amount to an undue burden.

Whether the mandatory 24-hour waiting period is nonetheless invalid because, in practice, it is a substantial obstacle to a woman's choice to terminate her pregnancy is a closer question. The findings of fact by the District Court indicate that, because of the distances many women must travel to reach an abortion provider, the practical effect will often be a delay of much more than a day because the waiting period requires that a woman seeking an abortion make at least two visits to the doctor. The District Court also found that, in many instances, this will increase the exposure of women seeking abortions to "the harassment and hostility of anti-abortion protestors demonstrating outside a clinic." As a result, the District Court found that, for those women who have the fewest financial resources, those who must travel long distances, and those who have difficulty explaining their whereabouts to husbands, employers, or others, the 24-hour waiting period will be "particularly burdensome."

These findings are troubling in some respects, but they do not demonstrate that the waiting period constitutes an undue burden.

### (C)

Section 3209 of Pennsylvania's abortion law provides, except in cases of medical emergency, that no physician shall perform an abortion on a married woman without receiving a signed statement from the woman that she has notified her spouse that she is about to undergo an abortion. The woman has the option of providing an alternative signed statement certifying that her husband is not the man who impregnated her; that her husband could not be located; that the pregnancy is the result of spousal sexual assault which she has reported; or that the woman believes that notifying her husband will

cause him or someone else to inflict bodily injury upon her. A physician who performs an abortion on a married woman without receiving the appropriate signed statement will have his or her license revoked, and is liable to the husband for damages.

In well-functioning marriages, spouses discuss important intimate decisions such as whether to bear a child. But there are millions of women in this country who are the victims of regular physical and psychological abuse at the hands of their husbands. Should these women become pregnant, they may have very good reasons for not wishing to inform their husbands of their decision to obtain an abortion. Many may have justifiable fears of physical abuse, but may be no less fearful of the consequences of reporting prior abuse to the Commonwealth of Pennsylvania. Many may have a reasonable fear that notifying their husbands will provoke further instances of child abuse; these women are not exempt from Section 3209's notification requirement. Many may fear devastating forms of psychological abuse from their husbands, including verbal harassment, threats of future violence, the destruction of possessions, physical confinement to the home, the withdrawal of financial support, or the disclosure of the abortion to family and friends. These methods of psychological abuse may act as even more of a deterrent to notification than the possibility of physical violence, but women who are the victims of the abuse are not exempt from Section 3209's notification requirement. And many women who are pregnant as a result of sexual assaults by their husbands will be unable to avail themselves of the exception for spousal sexual assault, because the exception requires that the woman have notified law enforcement authorities within 90 days of the assault, and her husband will be notified of her report once an investigation begins. If anything in this field is certain, it is that victims of spousal sexual assault are extremely reluctant to report the abuse to the government;

hence, a great many spousal rape victims will not be exempt from the notification requirement imposed by Section 3209.

#### (D)

We next consider the parental consent provision. Except in a medical emergency, an unemancipated young woman under 18 may not obtain an abortion unless she and one of her parents (or guardian) provides informed consent as defined above. If neither a parent nor a guardian provides consent, a court may authorize the performance of an abortion upon a determination that the young woman is mature and capable of giving informed consent and has, in fact, given her informed consent, or that an abortion would be in her best interests.

We have been over most of this ground before. Our cases establish, and we reaffirm today, that a State may require a minor seeking an abortion to obtain the consent of a parent or guardian, provided that there is an adequate judicial bypass procedure. Under these precedents, in our view, the one-parent consent requirement and judicial bypass procedure are constitutional.

The only argument made by petitioners respecting this provision and to which our prior decisions do not speak is the contention that the parental consent requirement is invalid because it requires informed parental consent. For the most part, petitioners' argument is a reprise of their argument with respect to the informed consent requirement in general, and we reject it for the reasons given above. Indeed, some of the provisions regarding informed consent have particular force with respect to minors: the waiting period, for example, may provide the parent or parents of a pregnant young woman the opportunity to consult with her in private, and to discuss the consequences of her decision in the context of the values and moral or religious principles of their family.

# Reproductive Technology

For most of human history, there was only one way to conceive a child (through sexual intercourse), one way to gestate it (in the womb of the woman who conceived it), and—according to common practice—one way to raise it (under the control of those contributing the egg and sperm).

Not anymore. The revered, time-tested order of procreation and parenthood has changed, thanks to an explosion of innovation in what is known as assisted reproductive technology (ART). Through ART procedures, doctors can fertilize a woman's egg in a laboratory dish to produce an embryo that can be implanted in any normal uterus; test ART embryos for genetic abnormalities before implantation (and cull defective ones); mechanically bring together selected sperm and eggs in fallopian tubes for fertilization; freeze embryos, eggs, and sperm for later use (and possible destruction); create embryos from donor eggs and sperm to offer up for adoption; and, in a sterile laboratory container, fertilize an egg by injecting into it a single sperm cell. The technology has also made possible the novel role of reproductive surrogate, a woman who contracts to gestate a baby for others who may or may not be genetically related to it. And behind these new realities lurks the theoretical possibility of what some believe will be the ultimate ART, both intriguing and disturbing: human reproductive cloning.

Assisted reproductive technologies are meant to address the agonizing problem of infertility and the powerful desire that many people have for children of their own, especially children with whom they have a biological link. The point of these advances is widely understood, but their uses are controversial. At every turn,

they generate ethical questions and serious debate about the nature and meaning of the family, the welfare of children, the treatment of women, the moral status of embryos, the value of human life, the sanctity of natural procreation, and the legitimacy of reproductive rights.

But despite the complexity and seriousness of these issues, it's possible to make at least modest progress in sorting them out. Historically the field of bioethics cut its teeth on the moral problems arising from reproductive technology and has much to offer those who want to try to make sense of them.

## IN VITRO FERTILIZATION

In normal (unassisted) reproduction, sperm inches through the woman's uterus and into one of the fallopian tubes, where a single sperm cell penetrates and thus fertilizes the egg released that month from an ovary. The resulting embryo (technically a zygote) backtracks through the fallopian tube, returning to the uterus where it implants itself in the uterine lining. At successful implantation, pregnancy begins. Infertility (usually defined as the inability to get pregnant after one year of unprotected sex) can befall a couple if there is a problem with any one of these processes. That is, a couple can become infertile if ovulation does not happen, either sperm or egg is of low quality, the fallopian tubes are blocked (often because of malformation or injury), the embryo is abnormal, or implantation is unsuccessful. In up to 90 percent of cases, physicians can treat such problems with conventional methods—drugs and surgery. But increasingly they turn to some form of ART, which usually means in vitro fertilization.

## Fact File Assisted Reproduction

- In 2015–2017, of the approximately 72 million women aged 15–49 years, 13 percent received infertility services.
- In 2015–2017, almost 9 percent of married women aged 15–49 years were unable to get pregnant after at least 12 consecutive months of trying to conceive.
- In 2017, a total of 196,454 ART procedures with at least one embryo transferred were performed in 448 U.S. fertility clinics and reported to the CDC. These procedures resulted in 68,908 live-birth deliveries and 78,052 infants born.
- In 2017, ART contributed to 1.9 percent of all infants born in the United States.
- In 2017, the percentage of retrievals resulting in live births for women aged 35 and younger was 55.1 percent; for women aged 35–37, 41.9 percent; for women aged 41–42, 13.2 percent.

From *2018 Assisted Reproductive Technology: Fertility Clinic Success Rates Report*, Centers for Disease Control and Prevention (CDC), Society for Assisted Reproductive Technology, and the American Society of Reproductive Medicine, UNSW Embryology, National Infertility Association, December 2020.

**In vitro fertilization (IVF)** is the uniting of sperm and egg in a laboratory dish, instead of inside a woman's body. (*In vitro* means "in glass" and refers to such outside-the-body containers; the term contrasts with *in utero*, or "in the uterus.") The idea is to create embryos that can be transferred to the woman's uterus, where they can develop to term. (In the much older technique known as artificial insemination, sperm is mechanically inserted into the uterus without sexual intercourse in hopes of achieving fertilization in the woman's body.) The process of IVF and embryo transfer is technically complex, typically consisting of five main steps:

**1. Ovarian stimulation (superovulation).** The woman takes ovulation stimulants (fertility drugs) to prompt her ovaries to produce several eggs at once instead of the usual one per month. Standard IVF procedure calls for multiple eggs because often some of them will be defective, and not every embryo may implant or develop properly once transferred to the uterus.

2. **Egg retrieval.** When the eggs are ready, they are extracted from the egg sacs, or follicles, of the ovaries—usually a 30-minute outpatient surgery. In a typical egg retrieval, an ultrasound-guided needle is inserted into the vagina, through the vaginal wall, and into the ovaries to the egg-bearing follicles. One by one, the eggs are suctioned out through the needle.
3. **Insemination/fertilization.** The retrieved eggs are inspected, and the ones judged to be of highest quality are mixed with sperm (a step called insemination), which results within a few hours in sperm cells penetrating the eggs (fertilization). Typically some eggs will not fertilize, and occasionally none will. Sometimes the chances of fertilization are greatly increased by a technique known as intracytoplasmic sperm injection (ICSI), in which an egg is pierced and a single sperm cell is injected into it.
4. **Embryo culture.** After fertilization, the embryos are left to grow in a culture medium. Within 48 hours, each one

consists of 2 to 4 cells; in three days, 6 to 10 cells. Around the third day, fertility experts can screen the embryos for genetic diseases using a technique known as preimplantation genetic diagnosis (PGD). Only embryos found to be free of defective genes are selected to be transferred to the uterus.

5. **Embryo transfer.** Delivery of embryos to the uterus is generally painless and is performed in the doctor's office up to six days after egg retrieval. To increase the chances of pregnancy, two or more embryos are usually transferred at once. The embryos, along with the fluid surrounding them, are placed in a long, strawlike tube called a transfer catheter. Then the catheter is eased into the vagina and through the cervix, and the embryos are pushed from the tube into the uterus. If all goes well, an embryo implants in the uterine lining.

Fertility experts have developed numerous variations on these steps. One is gamete intrafallopian transfer (GIFT). In this process, ovarian stimulation and egg retrieval proceed as they do in IVF, but then the eggs and sperm (gametes) are transferred together to a fallopian tube to fertilize. GIFT is rarely used (less than 1 percent of ART procedures performed are GIFTs), but it is an option for some who prefer that fertilization take place inside the body. Another variant of IVF is zygote intrafallopian transfer (ZIFT). Like IVF, this procedure depends on fertilization occurring in vitro, but an embryo (zygote) is transferred not to the uterus but to a fallopian tube. Some people believe that ZIFT offers an increased chance of implantation, but it too constitutes less than 1 percent of attempts at assisted reproduction.

Couples are generally not limited to using their own sperm and eggs in IVF and its variations. They can also rely on donors, either anonymous or known, primarily to avoid the transmission of a genetic disorder or to substitute

donor sperm or eggs for their own abnormal or absent gametes. Sperm donors are screened for sexually transmitted diseases and other health problems, and donor sperm is collected, frozen, analyzed, stored (in sperm banks), and used when needed. Egg donors are screened in the same way that sperm donors are, and donor eggs are acquired through standard ovarian stimulation and egg retrieval. The eggs are checked for maturity and, usually soon after retrieval, fertilized with donor sperm or sperm from the partner of the woman trying to become pregnant. (Increasingly eggs are also being frozen and stored for later use in achieving pregnancy.)

As with all forms of reproductive technology, in vitro fertilization (plus embryo transfer) brings with it a long list of risks and benefits—most of which have provoked or underscored a raft of thorny ethical questions. On the plus side is IVF's indisputable power to help many people overcome infertility, to enable desperate couples to do what they otherwise could not: have healthy, biologically related children. The need is great; at last count, in the United States there were over 2 million infertile couples. But since 1981, when the technology was introduced in America, the country has seen the birth of hundreds of thousands of IVF babies.

The other side of the ledger includes two disconcerting facts: IVF is expensive, and its success rates are lower than most people think. The average cost of a single attempt to overcome infertility using IVF is \$10,000 to \$15,000. (An attempt, called a cycle, typically includes the steps from retrieval to transfer, a sequence lasting about two weeks.) Some couples end up paying tens of thousands of dollars. On average, a live birth is the outcome in about 55 percent of IVF cycles for women aged 35 and younger in which the woman's own eggs are used. The rate varies with age: The older the woman, the lower the chances of a live birth. In most cases, then, more than one (expensive) cycle is required to achieve a live birth, and many health insurance plans will not cover the cost.

IVF cycles pose health risks for both woman and child. For the woman, the physical demands of the IVF process—the surgery, the monitoring, the waiting—can be uncomfortable, inconvenient, and stressful. The surgery itself comes with a risk, however low, of side effects such as bleeding, infection, and damaged tissue. There is also a chance of complications from taking the fertility drugs that instigate superovulation, including abdominal pain, memory loss, mood swings, nausea, temporary allergic reactions, and headaches. The most worrisome among these is a rare but potentially dangerous condition known as ovarian hyperstimulation syndrome, characterized by swollen and painful ovaries. Multiple pregnancies—caused mainly by transferring several embryos at once—increase the chances of high blood pressure, anemia, gestational diabetes, and uterine rupture. For the child, there are concerns that ART techniques may lead to birth defects, low birth weight, and diseases such as cancer. Some research has suggested a link between ART and a higher incidence of such problems than occurs in non-ART children, although the disorders are still rare. Researchers are generally not sure, however, if the link is causal, and they have been unable so far to rule out the possibility that these problems are related not to ART but to the infertility itself.

Multiple pregnancies—a common result of IVF cycles—dramatically raise the risks to children's life and health. The chances of prenatal and postnatal death are higher than for single pregnancies, and premature birth is much more likely. Prematurity increases the risk of cerebral palsy, blindness, heart defects, serious infection, respiratory distress syndrome, and other grave maladies. Even aside from prematurity, babies born after a multiple pregnancy have an elevated risk of birth defects and low birth weight, the latter being a separate risk factor for many diseases. One way that practitioners try to lower the risks of multiple pregnancy is to use fetal reduction (also known as selective abortion) to eliminate some of the fetuses in utero. But the procedure itself carries with it a risk of miscarriage.

Several issues—technological and ethical—arise from the handling of the unused embryos that inevitably result from IVF. The common practice is to freeze, or cryopreserve, the extra embryos for possible transfer in the future. Fertility clinics freeze thousands of embryos every year, and hundreds of thousands of them are now in cryostorage. Freezing a woman's leftover embryos gives her the option of using them in future IVF cycles rather than going through another arduous (and expensive) round of ovarian stimulation and egg retrieval. By having her embryos frozen, she can also select the timing of embryo transfer to avoid causing or aggravating any health problems in pregnancy. A significant drawback to the process is that cryopreserved embryos are less likely to result in live births than unfrozen embryos are. Another is that many embryos do not live through freezing and thawing.

Frozen embryos can remain in cryostorage for years—because the couple divorces, because one or both of them die, because they disagree about what to do with the embryos (for example, if one wants to donate them but the other does not), or because they have changed their minds about getting pregnant. The moral and legal implications of these possibilities are being debated now. One alternative is to donate the unused embryos to an infertile couple, which means that the prospective parents will have no genetic connection to the child born to them. Such an arrangement seems unproblematic to some people but is morally or legally questionable to others. Without legal guidance and ethical consensus, fertility clinics must decide what to do with frozen embryos that are unused, unclaimed, or undonated. Often they either donate the embryos for research or destroy them. To those who believe that embryos have a right to life, both of these options are morally impermissible. But even people who don't believe that embryos are persons may think that embryonic life should not be treated as if it has no moral worth at all.

Many of the moral arguments about IVF have involved objections only to a particular

## IN DEPTH

### “SAVIOR SIBLINGS”

The term “savior sibling” refers to a sibling created to provide biological material (such as bone marrow, umbilical cord blood, and organs) that can be used to treat or cure an existing child who is terminally ill (usually with a genetic disease). These siblings are conceived through PGD and IVF. PGD is used to screen embryos before implantation for genetic diseases and to ensure a tissue match with the child to be treated. The moral questions that this process evokes are weighty and painful. Consider this assessment from the Hastings Center:

The issue of savior siblings is fraught with ethical pitfalls. Thus, extraordinary care and planning must be invested to ensure that the process is undertaken only when absolutely necessary and is done in a way that respects the dignity of the new child. Protection of dignity and preservation of autonomy are fundamental tenets in bioethics, and must be kept in mind,

especially when dealing with a vulnerable population, such as children. Caution is paramount, as there is potential for serious ethical missteps. For instance, some hypothesize that the savior sibling may be irrevocably harmed by being a savior, if the child believes that they were not wanted for themselves, or if a child conceived for this reason enjoys a less close and loving relationship with his/her parents. Opponents of this practice go so far as to suggest that no matter how the parents choose to love and care for the new child, it still does not ameliorate the harm caused by the fact that this child may be aware that they were born for the purpose of saving their sibling. These potential harms contrast with the therapeutic benefits that having a savior sibling can provide, both for the existing sick child, who gets to continue living, and the family unit as a whole, who not only do not have to bury a child, but now have the enjoyment of two (hopefully healthy) children.

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From Zachary E. Shapiro, “Savior Siblings in the United States: Ethical Conundrum, Legal and Regulatory Void,” *Washington and Lee Journal of Civil Rights and Social Justice* 24, no. 2 (April 1, 2018).

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step or outcome of the technology, but much of the debate has been about the moral acceptability of IVF itself—about whether it should be used at all. A host of arguments against IVF have been based on alleged harm to children, harm to families or the natural order of procreation, and harm to women. The strongest arguments for IVF have appealed to individual autonomy or reproductive rights.

Some have objected to IVF because of its potential for causing birth defects and disease in children. As we have seen, research supports this worry, though the exact degree of risk is unknown. One commentator argues that

it would be wrong to use reproductive technologies to create children if this bore a significant chance of producing serious disease and impairments in

these very children. Questions are being raised about whether in vitro fertilization (IVF) and other reproductive technologies do, in fact, create serious illness and deficits in a small but significant proportion of children who are born of them. If these technologies were found to do so, it would be wrong to forge ahead with their use.<sup>1</sup>

For many, much depends on the magnitude of the risk. A low level of risk may be acceptable since even normal methods of conception carry a small risk of birth defects and other problems. To insist that IVF and its variants be safer than the usual way of bringing children into the world (or even risk-free) seems unreasonable.

Several writers argue that it would not be wrong to use reproductive technology to bring forth severely damaged children because if the

technology had not been used, the children would not be alive—and being alive is better than not being alive. That is, compared to not existing at all, being brought into the world—even to suffer horribly—is a net gain. As one proponent of this view says,

[A] higher incidence of birth defects in such offspring would not justify banning the [reproductive] technique in order to protect the offspring, because without these techniques these children would not have been born at all. Unless their lives are so full of suffering as to be worse than no life at all, a very unlikely supposition, the defective children of such a union have not been harmed if they would not have been born healthy.<sup>2</sup>

Others believe this view is confused. One critic says that it is based on the false assumption that nonexistence before birth is bad while existence is good and that the two can be meaningfully compared. The view assumes, she says,

that children with an interest in existing are waiting in a spectral world of nonexistence where their situation is less desirable than it would be were they released into this world. . . . Their admission into this realm is thwarted by the failure to use available new reproductive technologies. This failure negates their interest in existing and thereby harms them.<sup>3</sup>

On the contrary, she says, nonexistence before birth is neither good nor bad. Moreover, the notion that children cannot really be harmed by ART “justifies allowing the new technologies to create almost any harm to children conceived as a result of their use—as long as this is not devastating harm in which death is preferable to life with it.”<sup>4</sup>

Some people claim that the use of ART undermines the value we place on offspring. They argue that children are supposed to be regarded as inherently valuable but that reproductive technology tempts us to view them as manufactured products and as commodities acquired in the marketplace for a price. But others see no reason to assume that a couple who creates a child through ART would not love and care for it

as they would a child produced through the usual means. They also maintain that the mere involvement of money does not necessarily entail the treatment of children as commodities—otherwise adoption, which involves prices and payments, would also have to be considered morally unacceptable.

IVF has been condemned by some religious groups because it breaks the natural connection between procreation and sexual intercourse in marriage. The only morally permissible way to conceive a child, they say, is through sexual union between husband and wife. According to the Vatican, IVF and other forms of assisted reproduction are “contrary to the unity of marriage, to the dignity of the spouses, to the vocation proper to parents, and to the child’s right to be conceived and brought into the world in marriage and from marriage.”<sup>5</sup> Some critics, however, think this view has little credibility outside the particular religious tradition espousing it. According to Peter Singer,

Few infertile couples will take seriously the view that their marital relationship will be damaged if they use the technique [IVF] which offers them the best chance of having their own child. It is in any case extraordinarily paternalistic for anyone else to tell a couple that they should not use IVF because it will harm their marriage. That, surely, is for them to decide.<sup>6</sup>

Whether or not IVF harms marriages, it surely changes family relationships, and that is a pressing concern for many. Through ART, a child can have many parents—genetic (those who contribute egg or sperm), gestational (the woman who carries the baby to term), and social (the people who raise the child). With all these possibilities, the family can take forms that were unthinkable a few decades ago. These changes have prompted some to argue that by weakening the *biological* connections between parents and children, reproductive technology will also loosen the *social* bonds between them—the values, commitments, and feelings that have characterized families in the past. A common

reply is that such a claim requires empirical support, for it is not at all obvious that new family structures will be bad for all concerned. Research is scarce on the harm and benefits of new parental arrangements, and to assume the worst is unreasonable.

Many people insist that IVF is a boon to women because it enhances their freedom by multiplying their reproductive choices. But some feminists have repudiated this view. They argue that the pressure from patriarchal society for women to establish their worth by becoming mothers is so powerful that their choices regarding reproduction are not truly free but coerced. If so, then the existence of IVF and other reproductive technologies does not bring more freedom—it just reinforces social stereotypes.

Mary Anne Warren disagrees. She acknowledges that IVF comes with substantial risks and burdens but denies that women are too constrained or coerced by society to decide about the technology for themselves:

Neither the patriarchal power structure nor pronatalist [pro-childbearing] ideology makes women incapable of reasoned choice about childbearing. Rather, the social pressures upon some women to have children—and the pressures upon others not to have children—are circumstances which we must take into account in our deliberations. . . . In deliberating about either “natural” motherhood or the use of IVF, we may sometimes be wrong about what is in our own interests, and perhaps some of us are excessively influenced by pronatalist ideology. But it does not follow that we would benefit from additional paternalistic restraints. Autonomy necessarily implies the right to make our own mistakes.<sup>7</sup>

To defend the use of IVF, many commentators appeal to autonomy or individual rights. John Robertson, for example, argues for what he calls “procreative liberty”—the freedom to reproduce or not to reproduce. This amounts to a right to make a reproductive choice without interference from others, including a choice about use of reproductive technologies. He contends

that only very weighty considerations can override a person’s procreative liberty:

If procreative liberty is taken seriously, a strong presumption in favor of using technologies that centrally implicate reproductive interests should be recognized. Although procreative rights are not absolute, those who would limit procreative choice should have the burden of establishing substantial harm. . . . This will give persons directly involved the final say about use of a particular technology, unless tangible harm to the interests of others can be shown.<sup>8</sup>

As we have seen, many would argue that such substantial harms are inherent in reproductive technologies—most notably, harms to children, women, and families. Others would insist that at least some moral or religious rules (those concerning the treatment of embryos or the role of reproduction in marriage, for example) can always trump autonomy.

## SURROGACY

A **surrogate** is a woman who gestates a fetus for others, usually for a couple or another woman. She contracts with them to carry the pregnancy to term, to relinquish the baby at birth, and to let them legally adopt it. The surrogacy can take two different forms. In what has been called *traditional surrogacy*, sperm from either the couple’s male partner or a donor is used to artificially inseminate the surrogate (the “surrogate mother”). Since the egg fertilized is the surrogate’s, the baby produced from this arrangement is genetically related only to the surrogate and to whoever supplies the sperm. In *gestational surrogacy*, the surrogate receives a transferred embryo created through IVF using the sperm and egg of others (the contracting couple or donors). Because the gestational surrogate (also called the gestational carrier) does not contribute her own egg, she has no genetic connection to the baby.

In surrogacy relationships, we can distinguish between genetic (or biological), gestational, and

social (or rearing) parents. Thus, we can say that a traditional surrogate is the genetic mother because she contributes her egg to conception. She is also the gestational mother because she carries the pregnancy. But she is not meant to be the social mother who raises the child; the contractual, or intended, parents plan to do that. The man who contributes the sperm (typically the intended father) is the genetic father. In gestational surrogacy, the surrogate is the gestational mother while the prospective mother and father are usually the genetic parents, who are also likely to be the social parents. In moral and legal disputes over surrogacy arrangements, these distinctions come up again and again and are often used to parse questions about who the “real” parents are.

A woman may opt for gestational surrogacy because she has an abnormal uterus or no uterus

(because of hysterectomy or congenital defect) or because she suffers from health problems that make pregnancy dangerous, such as cystic fibrosis and serious forms of diabetes and heart disease. A couple may turn to a traditional surrogate for many of the same reasons. In both kinds of surrogacy, the intended parents generally want more than just a child—they want a biologically related child. For them, then, adoption may be less attractive. (Couples may also decide against adoption for other reasons, including its expense and the scarcity of adoptable children.)

Surrogate arrangements are generally complex and legally unsettled. Surrogacy contracts may specify all of the surrogate’s prenatal duties (including those regarding her alcohol consumption, smoking, prenatal testing, medical treatment, and sexual intercourse), the involvement

### IN DEPTH IVF AND CHILDREN’S FUTURE CHILDREN

IVF and the technology for freezing embryos have opened up an array of possibilities for treating infertility that until recently were unthinkable. Here is one example, one of many stunning reports from this new frontier:

(BBC News)—Israeli scientists say that they have extracted and matured eggs from girls as young as five to freeze for possible fertility treatment in the future.

The team said that the technique could give child cancer sufferers left infertile by chemotherapy treatment a shot at parenthood later in life.

The team took eggs from a group of girls between the ages of five and 10 who had cancer.

They artificially matured the eggs to make them viable and froze them.

Experts had previously thought the eggs of pre-pubescent girls could not be used in this way.

Dr. Ariel Revel, from Hadassah University Hospital in Jerusalem, is to present the team’s findings at a fertility conference in Lyon, France, this week.

“No eggs have yet been thawed, so we do not know whether pregnancies will result,” he said in a statement.

“But we are encouraged by our results so far, particularly the young ages of the patients from whom we have been able to collect eggs.”

Childhood cancers have a good cure rate—between 70 percent and 90 percent—but often require aggressive chemotherapy which can mean the child will be sterile in later life.

Geoff Thaxter, of the children’s cancer charity CLIC Sargent, said: “This report represents interesting initial research into potential fertility treatments for children being treated for cancer, and could help to make sure that childhood cancer does not have a lifelong impact.”

But Josephine Quintavalle, of Comment on Reproductive Ethics, expressed concern that if the eggs were donated to a woman of child-bearing age, a resulting child could have a biological mother who was only a few years older.<sup>9</sup>

of the intended parents in the pregnancy (for example, their presence or absence at the birth), the permissibility of abortion in case of fetal abnormalities, the arrangements for adoption of the child, and the money to be paid to the surrogate (including prorated compensation if there is a miscarriage). Whatever the financial arrangements, they cannot be construed as transactions involving the buying or selling of children, which is illegal. (Some states forbid surrogacy agreements allowing any kind of payment.) So money paid to surrogates—now probably in the range of \$10,000 to \$30,000—is supposed to be regarded as compensation for such things as her time and effort or her diminished job opportunities. (A few women agree to become surrogates for altruistic reasons and do not expect payment.) Complicating the picture further is the hodgepodge of surrogacy laws from state to state and the absence of national laws. Some states have outlawed surrogacy, some allow it with varying restrictions, some allow it but declare that the contracts are unenforceable, and some have no relevant legislation.

The kinds of questions and conflicts that surrogacy can engender have been accentuated in numerous cases, the most famous one being that of “Baby M.” Over 20 years ago Mary Beth Whitehead agreed to become a surrogate mother for William and Elizabeth Stern. For \$10,000 she consented to be artificially inseminated with Mr. Stern’s sperm, to carry the child to term, and to relinquish it to the Sterns after birth. The baby—named Melissa by the Sterns but known to the world as Baby M—was born on March 27, 1986. But then Whitehead had a change of heart. After declaring that she could not give the infant up, she left the state with her. The case eventually ended up in a New Jersey court, where the judge ruled that the surrogate agreement was binding and that Whitehead had to turn over Baby M to the Sterns. Whitehead appealed the ruling to the New Jersey Supreme Court and won a reversal. The court ruled that the surrogacy contract was actually invalid and that Whitehead was the legal mother. Citing the best

interests of the child, however, the court also held that Baby M should live with the Sterns and that Whitehead should have visitation rights.

Many of the arguments about surrogacy mirror those about IVF, clustering around reproductive autonomy and alleged harm to children, families, and women. But probably the most pervasive argument—and perhaps the strongest on the anti-surrogacy side—is that surrogacy arrangements amount to babyselling, a blatant affront to human dignity. (The charge is usually made against commercial surrogacy, in which money changes hands, not against altruistic surrogacy, in which women volunteer their surrogate services.) As one surrogacy critic says,

Commercial surrogacy substitutes market norms for some of the norms of parental love. Most importantly, it requires us to understand parental rights no longer as trusts but as things more like property rights—that is, rights of use and disposal over the things owned. For in this practice the natural mother deliberately conceives a child with the intention of giving it up for material advantage.... By engaging in the transfer of children by sale, all of the parties to the surrogate contract express a set of attitudes toward children which undermine the norms of parental love.<sup>10</sup>

Defenders of surrogacy deny that it constitutes baby-selling, claiming instead that a surrogate is simply relinquishing her right as a parent to have a relationship with the child. She is not selling an existing close relationship with someone; she is selling, or forfeiting, the right to enjoy a future parent-child relationship—and it is not obvious that doing so is wrong.

Moreover, says the surrogacy advocate, the practice is not that different from adoption, in which biological parents give away their children (as well as the hope of any relationship with them). On the contrary, says Elizabeth Anderson, adoption and surrogacy differ substantially:

The purpose of adoption is to provide a means for placing children in families when their parents

cannot or will not discharge their parental responsibilities. It is not a sphere for the existence of a supposed parental right to dispose of one's children for profit.<sup>11</sup>

Laura Purdy, however, reminds us that surrogacy provides a socially valuable service and asks,

Why then must it be motivated by altruistic considerations? We do not frown upon those who provide other socially valuable services even when they do not have the "right" motives. Nor do we require them to be unpaid. For instance, no one expects physicians, no matter what their motivation, to work for beans. They provide an important service; their motivation is important only to the extent that it affects quality.<sup>12</sup>

Bonnie Steinbock thinks that surrogacy arrangements have sometimes involved baby-selling, and she points to the Baby M case as an example. But she argues that this unsavory element can be eliminated if we view surrogacy as prenatal adoption:

The question, then, is whether we can reconcile paying the surrogate, beyond her medical expenses, with the idea of surrogacy as prenatal adoption. We can do this by separating the terms of the agreement, which include surrendering the infant at birth to the biological father, from the justification for payment. The payment should be seen as justification for the risks, sacrifice, and discomfort the surrogate undergoes during pregnancy. This means that if, through no fault on the part of the surrogate, the baby is stillborn, she should still be paid in full, since she has kept her part of the bargain. . . . If, on the other hand, the surrogate changes her mind and decides to keep the child, she would break the agreement, and would not be entitled to any fee, or compensation for expenses incurred during pregnancy.<sup>13</sup>

## CLONING

*Clones*, in the sense used by biologists, are genetically identical entities, whether cells, DNA molecules, plants, animals, or humans. Cloning

is the asexual production of a genetically identical entity from an existing one. In animals and humans, since the genetic blueprint for an individual is in each of its cells (mostly in the nucleus), all the cells of a clone contain the same blueprint as all the cells of the clone's progenitor. An animal or human clone is not a perfect copy of an individual—not like a photocopy of an original document—but a living thing that shares a set of genetic instructions with another.

In agriculture, cloning to propagate plant strains is commonplace, and for years scientists have been cloning human and animal cells for research purposes. Molecular biologists often clone fragments of DNA for study. Among animals and humans, clones appear naturally in the form of identical twins, individuals with identical sets of DNA. Scientists have managed to duplicate this process in a form of cloning known as *twinning*. Through in vitro fertilization they produce an embryo (zygote), and when it consists of two to four identical cells, they separate them and let them grow into discrete but genetically identical organisms.

The cloning that has provoked the most public consternation and media attention is the creation of a genetic duplicate of an adult animal or human, what has often been called **reproductive cloning**. The aim of this work is the live birth of an individual. (Cloning for other purposes is called **therapeutic**, or **research**, **cloning**, a topic we discuss further in Chapter 9.) This kind of cloning suddenly became front-page news in 1997 when scientists announced that they had managed to clone an adult sheep, resulting in the birth of an apparently healthy clone called Dolly. She was the genetic twin of her adult "parent" and the first mammal so cloned. After her, scientists cloned additional animals in similar fashion—cattle, goats, pigs, cats, rabbits, mice, and more—and are working on others.

The primary cloning method for producing live-birth mammals, and the one most likely to be considered for human cloning, is known as

somatic cell nuclear transfer (SCNT). The usual steps are:

1. Extract the DNA-packed nucleus from an egg cell (creating an enucleated egg).
2. Replace the egg's nucleus with the donor nucleus of an ordinary body (somatic) cell from the adult individual to be cloned. (It's also possible to use cells from existing embryos.)
3. Stimulate the reconfigured cell with chemicals or electricity to start cell division and growth to the embryo stage.
4. Transfer the cloned embryo to a host uterus for development and birth.

The egg and somatic nucleus can come from two different individuals or the same individual. If from two different ones, the largest portion of the clone's DNA will be from the nucleus donor since almost all DNA resides in the nucleus, with only a tiny amount located outside the nucleus in the cell's mitochondria. If from the same individual, the clone will get its entire complement of DNA from the nucleus and mitochondria of the same individual.

To date, no human has been successfully cloned, and for technical and moral reasons none is likely to be cloned any time soon. At this stage of the technology, both scientists and policymakers have serious concerns about the safety and ethics of human reproductive cloning.

A typical response to the prospect of human cloning is moral outrage—which too often is based on misunderstandings. Chief among these is the notion that a human clone would be identical to an existing person, the clone's "parent." This idea has led to a host of silly fantasies played out in movies, literature, and the popular mind: an army of Hitler clones spawned from one of the Führer's cells, a laboratory of Albert Einsteins discovering the secrets of the universe, the perfect team of Hank Aaron or Michael Jordan clones, a houseful of identical children who are exact copies of a rich, eccentric egotist. The underlying fallacy is that genes make the person, that genetics ordains all of an

individual's characteristics. This view is known as genetic determinism, and it is a myth. The National Academy of Sciences makes the point this way:

Even if clones are genetically identical with one another, they will not be identical in physical or behavioral characteristics, because DNA is not the only determinant of these characteristics. A pair of clones will experience different environments and nutritional inputs while in the uterus, and they would be expected to be subject to different inputs from their parents, society, and life experience as they grow up. If clones derived from identical nuclear donors and identical mitochondrial donors are born at different times, as is the case when an adult is the donor of the somatic cell nucleus, the environmental and nutritional differences would be expected to be more pronounced than for monozygotic (identical) twins. And even monozygotic twins are not fully identical genetically or epigenetically because mutations, stochastic [random] developmental variations, and varied imprinting effects (parent-specific chemical marks on the DNA) make different contributions to each twin.<sup>14</sup>

Einstein's clone would have Einstein's genes but would not and could not be Einstein. The clone would be unique and probably not much like his famous progenitor at all.

At this stage of scientific knowledge, human cloning seems likely to result in high rates of serious birth defects.<sup>15</sup> Under these circumstances, most commentators agree that cloning should not be attempted. (A few question this conclusion, noting that even now parents who are certain to conceive and bear children with terrible genetic disorders are permitted to do so.) Nevertheless, since 1997 the dispute over the moral permissibility of cloning has raged on, fueled by the thought that, given the usual pace of scientific progress, the problem of congenital malformations will be solved and the efficient cloning of human beings will soon be technologically feasible.

As we would expect, many of those who favor the use of cloning rest their case on its likely

benefits. For some people, their only hope of having a child with whom they are genetically related would be through cloning. Some men have no sperm; some women, no eggs; cloning could get around the problem. For couples who value this genetic connection and who also want to avoid passing on a genetic disease or health risk to their child, cloning would be an attractive option—perhaps the only option. Parents whose only child dies could have her cloned from a cell harvested from her body, ensuring that some part of her would live on. A boy who needs an organ transplant to live could be cloned so his clone could provide the needed organ, perfectly matched to avoid transplant rejection.

As in the case of IVF, many claim a moral right to use cloning, arguing that people have a basic right of reproductive liberty and that cloning is covered by that right. They deny that this right to cloning is absolute (overriding all other considerations) but believe that it carries great weight nonetheless. As one writer puts it:

[I]t is reasonable to hold that the freedom of infertile couples to use cloning is a form of procreative freedom. Procreative freedom is worthy of respect in part because freedom in general is worthy of respect. But more than this, procreative freedom is an especially important freedom because of the significance that procreative decisions can have for persons' lives. For these reasons, the freedom of infertile couples to use cloning is worthy of respect.<sup>16</sup>

Some critics of cloning have charged that it violates the rights of the resulting clone—specifically, the right to a unique identity. A clone by definition is not genetically unique; his genome is iterated in his “parent.” Aside from doubts about whether such a right exists, the strongest reply to this worry is that genetic uniqueness is neither necessary nor sufficient for personal uniqueness:

What is the sense of identity that might plausibly be each person has a right to have uniquely, which constitutes the special uniqueness of each individual? Even with the same genes, two individuals,

for example homozygous twins, are numerically distinct and not identical, so what is intended must be the various properties and characteristics that make each individual qualitatively unique and different than others. Does having the same genome as another person undermine that unique qualitative identity? Only in the crudest genetic determinism. . . . But there is no reason whatever to believe in that kind of genetic determinism, and I do not think that anyone does.<sup>17</sup>

A similar rights argument says that cloning would be wrong because it violates what has been called a “right to ignorance” or a “right to an open future.” Consider a situation in which a clone begins his life many years after his older twin does. The younger twin lives in the shadow of the older one, thinking—correctly or incorrectly—that his genetically identical sibling has already lived the life that he (the younger twin) has barely started. He believes that his future is already set. His sense of personal freedom and of a future of possibilities is diminished. In this way, the argument goes, his right to an open-ended life story has been flouted.

But some think this argument is built on flimsy assumptions:

[A]ll of these concerns are not only quite speculative, but are directly related to certain specific cultural values. Someone created through the use of somatic cell nuclear transfer techniques may or may not believe that their future is relatively constrained. Indeed, they may believe the opposite. In addition, quite normal parenting usually involves many constraints on a child's behavior that children may resent.<sup>18</sup>

Would the younger twin's right to ignorance or to an open future be violated just because she *believes* her future is fated, although her belief is false? Dan W. Brock insists that the answer is no:

I believe that if the twin's future in reality remains open and his to freely choose, then someone acting in a way that unintentionally leads him to believe that his future is closed and determined has

## IN DEPTH CLONING TIME LINE

- 1970** British developmental biologist John Gurdon clones a frog.
- 1978** Louise Brown is born, the first baby conceived through IVF.
- 1980** The U.S. Supreme Court holds that a genetically engineered life form—a bacterium—can be patented.
- 1996** Through the work of Ian Wilmut and his colleagues, the first animal cloned from adult cells—a sheep named Dolly—is born.
- 1997** President Bill Clinton declares a five-year moratorium on federal funding for research into human cloning.
- 1997** Wilmut and his colleagues create Polly, a sheep with a human gene in each of its cells.
- 1998** From a single cow, eight calves are cloned.
- 2001** Scientists in Massachusetts clone the first human embryo.
- 2002** The President's Council on Bioethics recommends a ban on reproductive cloning.
- 2003** Dolly, now 6 years old, is euthanized when she is found to have progressive lung disease.
- 2003** Italian scientists claim they have produced the first cloned horse.
- 2004** A company called Genetics Savings and Clone says it will clone people's cats for them for \$50,000 per cat.
- 2005** The creator of Dolly is licensed to clone human embryos for medical research.
- 2011** In South Korea, seven Labrador retriever clones are used to sniff out contraband luggage; they are genetically identical to a dog that was for a while the top dog in drug detection.
- 2013** Researchers at Oregon Health and Science University say in the journal *Cell* they have used cloning to produce embryonic stem cells. They first created human embryos with skin cells and then used those embryos to produce the stem cells.
- 2014** Cloning is used to produce stem cells that are genetically matched to the genome of adult patients.

not violated his right to ignorance or to an open future. . . . If we know that the twin will believe that his open future has been taken from him as a result of being cloned, even though in reality it has not, then we know that cloning will cause him psychological distress, but not that it will violate his right.<sup>19</sup>

Many oppose the use of cloning technology (and any other ART) because it is unnatural, a deviant way of bringing children into the world. But this view is criticized as narrowly dogmatic, for some natural processes are bad (such as bacterial infection), and some unnatural ones are good (such as medical treatment). A few believe that naturalness should be defined according to a thing's function. They reason that since each part of the human body has a natural function, we should not subvert that part by giving it an

additional function. Cloning, then, would be unnatural and wrong. But this take on naturalness has many detractors. For example:

Although there are certainly unhealthy or unwise uses of our body parts, there's no reason for us to always adhere to an organ's primary function. The bridge of a nose has the primary function of allowing us to exhale and inhale air, but do we sin if we use it to support our spectacles? . . . Bypass surgery improves our cardiovascular systems. Kidney dialysis allows people with kidney failure to survive. Transplants replace increasing numbers of our organs. All of these are human artificial interventions in nature. They seem morally justified, if anything does. So why not extend this reasoning to genetic engineering? Why not use genetics to produce a healthy child rather than a sickly one?<sup>20</sup>

A kindred objection to cloning and other reproductive technologies holds that they replace natural procreation with the artificial *manufacture* of children as products—a demeaning process that erodes our respect for human beings. Cloning is thus profoundly dehumanizing. “Human nature,” says Leon Kass, “becomes merely the last part of nature to succumb to the technological project, which turns all of nature into raw material at human disposal.”<sup>21</sup>

But why assume cloning is dehumanizing? Dan Brock says that we should not:

It would be a mistake, however, to conclude that a human being created by human cloning is of less value or is less worthy of respect than one created by sexual reproduction. It is the nature of a being, not how it is created, that is the source of its value and makes it worthy of respect.<sup>22</sup>

## APPLYING MAJOR THEORIES

We have the power to control human reproduction as never before. The question is: Should we? In the name of reproductive freedom and control, is it morally permissible to employ ART, surrogacy, even cloning?

The utilitarian will answer yes if the benefits of the technology outweigh its harms, no if they do not. Based on current knowledge of the good and bad effects, most utilitarians would probably see a net gain in the use of IVF and surrogacy arrangements, and they would likely endorse cloning if its risks to children could be decreased to an acceptable level. They presumably would calculate that IVF’s real but low risk of birth defects and maternal complications is outweighed by the happiness brought to infertile couples, and the loss of embryos in the process would not be a major factor. They would likely make a similar calculation regarding surrogacy, assuming that surrogacy arrangements are properly regulated. But some utilitarians may embrace a different calculus. They may reason that cloning and IVF are impermissible because the considerable money spent on them

could yield far more happiness if spent on, say, food for the hungry people of the world.

However, if the widespread use of reproductive technologies would harm society—if, for example, surrogacy or cloning would result in a general disregard for human life and welfare, as some critics argue—a rule-utilitarian might oppose these innovations. She could, with logical consistency, acknowledge that the technologies often increase net happiness in particular cases but oppose a public policy that allowed their use.

From a Kantian perspective, it is possible to either oppose or defend reproductive technologies. Someone could argue, for example, that IVF, surrogacy, and cloning are impermissible because they treat children merely as a means, instead of an end in themselves. Children are “manufactured” and sold as commodities to serve the ends of others. But a Kantian could refuse to take this view, arguing instead that couples who create children do so precisely because they wish to respect and love their offspring as persons. What matters is not how children are brought into the world, but how they are treated after they arrive.

According to the Roman Catholic interpretation of natural law theory, reproductive technologies must be rejected across the board. IVF is wrong because it defies the natural link between procreation and sexual union. It also involves the destruction of human embryos, each of which has a right to life. Surrogacy is immoral because it too is procreation outside of marriage and an affront to the integrity of the family. Human cloning is to be repudiated because it unnaturally separates procreation from sex and is a violation of the rights of the child.

## KEY TERMS

cloning

cloning, reproductive

cloning, therapeutic or research

cycle (in assisted reproductive technology)

infertility

in vitro fertilization

surrogate

**IN DEPTH****SHERRI SHEPHERD: HOW SURROGACY CAN GO WRONG**

When people involved in surrogacy arrangements change their minds about the surrogacy agreements, they find themselves in new legal, social, and emotional territory. Here's a report on a case that lit up the news media and social networks.

Last week, a Pennsylvania judge issued a ruling in a surrogacy case involving the actress Sherri Shepherd. It's a sad and complicated scenario: Shepherd and her ex-husband, Lamar Sally, conceived a baby using Sally's sperm, a donor's egg, and a surrogate's womb. Shepherd and Sally split in the middle of the pregnancy, and Shepherd subsequently claimed that she was tricked into signing the surrogacy documents so that Sally might get more money from her in the form of child support. Shepherd disavowed the child, who was born in August. The Pennsylvania judge ruled that Shepherd's name must go on the birth certificate as the child's legal mother. Before the ruling, the surrogate's name was on the certificate, and she, not Shepherd, was held responsible for child support in California.

To complicate matters further, this decision is just from one of three court cases pending in Shepherd and Sally's split, all of which are in different states. In addition to the Pennsylvania parentage case, which has been decided, there's a divorce action pending in New Jersey and a child support case pending in California. The surrogate resides in Pennsylvania, where the

baby was born; Shepherd filed for divorce in New Jersey, and Sally filed in California.

This type of dispute is rare, says Raegen N. Rasnic, an attorney at the Seattle law firm Skel勒ger Bender who focuses on assisted reproduction. Andrew V.W. Vorzimer, a surrogacy lawyer, told the *New York Times* in 2014 that there have been 81 cases where intended parents changed their minds about a surrogacy agreement, and 35 in which the surrogate wanted to keep the baby (24 of those involved surrogates whose eggs were also used). . . .

Despite the fact that Shepherd now claims she was tricked into the surrogacy agreement, her past statements to the press tell a different story. In June 2013, she spoke frankly and jokingly about finding a surrogate to *Essence.com*. "We're starting the process of making sure the uterus that we picked is not crazy," she said back then. And she did sign the papers, even if she now says it was under duress.

So what does it mean that Shepherd has been declared the parent of this baby? It means she's responsible for child support until the child is 18—or longer, if college support comes into play, says Rasnic. Shepherd can also seek custody or visitation, and the child could be entitled to certain benefits, like Social Security, upon Shepherd's death. The Pennsylvania ruling does not cover these specifics, though; the specifics will be determined by the other cases pending in Shepherd and Sally's divorce proceedings.

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From Jessica Grose, "The Sherri Shepherd Surrogacy Case Is in a Mess. Prepare for More Like It," *Slate/blog: XXfactor*, April 28, 2015, [http://www.slate.com/blogs/xx\\_factor/2015/04/28/](http://www.slate.com/blogs/xx_factor/2015/04/28/).

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**SUMMARY**

Assisted reproductive technology (ART) is designed to address the problem of infertility, which affects millions of couples in the United States and worldwide. In vitro fertilization (IVF) is one such

technology, consisting of the uniting of sperm and egg in a laboratory dish, instead of inside a woman's body. There are numerous variations on basic IVF, including gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer

(ZIFT). IVF can help many couples overcome infertility, but it is expensive, and IVF cycles pose health risks to both woman and child. Paramount among the risks are multiple pregnancies, a

frequent result of IVF cycles. Problems also arise from the practice of cryopreserving extra embryos often left over after IVF, a key question being what ultimately should be done with them.

#### CLASSIC CASE FILE

### Baby M

In recent years, no issue in assisted reproduction has generated more controversy than surrogate pregnancy. The kinds of questions and conflicts that surrogacy can engender have been accentuated in numerous cases, the most famous one being that of "Baby M."

In 1985 Mary Beth Whitehead agreed to become a surrogate mother for William and Elizabeth Stern. For \$10,000 she consented to be artificially inseminated with William Stern's sperm, to carry the child to term, to relinquish all rights to it, and to surrender it to the Sterns at birth. At the time, she was married and had two school-age children. She said that she had no desire for more children to raise and that her aim was to give a child to a couple who could not have any children of their own. The Sterns said that they decided on surrogacy because Mrs. Stern had a medical condition that made pregnancy risky for her.

The baby—named Melissa by the Sterns but known to the world as Baby M—was born on March 27, 1986. Whitehead turned over the baby to the Sterns as agreed, but then she had a change of heart. The next day she went to the Sterns and pleaded with them to allow her to take the baby home with her for a while. The Sterns quoted her as saying, "I just want her for a week and I'll be out of your lives forever." She was distraught and persistent, and the Sterns thought she was suicidal. "Something took over," Whitehead would say later. "I think it was just being a mother." Reluctantly the Sterns agreed to let Whitehead keep the baby for a few days.

Two weeks later Mary Beth Whitehead let the Sterns know that she was not going to give the baby

back. With a court order granting them custody of the child and backed by several police officers, the Sterns went to Whitehead's home to take custody. But the Whiteheads took the baby and fled to Florida, where they eluded the authorities for weeks. On July 31, however, a private detective located the baby, and authorities turned her over to the Sterns.

Whitehead tried to regain legal custody, and the case eventually ended up in a New Jersey court, where the judge ruled that the surrogate agreement was binding and that Whitehead had to turn over Baby M to the Sterns. After the judge's ruling, he signed papers allowing Elizabeth Stern to adopt her.

Whitehead appealed the ruling to the New Jersey Supreme Court and, on February 3, 1988, won an almost total reversal of the earlier decision. The court held in a unanimous ruling that the surrogacy contract was actually invalid, that it violated the state's adoption laws against selling babies, and that Whitehead was to have parental rights. "We thus restore the surrogate as the mother of the child," declared the court. "She is not only the natural mother, but also the legal mother, and is not to be penalized one iota because of the surrogate contract." Citing the best interests of the child, however, the court also held that Baby M should live with the Sterns and that Whitehead should have visitation rights. The ruling made it clear that, in New Jersey at least, surrogacy was permitted as long as the surrogate was not paid and she had the right to change her mind about giving up the baby.

The decision made history as the first one from a state's top court on the rights of surrogate mothers.

Critics contend that IVF should not be used because it leads to birth defects and disease in children, undermines the value we place on children, breaks the natural connection between procreation and sexual intercourse in marriage, and dramatically changes common family relationships. Others argue that IVF enhances women's freedom by multiplying their reproductive choices or that IVF should be allowed in the name of procreative liberty.

A surrogate is a woman who gestates a fetus for others, usually for a couple or another woman. She contracts with them to carry the pregnancy to term, to relinquish the baby at birth, and to let them legally adopt it. Thus, in surrogacy relationships, we can distinguish between genetic (or biological), gestational, and social (or rearing) parents. Probably the most pervasive argument against surrogacy is that surrogacy arrangements amount to baby-selling, a blatant affront to human dignity. Defenders of surrogacy deny that it constitutes baby-selling, claiming instead that a surrogate is simply relinquishing her right as a parent to have a relationship with the child. The surrogacy advocate says that the practice is not that different from adoption, in which biological parents give away their children (as well as the hope of any relationship with them).

Cloning is the asexual production of a genetically identical entity from an existing one. All the cells of a clone contain the same blueprint as all the cells of the clone's progenitor. The cloning that has provoked the most debate and media attention is human reproductive cloning, the creation of a genetic duplicate of an adult human. So far, no human has been successfully cloned and is not likely to be any time soon. Nevertheless, fear or outrage regarding human cloning is widespread, much of it based on incorrect information. A common myth is genetic determinism, the view that genes make the person, that genetics ordains all of an individual's characteristics.

Many in favor of human cloning appeal to reproductive liberty and to cloning's possible

benefits, such as enabling infertile couples to have a child that is genetically related to them. Critics charge that cloning is unnatural, that it violates the right of the resulting clone to a unique identity or future, and that it will result in the demeaning artificial manufacture of children as products.

## Cases for Evaluation

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### CASE I

#### The Fate of Frozen Embryos

##### Abstract

**BACKGROUND.** The moral status of the human embryo is particularly controversial in the United States, where one debate has centered on embryos created in excess at in vitro fertilization (IVF) clinics. Little has been known about the disposal of these embryos.

**METHODS.** We mailed anonymous, self-administered questionnaires to directors of 341 American IVF clinics.

**RESULTS.** 217 of 341 clinics (64 percent) responded. Nearly all (97 percent) were willing to create and cryopreserve extra embryos. Fewer, but still a majority (59 percent), were explicitly willing to avoid creating extras. When embryos did remain in excess, clinics offered various options: continual cryopreservation for a charge (96 percent) or for no charge (4 percent), donation for reproductive use by other couples (76 percent), disposal prior to (60 percent) or following (54 percent) cryopreservation, and donation for research (60 percent) or embryologist training (19 percent). Qualifications varied widely among those personnel responsible for securing couples' consent for disposal and for conducting disposal itself. Some clinics performed a religious or quasi-religious disposal ceremony. Some clinics required a couple's participation in disposal; some allowed but did not require it; some others discouraged or disallowed it.

**CONCLUSIONS.** The disposal of human embryos created in excess at American IVF clinics varies in ways suggesting both moral sensitivity and ethical divergence.\*

*One study estimates that as many as 400,000 embryos remain frozen in fertility clinics in the United States; this survey tried to document what happens to them. If you were faced with trying to decide what to do with frozen embryos, which of the options described here would you choose? Why? Do you believe that parents should have a say in what happens to their embryos? Do you think embryos have a right to exist regardless of the parents' wishes? Explain. Given that a frozen embryo is minute (comprising only two to four cells), do you think it merits a disposal ceremony? Why or why not?*

\*Andrea D. Gurkman, Dominic Sisti, and Arthur L. Caplan, "Embryo Disposal Practices in IVF Clinics in the United States," *Politics and Life Sciences* 22, no. 2 (August 2004): 3–8.

## CASE 2

### Surrogate Versus Father

(MSNBC)—Despite a court ruling against them, a Florida couple vows to continue their legal battle to gain custody of a child born by the woman they hired as a surrogate, but who then decided to keep the baby.

The issue, Tom and Gwyn Lamitina say, is not about Florida surrogacy law, which clearly gives the woman the right to the child. They are fighting for Tom Lamitina's rights as the father of the child.

"We filed an appeal," Scott Alan Salomon, the attorney for the couple, told TODAY co-host Meredith Vieira when all three appeared on the program Tuesday. "The trial judge overstepped his bounds. He had no right whatsoever to terminate parental rights in a paternity action."

Gwyn Lamitina, 46, said the couple wants custody of the child they think is rightfully theirs.

"We would ultimately like to have primary custody," she said. "If the judge deems that [the surrogate] has visitation, we would be up for that."

The child, Emma Grace, was born five months ago to Stephanie Eckard, whom the Lamitinas had met through an online site on which women who want to be surrogates advertise their availability.

Eckard, 30, is a teacher and a single mother of two other children of her own. According to Salomon, she had delivered three surrogate children for other couples before meeting the Lamitinas. Eckard lives in Jacksonville, in the northeast corner of the state, while the Lamitinas live in the Central Florida town of Oviedo. Eckard has declined all requests to be interviewed.

But a month after Eckard became pregnant, she and the Lamitinas had a confrontation over Eckard's smoking. Eckard broke off contact and decided to keep the child as her own. The Lamitinas had paid her \$1,500 to carry the child.

The Lamitinas have never seen the girl. "I haven't known anything about her," Gwyn Lamitina told Vieira. "I had to find out she was born through the press."

Because Emma Grace was conceived with Eckard's egg and not Gwyn Lamitina's, Florida law gives Eckard the absolute right to decide to keep the child up until 48 hours after the birth. The trial court upheld that law on Oct. 11.

For that reason, Florida surrogacy lawyer Charlotte Danciu told NBC News in a recorded interview, "Couples should never let a surrogate use her own egg." . . .

As Danciu said, the law in Florida is very clear: A surrogate pregnancy with the surrogate's own egg is treated as an adoption and the birth mother can decide to keep the child, even if there is a signed contract. Tom Lamitina is the father of the child, but the law treats him as a sperm donor with no parental rights.

"That is absolutely incorrect," said Salomon. "A sperm donor is one that signs a contract that says 'I am waiving my parental rights.' Tom voluntarily paid money to give a woman his sperm. He is not a sperm donor. He was doing this with the sole intent to become a father. That's the biggest joke of this whole case."

He said the Lamitinas' case is rightly a paternity case in which Tom Lamitina is seeking custody of his own daughter.

"Half of this child's DNA is Tom's," Salomon said. "The judge unilaterally said, 'We don't care about that. You have no rights.'"

Vieira asked if there is a legal precedent for that claim, to which Salomon replied, “There will be one now.”\*

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*Should the father have any rights to the child in this case? Is Florida law correct in giving the surrogate the right to decide to keep the child up until 48 hours after the birth, even if she had signed a surrogacy contract? In determining the custody of a child, should who gestates it carry more weight than genetic links to it (that is, where the egg and sperm come from)? Should genetic or gestational links carry more weight than the ability to properly care for the child? Explain your answers.*

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\*Mike Celizic, “Couple Vows to Fight Surrogate Who Kept Baby,” *MSNBC.com*, October 23, 2007, <http://www.msnbc.msn.com/id/21435600/>.

### CASE 3

#### Cloning to Bring Back a Child

(MSNBC)—Katherine Gordon of Great Falls, Mont., whose 17-year-old daughter, Emily, was killed by a drunk driver five years ago, says she became obsessed with bringing a part of her daughter back in some way. Spurred on by the news of [the birth of the cloned sheep Dolly], she had her daughter’s cells frozen and stored for possible future cloning. “I started to spend all day researching on the Internet and contacting biologists,” she recalls. “I really went off the deep end.”

Now she’s resigned herself to the fact that the technology probably won’t be available in time to help her bear Emily’s clone, as she’s now 42. But she says that if it were possible in the next couple of years, she would do it.

“I know it wouldn’t be Emily—it would be her twin sister,” she says. “Emily was perfect—she was beautiful and smart, too, and most of that is genetic. Her predisposition was real kind. Even if the clone had some of her negative qualities that would be fine, too. I don’t know what the new person would be like, but she would have a good start in life.”....

Dr. William Hurlbut, a bioethicist at Stanford University and member of President Bush’s Council on Bioethics, urges parents to look at cloning from the perspective of the child. “I don’t think anyone should have to live their life in the footsteps of someone else,” he says. “The baby may be held up in comparison with some idealized image of the lost child. It seems morbid and insensitive to the love of the child.”

But Gregory Pence, a pro-cloning bioethicist at the University of Alabama, Birmingham, and author of “Who’s Afraid of Human Cloning?” defends that choice. “People have replacement children all the time. It’s as good a reason as any to have a child sexually. Why are people creating children anyway? To create a sense of family, someone to take care of them when they’re older. There are many self-centered reasons people have kids, parents just normally don’t have to [spell] out these reasons.”\*

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*If Katharine Gordon could give birth to a clone of her deceased daughter, should she? Is grief over the loss of a child a morally legitimate reason for wanting to clone him or her? Is there a morally relevant difference between sexually producing a child to replace a lost one and producing a child through cloning for the same reason? Explain your answers.*

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## READINGS

### IVF: The Simple Case

PETER SINGER

Singer addresses seven moral objections that have been lodged against in vitro fertilization (IVF), focusing on its use in the "simple case" ("a married, infertile couple use an egg taken from the wife and sperm taken from the husband, and all embryos created are inserted into the womb of the wife"). The objections include the charges that IVF is unnatural, that it is risky for the offspring, and that it separates the procreative and conjugal aspects of marriage and so damages the marital relationship. He concludes that all the objections are weak and that "[t]hey should not count against going ahead with IVF when it is the best way of overcoming infertility" and when the infertile couple decides against adoption.

The so-called simple case of IVF is that in which a married, infertile couple use an egg taken from the wife and sperm taken from the husband, and all embryos created are inserted into the womb of the wife. This case allows us to consider the ethics of IVF in itself, without the complications of the many other issues that can arise in different circumstances. Then we can go on to look at these complications separately.

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From *Ethical Issues at the Outset of Life* (1987), edited by William B. Weil, Jr., and Martin Benjamin, pp. 44–49.  
Based on work done with Deane Wells and previously published in *Making Babies* (revised edition, 1985).  
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### The Technique

The technique itself is now well known and is fast becoming a routine part of infertility treatment in many countries. The infertile woman is given a hormone treatment to induce her ovaries to produce more than one egg in her next cycle. Her hormone levels are carefully monitored to detect the precise moment at which the eggs are ripening. At this time the eggs are removed. This is usually done by laparoscopy, a minor operation in which a fine tube is inserted into the woman's abdomen and the egg is sucked out up the tube. A laparoscope, a kind of periscope illuminated by fiber optics, is also inserted into the abdomen so that the surgeon can locate the place where the ripe egg is to be found. Instead of laparoscopy, some IVF teams are now using ultrasound techniques, which eliminate the need for a general anesthetic.

Once the eggs have been collected they are placed in culture in small glass dishes known as Petri dishes, not in test tubes despite the popular label of "test-tube babies." Sperm is then obtained from the male partner by means of masturbation and placed with the egg. Fertilization follows, in at least 80 percent of the ripe eggs. The resulting embryos are allowed to cleave once or twice and are usually transferred to the woman some 48 to 72 hours after fertilization. The actual transfer is done via the vagina and is a simple procedure.

It is after the transfer, when the embryo is back in the uterus and beyond the scrutiny of medical science, that things are most likely to go wrong. Even with the most experienced IVF teams, the majority of embryos transferred fail to implant in the uterus. One pregnancy for every five transfers is currently considered to be a good working average for a competent IVF team. Many of the newer teams fail to achieve anything like this rate. Nevertheless, there are so many units around the world now practicing IVF that thousands of babies have been produced as a result of the technique. IVF has ceased to be experimental and is now a routine, if still "last resort" method of treating some forms of infertility.

### **Objections to the Simple Case**

There is some opposition to IVF even in the simple case. The most frequently heard objections are as follows:

1. IVF is unnatural.
2. IVF is risky for the offspring.
3. IVF separates the procreative and the conjugal aspects of marriage and so damages the marital relationship.
4. IVF is illicit because it involves masturbation.
5. Adoption is a better solution to the problem of childlessness.
6. IVF is an expensive luxury and the resources would be better spent elsewhere.
7. IVF allows increased male control over reproduction and hence threatens the status of women in the community.

We can deal swiftly with the first four of these objections. If we were to reject medical advances on

the grounds that they are "unnatural" we would be rejecting modern medicine as a whole, for the very purpose of the medical enterprise is to resist the ravages of nature which would otherwise shorten our lives and make them much less pleasant. If anything is in accordance with the nature of our species, it is the application of our intelligence to overcome adverse situations in which we find ourselves. The application of IVF to infertile couples is a classic example of this application of human intelligence.

The claim that IVF is risky for the offspring is one that was argued with great force before IVF became a widely used technique. It is sufficient to note that the results of IVF so far have happily refuted these fears. The most recent Australian figures, for example, based on 934 births, indicate that the rate of abnormality was 2.7 percent, which is very close to the national average of 1.5 percent. When we take into account the greater average age of women seeking IVF, as compared with the child-bearing population as a whole, it does not seem that the *in vitro* technique itself adds to the risk of an abnormal offspring. This view is reinforced by the fact that the abnormalities were all ones that arise with the ordinary method of reproduction; there have been no new "monsters" produced by IVF.<sup>1</sup> Perhaps we still cannot claim with statistical certainty that the risk of defect is no higher with IVF than with the more common method of conception; but if the risk is higher at all, it would appear to be only very slightly higher, and still within limits which may be considered acceptable.

The third and fourth objections have been urged by spokesmen for certain religious groups, but they are difficult to defend outside the confines of particular religions. Few infertile couples will take seriously the view that their marital relationship will be damaged if they use the technique which offers them the best chance of having their own child. It is in any case extraordinarily paternalistic for anyone else to tell a couple that they should not use IVF because it will harm their marriage. That, surely, is for them to decide.

The objection to masturbation comes from a similar source and can be even more swiftly dismissed. Religious prohibitions on masturbation

are taboos from past times which even religious spokesmen are beginning to consider outdated. Moreover, even if one could defend a prohibition on masturbation for sexual pleasure—perhaps on the (very tenuous) ground that sexual activity is wrong unless it is directed either toward procreation or toward the strengthening of the bond between marriage partners—it would be absurd to extend a prohibition with that kind of rationale to a case in which masturbation is being used in the context of a marriage and precisely in order to make reproduction possible. (The fact that some religions do persist in regarding masturbation as wrong, even in these circumstances, is indicative of the folly of an ethical system based on absolute rules, irrespective of the circumstances in which those rules are being applied, or the consequences of their application.)

### **Overpopulation and the Allocation of Resources**

The next two objections, however, deserve more careful consideration. In an overpopulated world in which there are so many children who cannot be properly fed and cared for, there is something incongruous about using all the ingenuity of modern medicine to create more children. And similarly, when there are so many deaths caused by preventable diseases, is there not something wrong with the priorities which lead us to develop expensive techniques for overcoming the relatively less serious problem of infertility?

These objections are sound to the following extent: in an ideal world we would find loving families for unwanted children before we created additional children; and in an ideal world we would clear up all the preventable ill-health and malnutrition-related diseases before we went on to tackle the problem of infertility. But is it appropriate to ask, of IVF alone, whether it can stand the test of measurement against what we would do in an ideal world? In an ideal world, none of us would consume more than our fair share of resources. We would not drive expensive cars while others die for the lack of drugs costing a few cents. We would not eat a diet rich in wastefully produced animal products while others cannot get enough to nourish their bodies.

We cannot demand more of infertile couples than we are ready to demand of ourselves. If fertile couples are free to have large families of their own, rather than adopt destitute children from overseas, infertile couples must also be free to do what they can to have their own families. In both cases, overseas adoption, or perhaps the adoption of local children who are unwanted because of some impairment, should be considered; but if we are not going to make this compulsory in the former case, it should not be made compulsory in the latter.

There is a further question: to what extent do infertile couples have a right to assistance from community medical resources? Again, however, we must not single out IVF for harsher treatment than we give to other medical techniques. If tubal surgery is available and covered by one's health insurance, or is offered as part of a national health scheme, then why should IVF be treated any differently? And if infertile couples can get free or subsidized psychiatry to help them overcome the psychological problems of infertility, there is something absurd about denying them free or subsidized treatment which could overcome the root of the problem, rather than the symptoms. By today's standards, after all, IVF is not an inordinately expensive medical technique; and there is no country, as far as I know, which limits its provision of free or subsidized health care to those cases in which the patient's life is in danger. Once we extend medical care to cover cases of injury, incapacity, and psychological distress, IVF has a strong claim to be included among the range of free or subsidized treatments available.

### **The Effect on Women**

The final objection is one that has come from some feminists. In a recently published collection of essays by women titled *Test-Tube Women: What Future for Motherhood?*, several contributors are suspicious of the new reproductive technology. None is more hostile than Robyn Rowland, an Australian sociologist, who writes:

Ultimately the new technology will be used for the benefit of men and to the detriment of women. Although technology itself is not always a negative

development, the real question has always been—who controls it? Biological technology is in the hands of men.<sup>2</sup>

And Rowland concludes with a warning as dire as any uttered by the most conservative opponents of IVF:

What may be happening is the last battle in the long war of men against women. Women's position is most precarious . . . we may find ourselves without a product of any kind with which to bargain. For the history of "mankind" women have been seen in terms of their value as childbearers. We have to ask, if that last power is taken and controlled by men, what role is envisaged for women in the new world? Will women become obsolete? Will we be fighting to retain or reclaim the right to bear children—has patriarchy conned us once again? I urge you sisters to be vigilant.

I can see little basis for such claims. For a start, women have figured quite prominently in the leading IVF teams in Britain, Australia, and the United States: Jean Purdy was an early colleague of Edwards and Steptoe in the research that led to the birth of Louise Brown; Linda Mohr has directed the development of embryo freezing at the Queen Victoria Medical Centre in Melbourne; and in the United States Georgeanna Jones and Joyce Vargyas have played leading roles in the groundbreaking clinics in Norfolk, Virginia, and at the University of Southern California, respectively. It seems odd for a feminist to neglect the contributions these women have made.

Even if one were to grant, however, that the technology remains predominantly in male hands, it has to be remembered that it was developed in response to the needs of infertile couples. From interviews I have conducted and meetings I have attended, my impression is that while both partners are often very concerned about their childlessness, in those cases in which one partner is more distressed than the other by this situation, that partner is usually the woman. Feminists usually accept that this is so, attributing it to the power or social conditioning in a patriarchal society; but the origin of the strong female desire for children is not really what

is in question here. The question is: in what sense is the new technology an instrument of male domination over women? If it is true that the technology was developed at least as much in response to the needs of women as in response to the needs of men, then it is hard to see why a feminist should condemn it.

It might be objected that whatever the origins of IVF and no matter how benign it may be when used to help infertile couples, the further development of techniques such as ectogenesis—the growth of the embryo from conception totally outside the body, in an artificial womb—will reduce the status of women. Again, it is not easy to see why this should be so. Ectogenesis will, if it is ever successful, provide a choice for women. Shulamith Firestone argued several years ago in her influential feminist work *The Dialectic of Sex*<sup>3</sup> that this choice will remove the fundamental biological barrier to complete equality. Hence Firestone welcomed the prospect of ectogenesis and condemned the low priority given by our male-dominated society to research in this area.

Firestone's view is surely more in line with the drive to sexual equality than the position taken by Rowland. If we argue that to break the link between women and childbearing would be to undermine the status of women in our society, what are we saying about the ability of women to obtain true equality in other spheres of life? I am not so pessimistic about the abilities of women to achieve equality with men across the broad range of human endeavor. For that reason I think women will be helped, rather than harmed, by the development of a technology which makes it possible for them to have children without being pregnant. As Nancy Breeze, a very differently inclined contributor to the same collection of essays, puts it:

Two thousand years of morning sickness and stretch marks have not resulted in liberation for women or children. If you should run into a Petri dish, it could turn out to be your best friend. So rock it; don't knock it!<sup>14</sup>

So to sum up this discussion of the ethics of the simple case of IVF: the ethical objections urged

against IVF under these conditions are not strong. They should not count against going ahead with IVF when it is the best way of overcoming infertility and when the infertile couple are not prepared to consider adoption as a means of overcoming their problems. There is, admittedly, a serious question about how much of the national health budget should be allocated to this area. But then, there are serious questions about the allocation of resources in other areas of medicine as well.

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## The Presumptive Primacy of Procreative Liberty

JOHN A. ROBERTSON

Robertson argues for the fundamental freedom to reproduce or not to reproduce. This “procreative liberty,” he says, equates to the right to make a reproductive choice without interference from others. The right not to procreate includes the freedom to use various methods to avoid begetting or bearing offspring, including abortion. The right to procreate includes the right to use “noncoital technologies” such as IVF. Robertson contends that procreative liberty can be overridden—but only by very weighty considerations.

Procreative liberty has wide appeal but its scope has never been fully elaborated and often is contested. The concept has several meanings that must be clarified if it is to serve as a reliable guide for moral debate and public policy regarding new reproductive technologies.

### What Is Procreative Liberty?

At the most general level, procreative liberty is the freedom either to have children or to avoid having them. Although often expressed or realized in the context of a couple, it is first and foremost an individual interest. It is to be distinguished from freedom in the ancillary aspects of reproduction, such

as liberty in the conduct of pregnancy or choice of place or mode of childbirth.

The concept of reproduction, however, has a certain ambiguity contained within it. In a strict sense, reproduction is always genetic. It occurs by provision of one's gametes to a new person, and thus includes having or producing offspring. While female reproduction has traditionally included gestation, in vitro fertilization (IVF) now allows female genetic and gestational reproduction to be separated. Thus a woman who has provided the egg that is carried by another has reproduced, even if she has not gestated and does not rear resulting offspring. Because of the close link between gestation and female reproduction, a woman who gestates the embryo of another may also reasonably be viewed as having a reproductive experience, even though she does not reproduce genetically.

In any case, reproduction in the genetic or gestational sense is to be distinguished from child rearing. Although reproduction is highly valued in part

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because it usually leads to child rearing, one can produce offspring without rearing them and rear children without reproduction. One who rears an adopted child has not reproduced, while one who has genetic progeny but does not rear them has.

In this [excerpt] the terms “procreative liberty” and “reproductive freedom” will mean the freedom to reproduce or not to reproduce in the genetic sense, which may also include rearing or not, as intended by the parties. Those terms will also include female gestation whether or not there is a genetic connection to the resulting child.

Often the reproduction at issue will be important because it is intended to lead to child rearing. In cases where rearing is not intended, the value to be assigned to reproduction *tout court* will have to be determined. Similarly, when there is rearing without genetic or gestational involvement, the value of nonreproductive child rearing will also have to be assessed. In both cases the value assigned may depend on the proximity to reproduction where rearing is intended.

Two further qualifications on the meaning of procreative liberty should be noted. One is that “liberty” as used in procreative liberty is a negative right. It means that a person violates no moral duty in making a procreative choice, and that other persons have a duty not to interfere with that choice. However, the negative right to procreate or not does not imply the duty of others to provide the resources or services necessary to exercise one’s procreative liberty despite plausible moral arguments for governmental assistance.

As a matter of constitutional law, procreative liberty is a negative right against state interference with choices to procreate or to avoid procreation. It is not a right against private interference, though other laws might provide that protection. Nor is it a positive right to have the state or particular persons provide the means or resources necessary to have or avoid having children. The exercise of procreative liberty may be severely constrained by social and economic circumstances. Access to medical care, child care, employment, housing, and other services may significantly affect whether one is able to exercise procreative liberty. However, the state presently has no constitutional obligation to provide

those services. Whether the state should alleviate those conditions is a separate issue of social justice.

The second qualification is that not everything that occurs in and around procreation falls within liberty interests that are distinctively procreative. Thus whether the father may be present during childbirth, whether midwives may assist birth, or whether childbirth may occur at home rather than in a hospital may be important for the parties involved, but they do not implicate the freedom to reproduce (unless one could show that the place or mode of birth would determine whether birth occurs at all). Similarly, questions about a pregnant woman’s drug use or other conduct during pregnancy . . . implicates liberty in the course of reproduction but not procreative liberty in the basic sense. . . .

Procreative liberty should enjoy presumptive primacy when conflicts about its exercise arise because control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one’s life. For example, deprivation of the ability to avoid reproduction determines one’s self-definition in the most basic sense. It affects women’s bodies in a direct and substantial way. It also centrally affects one’s psychological and social identity and one’s social and moral responsibilities. The resulting burdens are especially onerous for women, but they affect men in significant ways as well.

On the other hand, being deprived of the ability to reproduce prevents one from an experience that is central to individual identity and meaning in life. Although the desire to reproduce is in part socially constructed, at the most basic level transmission of one’s genes through reproduction is an animal or species urge closely linked to the sex drive. In connecting us with nature and future generations, reproduction gives solace in the face of death. As Shakespeare noted, “nothing ‘gainst Time’s scythe can make defense/save breed.” For many people “breed”—reproduction and the parenting that usually accompanies it—is a central part of their life plan, and the most satisfying and meaningful experience they have. It also has primary importance as an expression of a couple’s love or unity. For many persons, reproduction also has religious significance and is experienced as a “gift from God.”

Its denial—through infertility or governmental restriction—is experienced as a great loss, even if one has already had children or will have little or no rearing role with them.

Decisions to have or to avoid having children are thus personal decisions of great import that determine the shape and meaning of one's life. The person directly involved is best situated to determine whether that meaning should or should not occur. An ethic of personal autonomy as well as ethics of community or family should then recognize a presumption in favour of most personal reproductive choices. Such a presumption does not mean that reproductive choices are without consequence to others, nor that they should never be limited. Rather, it means that those who would limit procreative choice have the burden of showing that the reproductive actions at issue would create such substantial harm that they could justifiably be limited. Of course, what counts as the "substantial harm" that justifies interference with procreative choice may often be contested, as the discussion of reproductive technologies in this book will show.

A closely related reason for protecting reproductive choice is to avoid the highly intrusive measures that governmental control of reproduction usually entails. State interference with reproductive choice may extend beyond exhortation and penalties to gestapo and police state tactics. Margaret Atwood's powerful futuristic novel *The Handmaid's Tale* expresses this danger by creating a world where fertile women are forcibly impregnated by the ruling powers and their pregnancies monitored to replenish a decimated population. . . .

### **Two Types of Procreative Liberty**

To see how values of procreative liberty affect the ethical and public policy evaluation of new reproductive technologies, we must determine whether the interests that underlie the high value accorded procreative liberty are implicated in their use. This is not a simple task because procreative liberty is not unitary, but consists of strands of varying interests in the conception and gestation of offspring. The different strands implicate different interests, have different legal and constitutional status, and are differently affected by technology.

An essential distinction is between the freedom to avoid reproduction and the freedom to reproduce. When people talk of reproductive rights, they usually have one or the other aspect in mind. Because different interests and justifications underlie each and countervailing interests for limiting each aspect vary, recognition of one aspect does not necessarily mean that the other will also be respected; nor does limitation of one mean that the other can also be denied.

However, there is a mirroring or reciprocal relationship here. Denial of one type of reproductive liberty necessarily implicates the other. If a woman is not able to avoid reproduction through contraception or abortion, she may end up reproducing, with all the burdens that unwanted reproduction entails. Similarly, if one is denied the liberty to reproduce through forcible sterilization, one is forced to avoid reproduction, thus experiencing the loss that absence of progeny brings. By extending reproductive options, new reproductive technologies present challenges to both aspects of procreative choice.

### **Avoiding Reproduction: The Liberty Not to Reproduce**

One sense in which people commonly understand procreative liberty is as the freedom to avoid reproduction—to avoid begetting or bearing offspring and the rearing demands they make. Procreative liberty in this sense could involve several different choices, because decisions to avoid procreation arise at several different stages. A decision not to procreate could occur prior to conception through sexual abstinence, contraceptive use, or refusal to seek treatment for infertility. At this stage, the main issues concern freedom to refrain from sexual intercourse, the freedom to use contraceptives, and the freedom to withhold gametes for use in noncoital conception. Countervailing interests concern societal interests in increasing population, a partner's interest in sexual intimacy and progeny, and moral views about the unity of sex and reproduction.

Once pregnancy has occurred, reproduction can be avoided only by termination of pregnancy. Procreative freedom here would involve the freedom to abort the pregnancy. Competing interests are

protection of embryos and fetuses and respect for human life generally, the most heated issue of reproductive rights. They may also include moral or social beliefs about the connectedness of sex and reproduction, or views about a woman's reproductive and work roles.

Once a child is born, procreation has occurred, and the procreators ordinarily have parenting obligations. Freeing oneself from rearing obligations is not strictly speaking a matter of procreative liberty, though it is an important personal interest. Even if parents relinquish the child for adoption, the psychological reality that one has reproduced remains. Opposing interests at this stage involve the need to provide parenting, nurturing, and financial support to offspring. The right to be free of those obligations, as well as the right to assume them after birth occurs, is not directly addressed in this book except to the extent that those rights affect reproductive decisions....

### **The Freedom to Procreate**

In addition to freedom to avoid procreation, procreative liberty also includes the freedom to procreate—the freedom to beget and bear children if one chooses. As with avoiding reproduction, the right to reproduce is a negative right against public or private interference, not a positive right to the services or the resources needed to reproduce. It is an important freedom that is widely accepted as a basic, human right. But its various components and dimensions have never been fully analyzed, as technologies of conception and selection now force us to do.

As with avoiding reproduction, the freedom to procreate involves the freedom to engage in a series of actions that eventuate in reproduction and usually in child rearing. One must be free to marry or find a willing partner, engage in sexual intercourse, achieve conception and pregnancy, carry a pregnancy to term, and rear offspring. Social and natural barriers to reproduction would involve the unavailability of willing or suitable partners, impotence or infertility, and lack of medical and child-care resources. State barriers to marriage, to sexual intercourse, to conception, to infertility treatment, to carrying pregnancies to term, and to certain child-rearing arrangements would also limit the

freedom to procreate. The most commonly asserted reasons for limiting coital reproduction are overpopulation, unfitness of parents, harm to offspring, and costs to the state or others. Technologies that treat infertility raise additional concerns that are discussed below.

The moral right to reproduce is respected because of the centrality of reproduction to personal identity, meaning, and dignity. This importance makes the liberty to procreate an important moral right, both for an ethic of individual autonomy and for ethics of community or family that view the purpose of marriage and sexual union as the reproduction and rearing of offspring. Because of this importance, the right to reproduce is widely recognized as a *prima facie* moral right that cannot be limited except for very good reason.

Recognition of the primacy of procreation does not mean that all reproduction is morally blameless, much less that reproduction is always responsible and praiseworthy and can never be limited. However, the presumptive primacy of procreative liberty sets a very high standard for limiting those rights, tilting the balance in favor of reproducing but not totally determining its acceptability. A two-step process of analysis is envisaged here. The first question is whether a distinctively procreative interest is involved. If so, the question then is whether the harm threatened by reproduction satisfies the strict standard for overriding this liberty interest....

An entirely different set of concerns arises with noncoital reproductive techniques. Charges that noncoital reproduction is unethical or irresponsible arise because of its expense, its highly technological character, its decomposition of parenthood into genetic, gestational, and social components, and its potential effects on women and offspring. To assess whether these effects justify moral condemnation or public limitation, we must first determine whether noncoital reproduction implicates important aspects of procreative liberty.

### **The Right to Reproduce and Noncoital Technology**

If the moral right to reproduce presumptively protects coital reproduction, then it should protect

noncoital reproduction as well. The moral right of the coitally infertile to reproduce is based on the same desire for offspring that the coitally fertile have. They too wish to replicate themselves, transmit genes, gestate, and rear children biologically related to them. Their infertility should no more disqualify them from reproductive experiences than physical disability should disqualify persons from walking with mechanical assistance. The unique risks posed by noncoital reproduction may provide independent justifications for limiting its use, but neither the noncoital nature of the means used nor the infertility of their beneficiaries means that the presumptively protected moral interest in reproduction is not present.

A major question about this position, however, is whether the noncoital or collaborative nature of the means used truly implicates reproductive interests. For example, what if only one aspect of reproduction—genetic transfer, gestation, or rearing—occurs, as happens with gamete donors or surrogates who play no rearing role? Is a person's procreative liberty substantially implicated in such partial reproductive roles? The answer will depend on the value attributed to the particular collaborative contribution and on whether the collaborative enterprise is viewed from the donor's or recipient's perspective.

Gamete donors and surrogates are clearly reproducing even though they have no intention to rear. Because reproduction *tout court* may seem less important than reproduction with intent to rear, the donor's reproductive interest may appear less important. However, more experience with these practices is needed to determine the inherent value of "partial" reproductive experiences to donors and surrogates. Experience may show that it is independently meaningful, regardless of their contact with offspring. If not, then countervailing interests would more easily override their right to enter these roles.

Viewed from the recipient's perspective, however, the donor or surrogate's reproduction *tout court* does not lessen the reproductive importance of her contribution. A woman who receives an egg or embryo donation has no genetic connection with offspring but has a gestational relation of great personal significance. In addition, gamete donors and

surrogates enable one or both rearing partners to have a biological relation with offspring. If one of them has no biological connection at all, they will still have a strong interest in rearing their partner's biologic offspring. Whether viewed singly through the eyes of the partner who is reproducing, or jointly as an endeavor of a couple seeking to rear children who are biologically related to at least one of the two, a significant reproductive interest is at stake. If so, noncoital, collaborative treatments for infertility should be respected to the same extent as coital reproduction is.

Questions about the core meaning of reproduction will also arise in the temporal dislocations that cryopreservation of sperm and embryos make possible. For example, embryo freezing allows siblings to be conceived at the same time, but born years apart and to different gestational mothers. Twins could be created by splitting one embryo into two. If one half is frozen for later use, identical twins could be born at widely different times. Sperm, egg, and embryo freezing also make posthumous reproduction possible.

Such temporally dislocative practices clearly implicate core reproductive interests when the ultimate recipient has no alternative means of reproduction. However, if the procreative interests of the recipient couple are not directly implicated, we must ask whether those whose gametes are used have an independent procreative interest, as might occur if they directed that gametes or embryos be thawed after their death for purposes of posthumous reproduction. In that case the question is whether the expectancy of posthumous reproduction is so central to an individual's procreative identity or life-plan that it should receive the same respect that one's reproduction when alive receives. The answer to such a question will be important in devising policy for storing and posthumously disposing of gametes and embryos. The answer will also affect inheritance questions and have implications for management of pregnant women who are irreversibly comatose or brain dead.

The problem of determining whether technology implicates a major reproductive interest also arises with technologies that select offspring characteristics. Some degree of quality control would

seem logically to fall within the realm of procreative liberty. For many couples the decision whether to procreate depends on the ability to have healthy children. Without some guarantee or protection against the risk of handicapped children, they might not reproduce at all.

Thus viewed, quality control devices become part of the liberty interest in procreating or in avoiding procreation, and arguably should receive the same degree of protection. If so, genetic screening and selective abortion, as well as the right to select a mate or a source for donated eggs, sperm, or embryos should be protected as part of procreative liberty. The same arguments would apply to positive interventions to cure disease at the fetal or embryo stage. However, futuristic practices such as nontherapeutic enhancement, cloning, or intentional diminishment of offspring characteristics may so deviate from the core interests that make reproduction meaningful as to fall outside the protective canopy of procreative liberty.

Finally, technology will present questions of whether one may use one's reproductive capacity to produce gametes, embryos, and fetuses for nonreproductive uses in research or therapy. Here the purpose is not to have children to rear, but to get material for research or transplant. Are such uses of reproductive capacity tied closely enough to the values and interests that underlie procreative freedom to warrant similar respect? Even if procreative choice is not directly involved, other liberties may protect the activity.

#### **Are Noncoital Technologies Unethical?**

If this analysis is accepted, then procreative liberty would include the right to use noncoital and other technologies to form a family and shape the characteristics of offspring. Neither infertility nor the fact that one will only partially reproduce eliminates the existence of a *prima facie* reproductive experience for someone. However, judgments about the proximity of these partial reproductive experiences to the core meanings of reproduction will be required in balancing those claims against competing moral concerns.

Judgment about the reproductive importance of noncoital technologies is crucial because many

people have serious ethical reservations about them, and are more than willing to restrict their use. The concerns here are not the fears of overpopulation, parental unfitness, and societal costs that arise with allegedly irresponsible coital reproduction. Instead, they include reduction of demand for hard-to-adopt children, the coercive or exploitative bargains that will be offered to poor women, the commodification of both children and reproductive collaborators, the objectification of women as reproductive vessels, and the undermining of the nuclear family.

However, often the harms feared are deontological in character. In some cases they stem from a religious or moral conception of the unity of sex and reproduction or the definition of family. Such a view characterizes the Vatican's strong opposition to IVF, donor sperm, and other noncoital and collaborative techniques. Other deontological concerns derive from a particular conception of the proper reproductive role of women. Many persons, for example, oppose paid surrogate motherhood because of a judgment about the wrongness of a woman's willingness to sever the mother-child bond for the sake of money. They also insist that the gestational mother is always morally entitled to rear, despite her preconception promise to the contrary. Closely related are dignitary objections to allowing any reproductive factors to be purchased, or to having offspring selected on the basis of their genes.

Finally, there is a broader concern that noncoital reproduction will undermine the deeper community interest in having a clear social framework to define boundaries of families, sexuality, and reproduction. The traditional family provides a container for the narcissism and irrationality that often drives human reproduction. This container assures commitments to the identifications and taboos that protect children from various types of abuse. The technical ability to disaggregate and recombine genetic, gestational, and rearing connections and to control the genes of offspring may thus undermine essential protections for offspring, couples, families, and society.

These criticisms are powerful ones that explain much of the ambivalence that surrounds the use of certain reproductive technologies. They call into

question the wisdom of individual decisions to use them, and the willingness of society to promote or facilitate their use. Unless one is operating out of a specific religious or deontological ethic, however, they do not show that all individual uses of these techniques are immoral, much less that public policy should restrict or discourage their use....

### **Resolving Disputes over Procreative Liberty**

As this brief survey shows, new reproductive technologies will generate ethical and legal disputes about the meaning and scope of procreative liberty. Because procreative liberty has never been fully elaborated, the importance of procreative choice in many novel settings will be a question of first impression. The ultimate decision reached will reflect the value assigned to the procreative interest at stake in light of the effects causing concern. In an important sense, the meaning of procreative liberty will be created or constituted for society in the process of resolving such disputes.

If procreative liberty is taken seriously, a strong presumption in favor of using technologies that centrally implicate reproductive interests should be recognized. Although procreative rights are not absolute, those who would limit procreative choice should have the burden of establishing substantial harm. This is the standard used in ethical and legal analyses of restrictions on traditional reproductive decisions. Because the same procreative goals are involved, the same standard of scrutiny should be used for assessing moral or governmental restrictions on novel reproductive techniques.

In arbitrating these disputes, one has to come to terms with the importance of procreative interests relative to other concerns. The precise procreative interest at stake must be identified and weighed against the core values of reproduction. As noted, this will raise novel and unique questions when the technology deviates from the model of two-person coital reproduction, or otherwise disaggregates or alters ordinary reproductive practices. However, if an important reproductive interest exists, then use of the technology should be presumptively permitted. Only substantial harm to tangible interests of others should then justify restriction.

In determining whether such harm exists, it will be necessary to distinguish between harms to individuals and harms to personal conceptions of morality, right order, or offense, discounted by their probability of occurrence. As previously noted, many objections to reproductive technology rest on differing views of what “proper” or “right” reproduction is aside from tangible effects on others. For example, concerns about the decomposition of parenthood through the use of donors and surrogates, about the temporal alteration of conception, gestation and birth, about the alienation or commercialization of gestational capacity, and about selection and control of offspring characteristics do not directly affect persons so much as they affect notions of right behavior. Disputes over early abortion and discard or manipulation of IVF-created embryos also exemplify this distinction, if we grant that the embryo/preivable fetus is not a person or entity with rights in itself.

At issue in these cases is the symbolic or constitutive meaning of actions regarding prenatal life, family, maternal gestation, and respect for persons over which people in a secular, pluralistic society often differ. A majoritarian view of “right” reproduction or “right” valuation of prenatal life, family, or the role of women should not suffice to restrict actions based on differing individual views of such preeminently personal issues. At a certain point, however, a practice such as cloning, enhancement, or intentional diminishment of offspring may be so far removed from even pluralistic notions of reproductive meaning that they leave the realm of protected reproductive choice. People may differ over where that point is, but it will not easily exclude most reproductive technologies of current interest.

To take procreative liberty seriously, then, is to allow it to have presumptive priority in an individual’s life. This will give persons directly involved the final say about use of a particular technology, unless tangible harm to the interests of others can be shown. Of course, people may differ over whether an important procreative interest is at stake or over how serious the harm posed from use of the reproductive technology is. Such a focused debate, however, is legitimate and ultimately essential in

developing ethical standards and public policy for use of new reproductive technologies.

### The Limits of Procreative Liberty

The emphasis on procreative liberty that informs this book provides a useful but by no means complete or final perspective on the technologies in question. Theological, social, psychological, economic, and feminist perspectives would emphasize different aspects of reproductive technology, and might be much less sanguine about potential benefits and risks. Such perspectives might also offer better guidance in how to use these technologies to protect offspring, respect women, and maintain other important values.

A strong rights perspective has other limitations as well. Recognition of procreative liberty, whether in traditional or in new technological settings, does not guarantee that people will achieve their reproductive goals, much less that they will be happy with what they do achieve. Nature may be recalcitrant to the latest technology. Individuals may lack

the will, the perseverance, or the resources to use effective technologies. Even if they do succeed, the results may be less satisfying than envisaged. In addition, many individual instances of procreative choice may cumulate into larger social changes that from our current vantage point seem highly undesirable. But these are the hazards and limitations of any scheme of individual rights.

Recognition of procreative liberty will protect the right of persons to use technology in pursuing their reproductive goals, but it will not eliminate the ambivalence that such technologies engender. Societal ambivalence about reproductive technology is recapitulated at the individual level, as individuals and couples struggle with whether to use the technologies in question. Thus recognition of procreative liberty will not eliminate the dilemmas of personal choice and responsibility that reproductive choice entails. The freedom to act does not mean that we will act wisely, yet denying that freedom may be even more unwise, for it denies individuals' respect in the most fundamental choices of their lives.

## Surrogate Mothering: Exploitation or Empowerment?

LAURA M. PURDY

Taking a consequentialist approach, Purdy asserts that in some cases the benefits of surrogate mothering may outweigh its costs and thus be morally permissible. Some feminists argue that the practice is necessarily wrong because it transfers the burden and risks of pregnancy from one woman to another, because it separates sex from reproduction, or because it separates reproduction from child-rearing. But Purdy finds these arguments unconvincing. She examines the claim that surrogacy is baby-selling and concludes that "selling babies" is not an accurate description of what happens in surrogacy. A better characterization is that the birth mother is "giving up her parental right to have a relationship with the child." Certainly in some circumstances, surrogate mothering can be rendered immoral by coercion of the surrogate or by unjust surrogacy contracts. "Fair and reasonable regulations," she says, "are essential to prevent exploitation of women."

## Introduction

“Pregnacy is barbaric” proclaimed Shulamith Firestone in the first heady days of the new women’s movement; she looked forward to the time when technology would free women from the oppression of biological reproduction. Yet as reproductive options multiply, some feminists are making common cause with conservatives for a ban on innovations. What is going on?

Firestone argued that nature oppresses women by leaving them holding the reproductive bag, while men are free of such burden; so long as this biological inequality holds, women will never be free (pp. 198–200). It is now commonplace to point out the naivety of her claim: it is not the biological difference per se that oppresses women, but its social significance. So we need not change biology, only attitudes and institutions.

This insight has helped us to see how to achieve a better life for women, but I wonder if it is the whole story. Has Firestone’s brave claim no lesson at all for us?

Her point was that being with child is uncomfortable and dangerous, and it can limit women’s lives. We have become more sensitive to the ways in which social arrangements can determine how much these difficulties affect us. However, even in feminist utopias, where sex or gender are considered morally irrelevant except where they may entail special needs, a few difficulties would remain. Infertility, for instance, would exist, as would the desire for a child in circumstances where pregnancy is impossible or undesirable.

At present, the problem of infertility is generating a whole series of responses and solutions. Among them are high-tech procedures like IVF, and social arrangements like surrogate motherhood. Both these techniques are also provoking a storm of concern and protest. As each raises a distinctive set of issues, they need to be dealt with separately, and I shall here consider only surrogate motherhood.

One might argue that no feminist paradise would need any practice such as this. As Susan Sherwin argues, it could not countenance “the capitalism, racism, sexism, and elitism of our culture [that] have combined to create a set of attitudes

which views children as commodities whose value is derived from their possession of parental chromosomes.”<sup>2</sup> Nor will society define women’s fulfilment as only in terms of their relationship to genetically-related children. No longer will children be needed as men’s heirs or women’s livelihood.

We will, on the contrary, desire relationships with children for the right reasons: the urge to nurture, teach and be close to them. No longer will we be driven by narcissistic wishes for clones or immortality to seek genetic offspring no matter what the cost. Indeed, we will have recognized that children are the promise and responsibility of the whole human community. And child-rearing practices will reflect these facts, including at least a more diffuse family life that allows children to have significant relationships with others. Perhaps child-rearing will be communal.

This radically different world is hard to picture realistically, even by those like myself who—I think—most ardently wish for it. The doubts I feel are fanned by the visions of so-called cultural feminists who glorify traditionally feminine values. Family life can be suffocating, distorting, even deadly.<sup>3</sup> Yet there is a special closeness that arises from being a child’s primary caretaker, just as there can be a special thrill in witnessing the unfolding of biologically-driven traits in that child. These pleasures justify risking neither the health of the child<sup>4</sup> nor that of the mother; nobody’s general well-being should be sacrificed to them, nor do they warrant high social investment. However, they are things that, other things being equal, it would be desirable to preserve so long as people continue to have anything like their current values. If this is so, then evaluating the morality of practices that open up new ways of creating children is worthwhile.<sup>5</sup>

## Moral or Immoral?

What is surrogate mothering exactly? Physically, its essential features are as follows: a woman is inseminated with the sperm of a man to whom she is not married. When the baby is born she relinquishes her claim to it in favour of another, usually the man from whom the sperm was obtained. As currently practiced, she provides the egg, so her biological

input is at least equal to that of the man.<sup>6</sup> Surrogate mothering may not therefore be the best term for what she is doing.

By doing these things she also acts socially—to take on the burden and risk of pregnancy for another, and to separate sex and reproduction, reproduction and child-rearing, and reproduction and marriage. If she takes money for the transaction (apart from payment of medical bills), she may even be considered to be selling a baby.

The bare physical facts would not warrant the welter of accusation and counter-accusation that surrounds the practice.<sup>7</sup> It is the social aspects that have engendered the acrimony about exploitation, destruction of the family, and baby-selling. So far we have reached no consensus about the practice's effect on women or its overall morality.

I believe that the appropriate moral framework for addressing questions about the social aspects of contracted pregnancy is consequentialist.<sup>8</sup> This framework requires us to attempt to separate those consequences that invariably accompany a given act from those that accompany it only in particular circumstances. Doing this compels us to consider whether a practice's necessary features lead to unavoidable overridingly bad consequences. It also demands that we look at how different circumstances are likely to affect the outcome. Thus a practice which is moral in a feminist society may well be immoral in a sexist one. This distinction allows us to tailor morality to different conditions for optimum results without thereby incurring the charge of malignant relativism.

Before examining arguments against the practice of contracted pregnancy, let us take note of why people might favour it. First, as noted before, alleviating infertility can create much happiness. Secondly, there are often good reasons to consider transferring burden and risk from one individual to another. Pregnancy may be a serious burden or risk for one woman, whereas it is much less so for another. Some women love being pregnant, others hate it; pregnancy interferes with work for some, not for others; pregnancy also poses much higher levels of risk to health (or even life) for some than for others. Reducing burden and risk is a benefit not only for the woman involved, but also for the

resulting child. High-risk pregnancies create, among other things, serious risk of prematurity, one of the major sources of handicap in babies. Furthermore, we could prevent serious genetic diseases by allowing carriers to avoid pregnancy. A third benefit of "surrogate mothering" is that it makes possible the creation of non-traditional families. This can be a significant source of happiness to single women and gay couples.

All of the above presuppose that there is some advantage in making possible at least partially genetically-based relationships between parents and offspring. Although, as I have argued above, we might be better off without this desire, I doubt that we will soon be free of it. Therefore, if we can satisfy it at little cost, we should try to do so.

### **Is Surrogate Mothering Always Wrong?**

Despite the foregoing advantages, some feminists argue that the practice is *necessarily* wrong: it is wrong because it must betray women's and society's basic interests.<sup>9</sup>

What, if anything is wrong with the practice? Let us consider the first three acts I described earlier: transferring burden and risk, separating sex and reproduction, and separating reproduction and child-rearing. Separation of reproduction and marriage will not be dealt with here.

Is it wrong to take on the burden of pregnancy for another? Doing this is certainly supererogatory, for pregnancy can threaten comfort, health, even life. One might argue that women should not be allowed to take these risks, but that would be paternalistic. We do not forbid mountain-climbing or riding a motorcycle on these grounds. How could we then forbid a woman to undertake this particular risk?

Perhaps the central issue is the transfer of burden from one woman to another. However, we frequently do just that—much more often than we recognize. Anyone who has her house cleaned, her hair done, or her clothes dry-cleaned is engaging in this procedure;<sup>10</sup> so is anyone who depends on agriculture or public works such as bridges.<sup>11</sup> To the objection that in this case the bargain includes the risk to life and limb, as well as use of time and skills, the answer is that the other activities just cited entail

surprisingly elevated risk rates from exposure to toxic chemicals or dangerous machinery.<sup>12</sup>

Furthermore, it is not even true that contracted pregnancy merely shifts the health burden and risks associated with pregnancy from one woman to another. In some cases (infertility, for example) it makes the impossible possible; in others (for women with potentially high-risk pregnancies) the net risk is lowered.<sup>13</sup> As we saw, babies benefit, too, from better health and fewer handicaps. Better health and fewer handicaps in both babies and women also means that scarce resources can be made available for other needs, thus benefiting society in general.

I do think that there is, in addition, something suspect about all this new emphasis on risk. Awareness of risks inherent in even normal pregnancy constitutes progress: women have always been expected to forge ahead with child-bearing oblivious to risk. Furthermore, child-bearing has been thought to be something women owed to men or to society at large, regardless of their own feelings about a given—or any—pregnancy. When women had little say about these matters, we never heard about risk.<sup>14</sup> Why are we hearing about risk only now, now that women finally have some choices, some prospect of remuneration?<sup>15</sup> For that matter, why is our attention not drawn to the fact that surrogacy is one of the least risky approaches to non-traditional reproduction?<sup>16</sup>

Perhaps what is wrong about this kind of transfer is that it necessarily involves exploitation. Such exploitation may take the form of exploitation of women by men and exploitation of the rich by the poor. This possibility deserves serious consideration, and will be dealt with shortly.

Is there anything wrong with the proposed separation of sex and reproduction? Historically, this separation—in the form of contraception—has been beneficial to women and to society as a whole. Although there are those who judge the practice immoral, I do not think we need belabour the issue here.

It may be argued that not all types of separation are morally on a par. Contraception is permissible, because it spares women's health, promotes autonomy, strengthens family life, and helps make population growth manageable. But separation of sex

and reproduction apart from contraception is quite another kettle of fish: it exploits women, weakens family life, and may increase population. Are these claims true and relevant?

Starting with the last first, if we face a population problem, it would make sense to rethink overall population policy, not exploit the problems of the infertile.<sup>17</sup> If family strengthening is a major justification for contraception, we might point out that contracted pregnancy will in some cases do the same. Whether or not having children can save a failing marriage, it will certainly prevent a man who wants children from leaving a woman incapable of providing them. We may bewail his priorities, but if his wife is sufficiently eager for the relationship to continue it would again be paternalistic for us to forbid "surrogacy" in such circumstances. That "surrogacy" reduces rather than promotes women's autonomy may be true under some circumstances, but there are good grounds for thinking that it can also enhance autonomy. It also remains to be shown that the practice systematically burdens women, or one class of women. In principle, the availability of new choices can be expected to nourish rather than stunt women's lives, so long as they retain control over their bodies and lives. The claim that contracted pregnancy destroys women's individuality and constitutes alienated labour, as Christine Overall argues, depends not only on a problematic Marxist analysis, but on the assumption that other jobs available to women are seriously less alienating.<sup>18</sup>

Perhaps what is wrong here is that contracted pregnancy seems to be the other side of the coin of prostitution. Prostitution is sex without reproduction; "surrogacy" is reproduction without sex. But it is difficult to form a persuasive argument that goes beyond mere guilt by association. Strictly speaking, contracted pregnancy is not prostitution; a broad-based Marxist definition would include it, but also traditional marriage. I think that in the absence of further argument, the force of this accusation is primarily emotional.

Perhaps the dreaded feature contracted pregnancy shares with prostitution is that it is a lazy person's way of exploiting their own "natural resources." But I suspect that this idea reveals a

touchingly naive view of what it takes to be a successful prostitute, not to mention the effort involved in running an optimum pregnancy. Overall takes up this point by asserting that it

is not and cannot be merely one career choice among others. It is not a real alternative. It is implausible to suppose that fond parents would want it for their daughters. We are unlikely to set up training courses for surrogate mothers. Schools holding “career days” for their future graduates will surely not invite surrogate mothers to address the class on advantages of “vocation.” And surrogate motherhood does not seem to be the kind of thing one would put on one’s curriculum vitae. (p. 126)

But this seems to me to be a blatant *ad populum* argument.

Such an objection ought, in any case, to entail general condemnation of apparently effortless ways of life that involved any utilization of our distinctive characteristics.

We surely exploit our personal “natural resources” whenever we work. Ditchdiggers use their bodies, professors use their minds. Overall seems particularly to object to some types of “work”: contracted pregnancy “is no more a real job option than selling one’s blood or one’s gametes or one’s bodily organs can be real job options” (p. 126). But her discussion makes clear that her denial that such enterprises are “real” jobs is not based on any social arrangements that preclude earning a living wage doing these things, but rather on the moral judgement that they are wrong. They are wrong because they constitute serious “personal and bodily alienation.” Yet her arguments for such alienation are weak. She contends that women who work as “surrogates” are deprived of any expression of individuality (p. 126), are interchangeable (p. 127), and that they have no choice about whose sperm to harbour (p. 128). It is true that, given a reasonable environment (partly provided by the woman herself), bodies create babies without conscious effort. This fact, it seems to me, has no particular moral significance: many tasks can be accomplished in similar ways yet are not thought valueless.<sup>19</sup>

It is also usually true that women involved in contracted pregnancy are, in some sense, interchangeable. But the same is true, quite possibly

necessarily so, of most jobs. No one who has graded mounds of logic exams or introductory ethics essays could reasonably withhold their assent to this claim, even though college teaching is one of the most autonomous careers available. Even those of us lucky enough to teach upper-level courses that involve more expression of individual expertise and choice can be slotted into standardized job descriptions. Finally, it is just false that a woman can have no say about whose sperm she accepts: this could be guaranteed by proper regulation.

I wonder whether there is not some subtle devaluing of the physical by Overall. If so, then we are falling into the trap set by years of elitist equations of women, nature and inferiority.

What I think is really at issue here is the disposition of the fruit of contracted pregnancy: babies. However, it seems to be generally permissible to dispose of or barter what we produce with both our minds and our bodies—except for that which is created by our reproductive organs. So the position we are considering may just be a version of the claim that it is wrong to separate reproduction and child-rearing.

Why? It is true that women normally expect to become especially attached to the product of this particular kind of labour, and we generally regard such attachment as desirable. It seems to be essential for successfully rearing babies the usual way. But if they are to be reared by others who are able to form the appropriate attachment, then what is wrong if a surrogate mother fails to form it? It seems to me that the central question here is whether this “maternal instinct” really exists, and, if it does, whether suppressing it is always harmful.

Underlying these questions is the assumption that bonding with babies is “natural” and therefore “good.” Perhaps so: the evolutionary advantage of such a tendency would be clear. It would be simple-minded, however, to assume that our habits are biologically determined: our culture is permeated with pronatalist bias.<sup>20</sup> “Natural” or not, whether a tendency to such attachment is desirable could reasonably be judged to depend on circumstance. When infant mortality is high<sup>21</sup> or responsibility for child-rearing is shared by the community, it could do more harm than good. Beware the naturalistic fallacy!<sup>22</sup>

But surely there is something special about gestating a baby. That is, after all, the assumption behind the judgement that Mary Beth Whitehead, not William Stern, had a stronger claim to Baby M. The moral scoreboard seems clear: they both had the same genetic input, but she gestated the baby, and therefore has a better case for social parenthood.<sup>23</sup>

We need to be very careful here. Special rights have a way of being accompanied by special responsibilities: women's unique gestational relationship with babies may be taken as reason to confine them once more to the nursery. Furthermore, positing special rights entailed directly by biology flirts again with the naturalistic fallacy and undermines our capacity to adapt to changing situations and forge our destiny.<sup>24</sup>

Furthermore, we already except many varieties of such separation. We routinely engage in sending children to boarding school, foster parenting, day-care, and so forth; in the appropriate circumstances, these practices are clearly beneficial. Hence, any blanket condemnation of separating reproduction and child-rearing will not wash; additional argument is needed for particular classes of cases.

John Robertson points out that the arguments against separating reproduction and child-rearing used against contracted pregnancy are equally valid—but unused—with respect to adoption.<sup>25</sup> Others, such as Herbert Krimmel, reject this view by arguing that there is a big moral difference between giving away an already existing baby and deliberately creating one to give away. This remains to be shown, I think. It is also argued that as adoption outcomes are rather negative, we should be wary of extending any practice that shares its essential features. In fact, there seems to be amazingly little hard information about adoption outcomes. I wonder if the idea that they are bad results from media reports of offspring seeking their biological forebears. There is, in any case, reason to think that there are differences between the two practices such that the latter is likely to be more successful than the former.<sup>26</sup>

None of the social descriptions of surrogacy thus seem to clearly justify the outcry against the practice. I suspect that the remaining central issue is the

crucial one: surrogacy is baby-selling and participating in this practice exploits and taints women.

### **Is Surrogacy Baby-Selling?**

In the foregoing, I deliberately left vague the question of payment in contracted pregnancy. It is clear that there is a recognizable form of the practice that does not include payment; however, it also seems clear that controversy is focusing on the commercial form. The charge is that it is baby-selling and that this is wrong.

Is paid “surrogacy” baby-selling? Proponents deny that it is, arguing that women are merely making available their biological services. Opponents retort that as women are paid little or nothing if they fail to hand over a live, healthy child, they are indeed selling a baby. If they are merely selling their services they would get full pay, even if the child were born dead.

It is true women who agree to contracts relieving clients of responsibility in this case are being exploited. They, after all, have done their part, risked their risks, and should be paid—just like the physicians involved. Normal child-bearing provides no guarantee of a live, healthy child—why should contracted pregnancy?

There are further reasons for believing that women are selling their services, not babies. Firstly, we do not consider children property. Therefore, as we cannot sell what we do not own, we cannot be selling babies. What creates confusion here is that we do think we own sperm and ova. (Otherwise, how could men sell their sperm?) Yet we do not own what they become, persons. At what point, then, does the relationship cease to be describable as “ownership”?

Resolution of this question is not necessary to the current discussion. If we can own babies, there seems to be nothing problematic about selling them. If ownership ceases at some time before birth (and could thus be argued to be unconnected with personhood), then it is not selling of babies that is going on.

Although this response deals with the letter of the objection about baby-selling, it fails to heed its spirit, which is that we are trafficking in persons, and that such trafficking is wrong. Even if we are not “selling,” something nasty is happening.

The most common analogy, with slavery, is weak. Slavery is wrong according to any decent moral theory: the institution allows people to be treated badly. Their desires and interests, whose satisfaction is held to be essential for a good life, are held in contempt. Particularly egregious is the callous disregard of emotional ties to family and self-determination generally. But the institution of surrogate mothering deprives babies of neither.<sup>27</sup> In short, as Robertson contends, “the purchasers do not buy the right to treat the child . . . as a commodity or property. Child abuse and neglect laws still apply” (p. 655).

If “selling babies” is not the right description of what is occurring, then how are we to explain what happens when the birth mother hands the child over to others? One plausible suggestion is that she is giving up her parental right to have a relationship with the child.<sup>28</sup> That it is wrong to do this for pay remains to be shown. Although it would be egoistic and immoral to “sell” an ongoing, friendly relationship (doing so would raise questions about whether it was friendship at all), the immorality of selling a relationship with an organism your body has created but with which you do not yet have a unique social bond, is a great deal less clear.<sup>29</sup>

People seem to feel much less strongly about the wrongness of such acts when motivated by altruism; refusing compensation is the only acceptable proof of such altruism. The act is, in any case, socially valuable. Why then must it be motivated by altruistic considerations? We do not frown upon those who provide other socially valuable services even when they do not have the “right” motive. Nor do we require them to be unpaid. For instance, no one expects physicians, no matter what their motivation, to work for beans. They provide an important service; their motivation is important only to the extent that it affects quality.

In general, workers are required to have appropriate skills, not particular motivations.<sup>30</sup> Once again, it seems that there is a different standard for women and for men.

One worry is that women cannot be involved in contracted pregnancy without harming themselves, as it is difficult to let go of a child without lingering concern. So far, despite the heavily-publicized Baby M case, this appears not to be necessarily true.<sup>31</sup>

Another worry is that the practice will harm children. Children’s welfare is, of course, important. Children deserve the same consideration as other persons, and no society that fails to meet their basic needs is morally satisfactory. Yet I am suspicious of the objections raised on their behalf in these discussions: recourse to children’s alleged well-being is once again being used as a trump card against women’s autonomy.

First, we hear only about possible risks, never possible benefits, which, as I have been arguing, could be substantial.<sup>32</sup> Second, the main objection raised is the worry about how children will take the knowledge that their genetic mother conceived on behalf of another. We do not know how children will feel about having had such “surrogate” mothers. But as it is not a completely new phenomenon we might start our inquiry about this topic with historical evidence, not pessimistic speculation. In any case, if the practice is dealt with in an honest and commonsense way, particularly if it becomes quite common (and therefore “normal”), there is likely to be no problem. We are also hearing about the worries of existing children of women who are involved in the practice: there are reports that they fear their mother will give them away, too. But surely we can make clear to children the kinds of distinctions that distinguish the practice from slavery or baby-selling in the first place.

Although we must try to foresee what might harm children, I cannot help but wonder about the double standards implied by this speculation. The first double standard occurs when those who oppose surrogacy (and reproductive technologies generally) also oppose attempts to reduce the number of handicapped babies born.<sup>33</sup> In the latter context, it is argued that despite their problems handicapped persons are often glad to be alive. Hence it would be paternalistic to attempt to prevent their birth.

Why then do we not hear the same argument here? Instead, the possible disturbance of children born of surrogacy is taken as a reason to prevent their birth. Yet this potential problem is both more remote and most likely involves less suffering than such ailments as spina bifida, Huntington’s Disease or cystic fibrosis, which some do not take to be reasons to refrain from child-bearing.<sup>34</sup>

Considering the sorts of reasons why parents have children, it is hard to see why the idea that one was conceived in order to provide a desperately-wanted child to another is thought to be problematic. One might well prefer that to the idea that one was an “accident,” adopted, born because contraception or abortion were not available, conceived to cement a failing marriage, to continue a family line, to qualify for welfare aid, to sex-balance a family, or as an experiment in child-rearing. Surely what matters for a child’s well-being in the end is whether it is being raised in a loving, intelligent environment.

The second double standard involves a disparity between the interests of women and children. Arguing that surrogacy is wrong because it may upset children suggests a disturbing conception of the moral order. Women should receive consideration at least equal to that accorded children. Conflicts of interest between the two should be resolved according to the same rules we use for any other moral subjects. Those rules should never prescribe sacrificing one individual’s basic interest at the mere hint of harm to another.

In sum, there seems to be no reason to think that there is anything necessarily wrong with “surrogate mothering,” even the paid variety. Furthermore, some objections to it depend on values and assumptions that have been the chief building blocks of women’s inequality. Why are some feminists asserting them? Is it because “surrogacy” as currently practiced often exploits women?

### **Is “Surrogate Mothering” Wrong in Certain Situations?**

Even if “surrogate mothering” is not necessarily immoral, circumstances can render it so. For instance, it is obviously wrong to coerce women to engage in the practice. Also, certain conditions are unacceptable. Among them are clauses in a contract that subordinate a woman’s reasonable desires and judgements to the will of another contracting party,<sup>35</sup> clauses legitimating inadequate pay for the risks and discomforts involved, and clauses that penalize her for the birth of a handicapped or dead baby through no fault of her own. Such contracts are now common.<sup>36</sup>

One popular solution to the problem of such immoral contracts is a law forbidding all surrogacy agreements; their terms would then be unenforceable. But I believe that women will continue to engage in surrogate mothering, even if it is unregulated, and this approach leaves them vulnerable to those who change their mind, or will not pay. Fair and reasonable regulations are essential to prevent exploitation of women. Although surrogate mothering may seem risky and uncomfortable to middle-class persons safely ensconced in healthy, interesting, relatively well-paid jobs, with adequate regulation it becomes an attractive option for some women. That these women are more likely than not to be poor is no reason to prohibit the activity.

As I suggested earlier, poor women now face substantial risks in the workplace. Even a superficial survey of hazards in occupations available to poor women would give pause to those who would prohibit surrogacy on the grounds of risk.<sup>37</sup>

Particularly shocking is the list of harmful substances and conditions to which working women are routinely exposed. For instance, cosmeticians and hairdressers, dry-cleaners and dental technicians are all exposed to carcinogens in their daily work (Stellman, Appendixes 1 and 2). Most low-level jobs also have high rates of exposure to toxic chemicals and dangerous machinery, and women take such jobs in disproportionate numbers. It is therefore unsurprising that poor women sicken and die more often than other members of society.<sup>38</sup>

This is not an argument in favour of adding yet another dangerous option to those already facing such women. Nor does it follow that the burdens they already bear justify the new ones. On the contrary, it is imperative to clean up dangerous workplaces. However, it would be utopian to think that this will occur in the near future. We must therefore attempt to improve women’s lot under existing conditions. Under these circumstances it would be irrational to prohibit surrogacy on the grounds of risk when women would instead have to engage in still riskier pursuits.

Overall’s emphatic assertion that contracted pregnancy is not a “real choice” for women is unconvincing. Her major argument, as I suggested earlier, is that it is an immoral, alienating option.

But she also believes that such apparently expanded choices simply mask an underlying contraction of choice (p. 124). She also fears that by “endorsing an uncritical freedom of reproductive choice, we may also be implicitly endorsing all conceivable alternatives that an individual might adopt; we thereby abandon the responsibility for evaluating substantive actions in favour of advocating merely formal freedom of choice” (p. 125). Both worries are, as they stand, unpersuasive.

As I argued before, there is something troubling here about the new and one-sided emphasis on risk. If nothing else, we need to remember that contracted pregnancy constitutes a low-tech approach to a social problem, one which would slow the impetus toward expensive and dangerous high-tech solutions.<sup>39</sup>

A desire for children on the part of those who normally could not have them is not likely to disappear anytime soon. We could discount it, as many participants in debate about new reproductive technologies do. After all, nobody promised a rose garden to infertile couples, much less to homosexuals or to single women. Nor is it desirable to propagate the idea that having children is essential for human fulfilment.

But appealing to the sacrosanctity of traditional marriage or of blood ties to prohibit otherwise acceptable practices that would satisfy people’s desires hardly makes sense, especially when those practices may provide other benefits. Not only might contracted pregnancy be less risky and more enjoyable than other jobs women are forced to take, but there are other advantages as well. Since being pregnant is not usually a full-time occupation, “surrogate mothering” could buy time for women to significantly improve their lot: students, aspiring writers, and social activists could make real progress toward their goals.

Women have until now done this reproductive labour for free.<sup>40</sup> Paying women to bear children should force us all to recognize this process as the socially useful enterprise that it is, and children as socially valuable creatures whose upbringing and welfare are critically important.

In short, “surrogate mothering” has the potential to empower women and increase their status in

society. The darker side of the story is that it also has frightening potential for deepening their exploitation. The outcome of the current warfare over control of new reproductive possibilities will determine which of these alternatives comes to pass.

#### NOTES

1. Shulamith Firestone, *The Dialectic of Sex* (New York: Bantam Books, 1970), p. 198. A version of this paper was given at the Eastern SWIP meeting, 26 March 1988. I would like especially to thank Helen B. Holmes and Sara Ann Ketchum for their useful comments on this paper; they are, of course, in no way responsible for its perverse position! Thanks also to the editors and referees of *Bioethics* for their helpful criticisms.
2. Susan Sherwin, “Feminist Ethics and *In Vitro Fertilization*,” *Science, Morality and Feminist Theory*, ed. Marsha Hanen and Kai Nielsen, *Canadian Journal of Philosophy*, supplementary volume 13 (1987), p. 277.
3. Consider the many accounts of the devastating things parents have done to children, in particular.
4. See L. M. Purdy, “Genetic Diseases: Can Having Children be Immoral?” *Moral Problems in Medicine*, ed. Samuel Gorovitz (Englewood Cliffs, NJ: Prentice-Hall, 1983), pp. 377–84.
5. Another critical issue is that no feminist utopia will have a supply of “problem” children whom no one wants. Thus the proposal often heard nowadays that people should just adopt all those handicapped, non-white kids will not do. (Nor does it “do” now.)
6. I share with Sara Ann Ketchum the sense that this term is not adequate, although I am not altogether happy with her suggestion that we call it “contracted motherhood” (“New Reproductive Technologies and the Definition of Parenthood: A Feminist Perspective,” paper given at the 1987 *Feminism and Legal Theory Conference*, at the University of Wisconsin at Madison, summer 1987, pp. 44ff.). It would be better, I think, to reserve terms like “mother” for the social act of nurturing. I shall therefore substitute the terms “contracted pregnancy” and “surrogacy” (in quotes).
7. This is not to say that no one would take the same view as I: the Catholic Church, for instance, objects to the masturbatory act required for surrogacy to proceed.
8. The difficulty in choosing the “right” moral theory to back up judgments in applied ethics, given that none are fully satisfactory, continues to be vexing. I would like to reassure those who lose interest at the mere sight of consequentialist—let alone utilitarian—judgement, that there are good reasons for considering justice an

integral part of moral reasoning, as it quite obviously has utility. A different issue is raised by the burgeoning literature on feminist ethics. I strongly suspect that utilitarianism could serve feminists well, if properly applied. (For a defence of this position, see my paper "Do Feminists Need a New Moral Theory," given at the University of Minnesota, Duluth, at the conference *Explorations in Feminist Ethics: Theory and Practice*, 8–9 October 1988.)

9. See for example Gena Corea, *The Mother Machine*, and Christine Overall, *Ethics and Human Reproduction* (Winchester, MA: Allen & Unwin, 1987).

10. These are just a couple of examples in the sort of risky service that we tend to take for granted.

11. Modern agricultural products are brought to us as some risk by farm workers. Any large construction project will also result in some morbidity and mortality.

12. Even something so mundane as postal service involves serious risk on the part of workers.

13. The benefit to both high-risk women, and to society is clear. Women need not risk serious deterioration of health or abnormally high death rates.

14. See Laura Purdy, "The Morality of New Reproductive Technologies," *Journal of Social Philosophy* (Winter 1987), 38–48.

15. For elaboration of this view, consider Jane Ollenger and John Hamlin, "All Birthing Should Be Paid Labor"—a Marxist Analysis of the Commodification of Motherhood," in *On the Problem of Surrogate Parenthood: Analyzing the Baby M Case*, ed. Herbert Richardson, (Lewiston, NY: Edwin Mellen Press, 1987).

16. Compare the physical risk with that of certain contraceptive technologies, and high-tech fertility treatments like IVF.

17. Infertility is often a result of social arrangements. This process would therefore be especially unfair to those who have already been exposed to more than their share of toxic chemicals or other harmful conditions.

18. Christine Overall, *Ethics and Human Reproduction* (Winchester, MA: Allen & Unwin, 1987), ch. 6. Particularly problematic are her comments about women's loss of individuality, as I will be arguing shortly.

19. Men have been getting handsome pay for sperm donation for years; by comparison with child-bearing, such donation is a lark. Yet there has been no outcry about its immorality. Another double standard?

20. See Ellen Peck and Judith Senderowitz, *Pronatalism: The Myth of Mom and Apple Pie* (New York: Thomas Y. Crowell, 1974).

21. As it has been at some periods in the past: see for example information about family relationships in Philippe Ariès, *Centuries of Childhood: A Social History of Family Life*, trans. Robert Baldick (New York, 1982), and Lloyd DeMause's work.

22. Consider the arguments in ch. 8 of *Women's Work*, by Ann Oakley (New York: Vintage Books, 1974).

23. One of the interesting things about the practice of contracted pregnancy is that it can be argued to both strengthen and weaken the social recognition of biological relationships. On the one hand, the pregnant woman's biological relationship is judged irrelevant beyond a certain point; on the other, the reason for not valuing it is to enhance that of the sperm donor. This might be interpreted as yet another case where men's interests are allowed to overrule women's. But it might also be interpreted as a salutary step toward awareness that biological ties can and sometimes should be subordinated to social ones. Deciding which interpretation is correct will depend on the facts of particular cases, and the arguments taken to justify the practice in the first place.

24. Science fiction, most notably John Wyndham's *The Midwich Cuckoos*, provides us with thought-provoking material.

25. John Robertson, "Surrogate Mothers: Not So Novel after All," *Hastings Center Report*, vol. 13, no. 5 (October 1983). This article is reprinted in *Bioethics*, ed. Rem B. Edwards and Glen C. Gruber (San Diego, CA: Harcourt, Brace Jovanovich, 1988). Krimmel's article ("The Case Against Surrogate Parenting") was also originally published in the *Hastings Center Report* and is reprinted in *Bioethics*. References here are to the latter.

26. One major difference between adoption and contracted pregnancy is that the baby is handed over virtually at birth, thus ensuring that the trauma sometimes experienced by older adoptees is not experienced. Although children of contracted pregnancy might well be curious to know about their biological mother, I do not see this as a serious obstacle to the practice, since we could change our policy about this. There is also reason to believe that carefully-screened women undertaking a properly-regulated contracted pregnancy are less likely to experience lingering pain of separation. First, they have deliberately chosen to go through pregnancy, knowing that they will give the baby up. The resulting sense of control is probably critical to their short- and long-term well-being. Second, their pregnancy is not the result of trauma. See also Monica B. Morris, "Reproductive Technology and Restraints," *Transaction/SOCIETY* (March/April 1988), 16–22, esp. p. 18.

27. There may be a problem for the woman who gives birth, as the Baby M case has demonstrated. There is probably a case for a waiting period after the birth during which the woman can change her mind.
28. Heidi Malm suggested this position in her comment on Sara Ann Ketchum's paper "Selling Babies and Selling Bodies: Surrogate Motherhood and the Problem of Commodification," at the Eastern Division APA meetings, 30 December 1987.
29. Mary Anne Warren suggests, alternately, that this objection could be obviated by women and children retaining some rights and responsibilities toward each other in contracted pregnancy. Maintaining a relationship of sorts might also, she suggests, help forestall and alleviate whatever negative feelings children might have about such transfers. I agree that such openness is probably a good idea in any case. (Referee's comment.)
30. Perhaps lurking behind the objections of surrogacy is some feeling that it is wrong to earn money by letting your body work, without active effort on your part. But this would rule out sperm selling, as well as using women's beauty to sell products and services.
31. See, for example, James Rachels, "A Report from America: The Baby M Case," *Bioethics*, vol. 1, no. 4 (October 1987), 365. He reports that there have been over 600 successful cases; see also the above note on adoption.
32. Among them the above-mentioned one of being born healthier.
33. To avoid the difficulties about abortion added by the assumption that we are talking about existing fetuses, let us consider here only the issue of whether certain couples should risk pregnancy.
34. There is an interesting link here between these two aspects of reproduction, as the promise of healthier children is, I think, one of the strongest arguments for contracted pregnancy.
35. What this may consist of naturally requires much additional elucidation.
36. See Susan Ince, "Inside the Surrogate Industry," *Test-Tube Women*, ed. Rita Arditti, Renate Duelli Klein, and Shelley Minden (London: Pandora Press, 1984).
37. See, for example, Jeanne Mager Stellman, *Women's Work, Women's Health* (New York: Pantheon, 1977).
38. See George L. Waldbott, *Health Effects of Environmental Pollutants* (St Louis: C.V. Mosby, 1973); Nicholas Ashford, *Crisis in the Workplace: Occupational Disease and Injury* (Cambridge: MIT Press, 1976); *Cancer and the Worker* (New York Academy of Science, 1977); *Environmental Problems in Medicine*, ed. William D. McKee (Springfield, IL: Charles C. Thomas, 1977).
39. These are the ones most likely to put women in the clutches of the paternalistic medical establishment. Exploitation by commercial operations such as that of Noel Keane could be avoided by tight regulation or prohibition altogether of for-profit enterprises.
40. The implications of this fact remain to be fully understood; I suspect that they are detrimental to women and children, but that this is a topic for another paper.

## Is Women's Labor a Commodity?

ELIZABETH S. ANDERSON

Anderson opposes commercial surrogacy on the grounds that it reduces both surrogate mothers and babies to market commodities. This "commodification," she says, entails a type of evaluation that regards women and children as property, as things to be used—which is a far cry from seeing them as they should be seen: beings worthy of respect.

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From Elizabeth S. Anderson, "Is Women's Labor a Commodity?" *Philosophy and Public Affairs* 19, no. 1 (Winter 1990): 71–92.

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In the past few years the practice of commercial surrogate motherhood has gained notoriety as a method for acquiring children. A commercial surrogate mother is anyone who is paid money to bear

a child for other people and terminate her parental rights, so that the others may raise the child as exclusively their own. The growth of commercial surrogacy has raised with new urgency a class of concerns regarding the proper scope of the market. Some critics have objected to commercial surrogacy on the ground that it improperly treats children and women's reproductive capacities as commodities.<sup>1</sup> The prospect of reducing children to consumer durables and women to baby factories surely inspires revulsion. But are there good reasons behind the revulsion? And is this an accurate description of what commercial surrogacy implies? This article offers a theory about what things are properly regarded as commodities which supports the claim that commercial surrogacy constitutes an unconscionable commodification of children and of women's reproductive capacities.

### **What Is a Commodity?**

The modern market can be characterized in terms of the legal and social norms by which it governs the production, exchange, and enjoyment of commodities. To say that something is properly regarded as a commodity is to claim that the norms of the market are appropriate for regulating its production, exchange, and enjoyment. To the extent that moral principles or ethical ideals preclude the application of market norms to a good, we may say that the good is not a (proper) commodity.

Why should we object to the application of a market norm to the production or distribution of a good? One reason may be that to produce or distribute the good in accordance with the norm is to *fail to value it in an appropriate way*. Consider, for example, a standard Kantian argument against slavery, or the commodification of persons. Slaves are treated in accordance with the market norm that owners may use commodities to satisfy their own interests without regard for the interests of the commodities themselves. To treat a person without regard for her interests is to fail to respect her. But slaves are persons who may not be merely used in this fashion, since as rational beings they possess a dignity which commands respect. In Kantian theory, the problem with slavery is that it treats beings worthy of *respect* as if they were worthy

merely of *use*. "Respect" and "use" in this context denote what we may call different *modes of valuation*. We value things and persons in other ways than by respecting and using them. For example, love, admiration, honor, and appreciation constitute distinct modes of valuation. To value a thing or person in a distinctive way involves treating it in accordance with a particular set of norms. For example, courtesy expresses a mode of valuation we may call "civil respect," which differs from Kantian respect in that it calls for obedience to the rules of etiquette rather than to the categorical imperative.

Any ideal of human life includes a conception of how different things and persons should be valued. Let us reserve the term "use" to refer to the mode of valuation proper to commodities, which follows the market norm of treating things solely in accordance with the owner's nonmoral preferences. Then the Kantian argument against commodifying persons can be generalized to apply to many other cases. It can be argued that many objects which are worthy of a higher mode of valuation than use are not properly regarded as mere commodities.<sup>2</sup> Some current arguments against the colorization of classic black-and-white films take this form. Such films have been colorized by their owners in an attempt to enhance their market value by attracting audiences unused to black-and-white cinematography. But some opponents of the practice object that such treatment of the film classics fails to appreciate their aesthetic and historical value. True appreciation of these films would preclude this kind of crass commercial exploitation, which debases their aesthetic qualities in the name of profits. Here the argument rests on the claim that the goods in question are worthy of appreciation, not merely of use.

The ideals which specify how one should value certain things are supported by a conception of human flourishing. Our lives are enriched and elevated by cultivating and exercising the capacity to appreciate art. To fail to do so reflects poorly on ourselves. To fail to value things appropriately is to embody in one's life an inferior conception of human flourishing.<sup>3</sup>

These considerations support a general account of the sorts of things which are appropriately regarded as commodities. Commodities are those

things which are properly treated in accordance with the norms of the modern market. We can question the application of market norms to the production, distribution, and enjoyment of a good by appealing to ethical ideals which support arguments that the good should be valued in some other way than use. Arguments of the latter sort claim that to allow certain market norms to govern our treatment of a thing expresses a mode of valuation not worthy of it. If the thing is to be valued appropriately, its production, exchange, and enjoyment must be removed from market norms and embedded in a different set of social relationships.

### **The Case of Commercial Surrogacy**

Let us now consider the practice of commercial surrogate motherhood in the light of this theory of commodities. Surrogate motherhood as a commercial enterprise is based upon contracts involving three parties: the intended father, the broker, and the surrogate mother. The intended father agrees to pay a lawyer to find a suitable surrogate mother and make the requisite medical and legal arrangements for the conception and birth of the child, and for the transfer of legal custody to himself.<sup>4</sup> The surrogate mother agrees to become impregnated with the intended father's sperm, to carry the resulting child to term, and to relinquish her parental rights to it, transferring custody to the father in return for a fee and medical expenses. Both she and her husband (if she has one) agree not to form a parent-child bond with her child and to do everything necessary to effect the transfer of the child to the intended father. At current market prices, the lawyer arranging the contract can expect to gross \$15,000 from the contract, while the surrogate mother can expect a \$10,000 fee.<sup>5</sup>

The practice of commercial surrogacy has been defended on four main grounds. First, given the shortage of children available for adoption and the difficulty of qualifying as adoptive parents, it may represent the only hope for some people to be able to raise a family. Commercial surrogacy should be accepted as an effective means for realizing this highly significant good. Second, two fundamental human rights support commercial surrogacy: the right to procreate and freedom of contract.

Fully informed autonomous adults should have the right to make whatever arrangements they wish for the use of their bodies and the reproduction of children, so long as the children themselves are not harmed. Third, the labor of the surrogate mother is said to be a labor of love. Her altruistic acts should be permitted and encouraged.<sup>6</sup> Finally, it is argued that commercial surrogacy is no different in its ethical implications from many already accepted practices which separate genetic, gestational, and social parenting, such as artificial insemination by donor, adoption, wet-nursing, and day care. Consistency demands that society accept this new practice as well.<sup>7</sup>

In opposition to these claims, I shall argue that commercial surrogacy does raise new ethical issues, since it represents an invasion of the market into a new sphere of conduct, that of specifically women's labor—that is, the labor of carrying children to term in pregnancy. When women's labor is treated as a commodity, the women who perform it are degraded. Furthermore, commercial surrogacy degrades children by reducing their status to that of commodities. Let us consider each of the goods of concern in surrogate motherhood—the child, and women's reproductive labor—to see how the commercialization of parenthood affects people's regard for them.

### **Children as Commodities**

The most fundamental calling of parents to their children is to love them. Children are to be loved and cherished by their parents, not to be used or manipulated by them for merely personal advantage. Parental love can be understood as a passionate, unconditional commitment to nurture one's child, providing it with the care, affection, and guidance it needs to develop its capacities to maturity. This understanding of the way parents should value their children informs our interpretation of parental rights over their children. Parents' rights over their children are trusts, which they must always exercise for the sake of the child. This is not to deny that parents have their own aspirations in raising children. But the child's interests beyond subsistence are not definable independently of the flourishing of the family, which is the object of

specifically parental aspirations. The proper exercise of parental rights includes those acts which promote their shared life as a family, which realize the shared interests of the parents and the child.

The norms of parental love carry implications for the ways other people should treat the relationship between parents and their children. If children are to be loved by their parents, then others should not attempt to compromise the integrity of parental love or work to suppress the emotions supporting the bond between parents and their children. If the rights to children should be understood as trusts, then if those rights are lost or relinquished, the duty of those in charge of transferring custody to others is to consult the best interests of the child.

Commercial surrogacy substitutes market norms for some of the norms of parental love. Most importantly, it requires us to understand parental rights no longer as trusts but as things more like property rights—that is, rights of use and disposal over the things owned. For in this practice the natural mother deliberately conceives a child with the intention of giving it up for material advantage. Her renunciation of parental responsibilities is not done for the child's sake, nor for the sake of fulfilling an interest she shares with the child, but typically for her own sake (and possibly, if "altruism" is a motive, for the intended parents' sakes). She and the couple who pay her to give up her parental rights over her child thus treat her rights as a kind of property right. They thereby treat the child itself as a kind of commodity, which may be properly bought and sold.

Commercial surrogacy insinuates the norms of commerce into the parental relationship in other ways. Whereas parental love is not supposed to be conditioned upon the child having particular characteristics, consumer demand is properly responsive to the characteristics of commodities. So the surrogate industry provides opportunities to adoptive couples to specify the height, I.Q., race, and other attributes of the surrogate mother, in the expectation that these traits will be passed on to the child.<sup>8</sup> Since no industry assigns agents to look after the "interests" of its commodities, no one represents the child's interests in the surrogate industry. The surrogate agency promotes the adoptive

parents' interests and not the child's interests where matters of custody are concerned. Finally, as the agent of the adoptive parents, the broker has the task of policing the surrogate (natural) mother's relationship to her child, using persuasion, money, and the threat of a lawsuit to weaken and destroy whatever parental love she may develop for her child.<sup>9</sup>

All of these substitutions of market norms for parental norms represent ways of treating children as commodities which are degrading to them. Degradation occurs when something is treated in accordance with a lower mode of valuation than is proper to it. We value things not just "more" or "less," but in qualitatively higher and lower ways. To love or respect someone is to value her in a higher way than one would if one merely used her. Children are properly loved by their parents and respected by others. Since children are valued as mere use-objects by the mother and the surrogate agency when they are sold to others, and by the adoptive parents when they seek to conform the child's genetic makeup to their own wishes, commercial surrogacy degrades children insofar as it treats them as commodities.<sup>10</sup>

One might argue that since the child is most likely to enter a loving home, no harm comes to it from permitting the natural mother to treat it as property. So the purchase and sale of infants is unobjectionable, at least from the point of view of children's interests.<sup>11</sup> But the sale of an infant has an expressive significance which this argument fails to recognize. By engaging in the transfer of children by sale, all of the parties to the surrogate contract express a set of attitudes toward children which undermine the norms of parental love. They all agree in treating the ties between a natural mother and her children as properly loosened by a monetary incentive. Would it be any wonder if a child born of a surrogacy agreement feared resale by parents who have such an attitude? And a child who knew how anxious her parents were that she have the "right" genetic makeup might fear that her parent's love was contingent upon her expression of these characteristics.<sup>12</sup>

The unsold children of surrogate mothers are also harmed by commercial surrogacy. The children

of some surrogate mothers have reported their fears that they may be sold like their half-brother or half-sister, and express a sense of loss at being deprived of a sibling.<sup>13</sup> Furthermore, the widespread acceptance of commercial surrogacy would psychologically threaten all children. For it would change the way children are valued by people (parents and surrogate brokers)—from being loved by their parents and respected by others, to being sometimes used as objects of commercial profit-making.<sup>14</sup>

Proponents of commercial surrogacy have denied that the surrogate industry engages in the sale of children. For it is impossible to sell to someone what is already his own, and the child is already the father's own natural offspring. The payment to the surrogate mother is not for her child, but for her services in carrying it to term.<sup>15</sup> The claim that the parties to the surrogate contract treat children as commodities, however, is based on the way they treat the *mother's* rights over her child. It is irrelevant that the natural father also has some rights over the child; what he pays for is exclusive rights to it. He would not pay her for the "service" of carrying the child to term if she refused to relinquish her parental rights to it. That the mother regards only her labor and not her child as requiring compensation is also irrelevant. No one would argue that the baker does not treat his bread as property just because he sees the income from its sale as compensation for his labor and expenses and not for the bread itself, which he doesn't care to keep.<sup>16</sup>

Defenders of commercial surrogacy have also claimed that it does not differ substantially from other already accepted parental practices. In the institutions of adoption and artificial insemination by donor (AID), it is claimed, we already grant parents the right to dispose of their children.<sup>17</sup> But these practices differ in significant respects from commercial surrogacy. The purpose of adoption is to provide a means for placing children in families when their parents cannot or will not discharge their parental responsibilities. It is not a sphere for the existence of a supposed parental right to dispose of one's children for profit. Even AID does not sanction the sale of fully formed human beings. The semen donor sells only a product of his body, not

his child, and does not initiate the act of conception.

Two developments might seem to undermine the claim that commercial surrogacy constitutes a degrading commerce in children. The first is technological: the prospect of transplanting a human embryo into the womb of a genetically unrelated woman. If commercial surrogacy used women only as gestational mothers and not as genetic mothers, and if it was thought that only genetic and not gestational parents could properly claim that a child was "theirs," then the child born of a surrogate mother would not be hers to sell in the first place. The second is a legal development: the establishment of the proposed "consent-intent" definition of parenthood.<sup>18</sup> This would declare the legal parents of a child to be whoever consented to a procedure which leads to its birth, with the intent of assuming parental responsibilities for it. This rule would define away the problem of commerce in children by depriving the surrogate mother of any legal claim to her child at all, even if it was hers both genetically and gestationally.<sup>19</sup>

There are good reasons, however, not to undermine the place of genetic and gestational ties in these ways. Consider first the place of genetic ties. By upholding a system of involuntary (genetic) ties of obligation among people, even when the adults among them prefer to divide their rights and obligations in other ways, we help to secure children's interests in having an assured place in the world, which is more firm than the wills of their parents. Unlike the consent-intent rule, the principle of respecting genetic ties does not make the obligation to care for those whom one has created (intentionally or not) contingent upon an arbitrary desire to do so. It thus provides children with a set of preexisting social sanctions which give them a more secure place in the world. The genetic principle also places children in a far wider network of associations and obligations than the consent-intent rule sanctions. It supports the roles of grandparents and other relatives in the nurturing of children, and provides children with a possible focus of stability and an additional source of claims to care if their parents cannot sustain a well-functioning household.

In the next section I will defend the claims of gestational ties to children. To deny these claims, as commercial surrogacy does, is to deny the significance of reproductive labor to the mother who undergoes it and thereby to dehumanize and degrade the mother herself. Commercial surrogacy would be a corrupt practice even if it did not involve commerce in children.

### **Women's Labor as a Commodity**

Commercial surrogacy attempts to transform what is specifically women's labor—the work of bringing forth children into the world—into a commodity. It does so by replacing the parental norms which usually govern the practice of gestating children with the economic norms which govern ordinary production processes. The application of commercial norms to women's labor reduces the surrogate mothers from persons worthy of respect and consideration to objects of mere use.

Respect and consideration are two distinct modes of valuation whose norms are violated by the practices of the surrogate industry. To respect a person is to treat her in accordance with principles she rationally accepts—principles consistent with the protection of her autonomy and her rational interests. To treat a person with consideration is to respond with sensitivity to her and to her emotional relations with others, refraining from manipulating or denigrating these for one's own purposes. Given the understanding of respect as a dispassionate, impersonal regard for people's interests, a different ethical concept—consideration—is needed to capture the engaged and sensitive regard we should have for people's emotional relationships. The failure of consideration on the part of the other parties to the surrogacy contract explains the judgment that the contract is not simply disrespectful of the surrogate mother, but callous as well.<sup>20</sup>

The application of economic norms to the sphere of women's labor violates women's claims to respect and consideration in three ways. First, by requiring the surrogate mother to repress whatever parental love she feels for the child, these norms convert women's labor into a form of alienated labor. Second, by manipulating and denying legitimacy to the surrogate mother's evolving perspective on her

own pregnancy, the norms of the market degrade her. Third, by taking advantage of the surrogate mother's noncommercial motivations without offering anything but what the norms of commerce demand in return, these norms leave her open to exploitation. The fact that these problems arise in the attempt to commercialize the labor of bearing children shows that women's labor is not properly regarded as a commodity.

The key to understanding these problems is the normal role of the emotions in noncommercialized pregnancies. Pregnancy is not simply a biological process but also a social practice. Many social expectations and considerations surround women's gestational labor, marking it off as an occasion for the parents to prepare themselves to welcome a new life into their family. For example, obstetricians use ultrasound not simply for diagnostic purposes but also to encourage maternal bonding with the fetus.<sup>21</sup> We can all recognize that it is good, although by no means inevitable, for loving bonds to be established between the mother and her child during this period.

In contrast with these practices, the surrogate industry follows the putting-out system of manufacturing. It provides some of the raw materials of production (the father's sperm) to the surrogate mother, who then engages in production of the child. Although her labor is subject to periodic supervision by her doctors and by the surrogate agency, the agency does not have physical control over the product of her labor as firms using the factory system do. Hence, as in all putting-out systems, the surrogate industry faces the problem of extracting the final product from the mother. This problem is exacerbated by the fact that the social norms surrounding pregnancy are designed to encourage parental love for the child. The surrogate industry addresses this problem by requiring the mother to engage in a form of emotional labor.<sup>22</sup> In the surrogate contract, she agrees not to form or to attempt to form a parent-child relationship with her offspring.<sup>23</sup> Her labor is alienated, because she must divert it from the end which the social practices of pregnancy rightly promote—an emotional bond with her child. The surrogate contract thus replaces a norm of parenthood, that during pregnancy one

create a loving attachment to one's child, with a norm of commercial production, that the producer shall not form any special emotional ties to her product.

The demand to deliberately alienate oneself from one's love for one's own child is a demand which can reasonably and decently be made of no one. Unless we were to remake pregnancy into a form of drudgery which is only performed for a wage, there is every reason to expect that many women who do sign a surrogate contract will, despite this fact, form a loving attachment to the child they bear. For this is what the social practices surrounding pregnancy encourage. Treating women's labor as just another kind of commercial production process violates the precious emotional ties which the mother may rightly and properly establish with her "product," the child, and thereby violates her claims to consideration.<sup>24</sup>

Commercial surrogacy is also a degrading practice. The surrogate mother, like all persons, has an independent evaluative perspective on her activities and relationships. The realization of her dignity demands that the other parties to the contract acknowledge rather than evade the claims which her independent perspective makes upon them. But the surrogate industry has an interest in suppressing, manipulating, and trivializing her perspective, for there is an ever-present danger that she will see her involvement in her pregnancy from the perspective of a parent rather than from the perspective of a contract laborer.

How does this suppression and trivialization take place? The commercial promoters of surrogacy commonly describe the surrogate mothers as inanimate objects: mere "hatcheries," "plumbing," or "rented property"—things without emotions which could make claims on others.<sup>25</sup> They also refuse to acknowledge any responsibility for the consequences of the mother's emotional labor. Should she suffer psychologically from being forced to give up her child, the father is not liable to pay for therapy after her pregnancy, although he is liable for all other medical expenses following her pregnancy.<sup>26</sup>

The treatment and interpretation of surrogate mothers' grief raises the deepest problems of degradation. Most surrogate mothers experience grief

upon giving up their children—in 10 percent of cases, seriously enough to require therapy.<sup>27</sup> Their grief is not compensated by the \$10,000 fee they receive. Grief is not an intelligible response to a successful deal, but rather reflects the subject's judgment that she has suffered a grave and personal loss. Since not all cases of grief resolve themselves into cases of regret, it may be that some surrogate mothers do not regard their grief, in retrospect, as reflecting an authentic judgment on their part. But in the circumstances of emotional manipulation which pervade the surrogate industry, it is difficult to determine which interpretation of her grief more truly reflects the perspective of the surrogate mother. By insinuating a trivializing interpretation of her emotional responses to the prospect of losing her child, the surrogate agency may be able to manipulate her into accepting her fate without too much fuss, and may even succeed in substituting its interpretation of her emotions for her own. Since she has already signed a contract to perform emotional labor—to express or repress emotions which are dictated by the interests of the surrogate industry—this might not be a difficult task.<sup>28</sup> A considerate treatment of the mothers' grief, on the other hand, would take the evaluative basis of their grief seriously.

Some defenders of commercial surrogacy demand that the provision for terminating the surrogate mother's parental rights in her child be legally enforceable, so that peace of mind for the adoptive parents can be secured.<sup>29</sup> But the surrogate industry makes no corresponding provision for securing the peace of mind of the surrogate. She is expected to assume the risk of a transformation of her ethical and emotional perspective on herself and her child with the same impersonal detachment with which a futures trader assumes the risk of a fluctuation in the price of pork bellies. By applying the market norms of enforcing contracts to the surrogate mother's case, commercial surrogacy treats a moral transformation as if it were merely an economic change.<sup>30</sup>

The manipulation of the surrogate mother's emotions which is inherent in the surrogate parenting contract also leaves women open to grave forms of exploitation. A kind of exploitation occurs when

one party to a transaction is oriented toward the exchange of "gift" values, while the other party operates in accordance with the norms of the market exchange of commodities. Gift values, which include love, gratitude, and appreciation of others, cannot be bought or obtained through piecemeal calculations of individual advantage. Their exchange requires a repudiation of a self-interested attitude, a willingness to give gifts to others without demanding some specific equivalent good in return each time one gives. The surrogate mother often operates according to the norms of gift relationships. The surrogate agency, on the other hand, follows market norms. Its job is to get the best deal for its clients and itself, while leaving the surrogate mother to look after her own interests as best as she can. This situation puts the surrogate agencies in a position to manipulate the surrogate mothers' emotions to gain favorable terms for themselves. For example, agencies screen prospective surrogate mothers for submissiveness, and emphasize to them the importance of the motives of generosity and love. When applicants question some of the terms of the contract, the broker sometimes intimidates them by questioning their character and morality: if they were really generous and loving they would not be so solicitous about their own interests.<sup>31</sup>

Some evidence supports the claim that most surrogate mothers are motivated by emotional needs and vulnerabilities which lead them to view their labor as a form of gift and not a purely commercial exchange. Only 1 percent of applicants to surrogate agencies would become surrogate mothers for money alone; the others have emotional as well as financial reasons for applying. One psychiatrist believes that most, if not all, of the 35 percent of applicants who had had a previous abortion or given up a child for adoption wanted to become surrogate mothers in order to resolve their guilty feelings or deal with their unresolved loss by going through a process of losing a child again.<sup>32</sup> Women who feel that giving up another child is an effective way to punish themselves for past abortions, or a form of therapy for their emotional problems, are not likely to resist manipulation by surrogate brokers.

Many surrogate mothers see pregnancy as a way to feel "adequate," "appreciated," or "special." In

other words, these women feel inadequate, unappreciated, or unadmired when they are not pregnant.<sup>33</sup> Lacking the power to achieve some worthwhile status in their own right, they must subordinate themselves to others' definitions of their proper place (as baby factories) in order to get from them the appreciation they need to attain a sense of self-worth. But the sense of self-worth one can attain under such circumstances is precarious and ultimately self-defeating. For example, those who seek gratitude on the part of the adoptive parents and some opportunity to share the joys of seeing their children grow discover all too often that the adoptive parents want nothing to do with them.<sup>34</sup> For while the surrogate mother sees in the arrangement some basis for establishing the personal ties she needs to sustain her emotionally, the adoptive couple sees it as an impersonal commercial contract, one of whose main advantages to them is that all ties between them and the surrogate are ended once the terms of the contract are fulfilled.<sup>35</sup> To them, her presence is a threat to marital unity and a competing object for the child's affections.

These considerations should lead us to question the model of altruism which is held up to women by the surrogacy industry. It is a strange form of altruism which demands such radical self-effacement, alienation from those whom one benefits, and the subordination of one's body, health, and emotional life to the independently defined interests of others.<sup>36</sup> Why should this model of "altruism" be held up to *women*? True altruism does not involve such subordination, but rather the autonomous and self-confident exercise of skill, talent, and judgment. (Consider the dedicated doctor.) The kind of altruism we see admired in surrogate mothers involves a lack of self-confidence, a feeling that one can be truly worthy only through self-effacement. This model of altruism, far from affirming the freedom and dignity of women, seems all too conveniently designed to keep their sense of self-worth hostage to the interests of a more privileged class.<sup>37</sup>

The primary distortions which arise from treating women's labor as a commodity—the surrogate mother's alienation from loved ones, her degradation, and her exploitation—stem from a common

source. This is the failure to acknowledge and treat appropriately the surrogate mother's emotional engagement with her labor. Her labor is alienated, because she must suppress her emotional ties with her own child, and may be manipulated into reinterpreting these ties in a trivializing way. She is degraded, because her independent ethical perspective is denied, or demoted to the status of a cash sum. She is exploited, because her emotional needs and vulnerabilities are not treated as characteristics which call for consideration, but as factors which may be manipulated to encourage her to make a grave self-sacrifice to the broker's and adoptive couple's advantage. These considerations provide strong grounds for sustaining the claims of women's labor to its "product," the child. The attempt to redefine parenthood so as to strip women of parental claims to the children they bear does violence to their emotional engagement with the project of bringing children into the world.

### **Commercial Surrogacy, Freedom, and the Law**

In the light of these ethical objections to commercial surrogacy, what position should the law take on the practice? At the very least, surrogate contracts should not be enforceable. Surrogate mothers should not be forced to relinquish their children if they have formed emotional bonds with them. Any other treatment of women's ties to the children they bear is degrading.

But I think these arguments support the stronger conclusion that commercial surrogate contracts should be illegal, and that surrogate agencies who arrange such contracts should be subject to criminal penalties.<sup>38</sup> Commercial surrogacy constitutes a degrading and harmful traffic in children, violates the dignity of women, and subjects both children and women to a serious risk of exploitation. But are these problems inherent in the practice of commercial surrogacy? Defenders of the practice have suggested three reforms intended to eliminate these problems:

- (1) give the surrogate mother the option of keeping her child after birth; (2) impose stringent regulations on private surrogate agencies; (3) replace private surrogate agencies with a state-run

monopoly on surrogate arrangements. Let us consider each of these options in turn.

Some defenders of commercial surrogacy suggest that the problem of respecting the surrogate mother's potential attachment to her child can be solved by granting the surrogate mother the option to reserve her parental rights after birth.<sup>39</sup> But such an option would not significantly change the conditions of the surrogate mother's labor. Indeed, such a provision would pressure the agency to demean the mother's self-regard more than ever. Since it could not rely on the law to enforce the adoptive parents' wishes regardless of the surrogate's feelings, it would have to make sure that she assumed the perspective which it and its clients have of her: as "rented plumbing."

Could such dangers be avoided by careful regulation of the surrogate industry? Some have suggested that exploitation of women could be avoided by such measures as properly screening surrogates, setting low fixed fees (to avoid tempting women in financial duress), and requiring independent counsel for the surrogate mother.<sup>40</sup> But no one knows how to predict who will suffer grave psychological damage from surrogacy, and the main forms of duress encountered in the industry are emotional rather than financial. Furthermore, there is little hope that regulation would check the exploitation of surrogate mothers. The most significant encounters between the mothers and the surrogate agencies take place behind closed doors. It is impossible to regulate the multifarious ways in which brokers can subtly manipulate the emotions of the vulnerable to their own advantage. Advocates of commercial surrogacy claim that their failure rate is extremely low, since only five out of the first five hundred cases were legally contested by surrogate mothers. But we do not know how many surrogate mothers were browbeaten into relinquishing their children, feel violated by their treatment, or would feel violated had their perspectives not been manipulated by the other parties to the contract. The dangers of exploiting women through commercial surrogacy are too great to ignore, and too deep to effectively regulate.

Could a state-run monopoly on surrogate arrangements eliminate the risk of degrading and

exploiting surrogate mothers.<sup>41</sup> A nonprofit state agency would arguably have no incentive to exploit surrogates, and it would screen the adoptive parents for the sake of the best interests of the child. Nevertheless, as long as the surrogate mother is paid money to bear a child and terminate her parental rights, the commercial norms leading to her degradation still apply. For these norms are constitutive of our understanding of what the surrogate contract is for. Once such an arrangement becomes socially legitimized, these norms will govern the understandings of participants in the practice and of society at large, or at least compete powerfully with the rival parental norms. And what judgment do these norms make of a mother who, out of love for her child, decides that she cannot relinquish it? They blame her for commercial irresponsibility and flighty emotions. Her transformation of moral and emotional perspective, which she experiences as real but painful growth, looks like a capricious and selfish exercise of will from the standpoint of the market, which does not distinguish the deep commitments of love from arbitrary matters of taste.<sup>42</sup>

The fundamental problem with commercial surrogacy is that commercial norms are inherently manipulative when they are applied to the sphere of parental love. Manipulation occurs whenever norms are deployed to psychologically coerce others into a position where they cannot defend their own interests or articulate their own perspective without being charged with irresponsibility or immorality for doing so. A surrogate contract is inherently manipulative, since the very form of the contract invokes commercial norms which, whether upheld by the law or by social custom only, imply that the mother should feel guilty and irresponsible for loving her own child.

But hasn't the surrogate mother decided in advance that she is not interested in viewing her relationship to her child in this way? Regardless of her initial state of mind, once she enters the contract, she is not free to develop an autonomous perspective on her relationship with her child. She is contractually bound to manipulate her emotions to agree with the interests of the adoptive parents. Few things reach deeper into the self than a parent's evolving relationship with her own child. To lay

claim to the course of this relationship in virtue of a cash payment constitutes a severe violation of the mother's personhood and a denial of the mother's autonomy.

Two final objections stand in the way of criminalizing commercial surrogacy. Prohibiting the practice might be thought to infringe two rights: the right of procreation, and the right to freedom of contract. Judge Harvey Sorkow, in upholding the legality and enforceability of commercial surrogate parenting contracts, based much of his argument on an interpretation of the freedom to procreate. He argued that the protection of the right to procreate requires the protection of noncoital means of procreation, including commercial surrogacy. The interests upheld by the creation of the family are the same, regardless of the means used to bring the family into existence.<sup>43</sup>

Sorkow asserts a blanket right to procreate, without carefully examining the specific human interests protected by such a right. The interest protected by the right to procreate is that of being able to create and sustain a family life with some integrity. But the enforcement of surrogate contracts against the will of the mother destroys one family just as surely as it creates another. And the same interest which generates the right to procreate also generates an obligation to uphold the integrity of family life which constrains the exercise of this right.<sup>44</sup> To recognize the legality of commercial surrogate contracts would undermine the integrity of families by giving public sanction to a practice which expresses contempt for the moral and emotional ties which bind a mother to her children, legitimates the view that these ties are merely the product of arbitrary will, properly loosened by the offering of a monetary incentive, and fails to respect the claims of genetic and gestational ties to children which provide children with a more secure place in the world than commerce can supply.

The freedom of contract provides weaker grounds for supporting commercial surrogacy. This freedom is already constrained, notably in preventing the purchase and sale of human beings. Yet one might object that prohibiting surrogate contracts could undermine the status of women by implying that they do not have the competence to enter into

and rationally discharge the obligations of commercial contracts. Insofar as the justification for prohibiting commercial surrogacy depends upon giving special regard to women's emotional ties to their children, it might be thought to suggest that women as a group are too emotional to subject themselves to the dispassionate discipline of the market. Then prohibiting surrogate contracts would be seen as an offensive, paternalistic interference with the autonomy of the surrogate mothers.

We have seen, however, that the content of the surrogate contract itself compromises the autonomy of surrogate mothers. It uses the norms of commerce in a manipulative way and commands the surrogate mothers to conform their emotions to the interests of the other parties to the contract. The surrogate industry fails to acknowledge the surrogate mothers as possessing an independent perspective worthy of consideration. And it takes advantage of motivations—such as self-effacing “altruism”—which women have formed under social conditions inconsistent with genuine autonomy. Hence the surrogate industry itself, far from expanding the realm of autonomy for women, actually undermines the external and internal conditions required for fully autonomous choice by women.

If commercial surrogate contracts were prohibited, this would be no cause for infertile couples to lose hope for raising a family. The option of adoption is still available, and every attempt should be made to open up opportunities for adoption to couples who do not meet standard requirements—for example, because of age. While there is a shortage of healthy white infants available for adoption, there is no shortage of children of other races, mixed-race children, and older and handicapped children who desperately need to be adopted. Leaders of the surrogate industry have proclaimed that commercial surrogacy may replace adoption as the method of choice for infertile couples who wish to raise families. But we should be wary of the racist and eugenic motivations which make some people rally to the surrogate industry at the expense of children who already exist and need homes.

The case of commercial surrogacy raises deep questions about the proper scope of the market in

modern industrial societies. I have argued that there are principled grounds for rejecting the substitution of market norms for parental norms to govern the ways women bring children into the world. Such substitutions express ways of valuing mothers and children which reflect an inferior conception of human flourishing. When market norms are applied to the ways we allocate and understand parental rights and responsibilities, children are reduced from subjects of love to objects of use. When market norms are applied to the ways we treat and understand women's reproductive labor, women are reduced from subjects of respect and consideration to objects of use. If we are to retain the capacity to value children and women in ways consistent with a rich conception of human flourishing, we must resist the encroachment of the market upon the sphere of reproductive labor. Women's labor is *not* a commodity.

#### NOTES

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1. See, for example, Gena Corea, *The Mother Machine* (New York: Harper and Row, 1985), pp. 216, 219; Angela Holder, “Surrogate Motherhood: Babies for Fun and Profit,” *Case and Comment* 90 (1985): 3–11; and Margaret Jane Radin, “Market Inalienability,” *Harvard Law Review* 100 (June 1987): 1849–1937.

2. The notion of valuing something more highly than another can be understood as follows. Some preferences are neither obligatory nor admirable. To value a thing as a mere use-object is to treat it solely in accordance with such nonethical preferences. To value a thing or person more highly than as a mere use-object is to recognize it as having some special intrinsic worth, in virtue of which we form preferences about how to treat the thing which we regard as obligatory or admirable. The person who truly appreciates art does not conceive of art merely as a thing which she can use as she pleases, but as something which commands appreciation. It would be contemptible to willfully destroy the aesthetic qualities of a work of art simply to satisfy some of one's nonethical preferences, and it is a mark of a cultivated and hence admirable person that she has preferences for

appreciating art. This account of higher and lower modes of valuation is indebted to Charles Taylor's account of higher and lower values. See Charles Taylor, "The Diversity of Goods," in *Utilitarianism and Beyond*, ed. Amartya Sen and Bernard Williams (Cambridge: Cambridge University Press, 1982), pp. 129–44.

3. This kind of argument shows why treating something as a commodity may be deplorable. Of course, more has to be said to justify prohibiting the commodification of a thing. I shall argue below that the considerations against the commodification of children and of women's labor are strong enough to justify prohibiting the practice of commercial surrogacy.

4. State laws against selling babies prevent the intended father's wife (if he has one) from being a party to the contract.

5. See Katie Marie Brophy, "A Surrogate Mother Contract to Bear a Child," *Journal of Family Law* 20 (1981–82): 263–91, and Noel Keane, "The Surrogate Parenting Contract," *Adelphia Law Journal* 2 (1983): 45–53, for examples and explanations of surrogate parenting contracts.

6. Mary Warnock, *A Question of Life* (Oxford: Blackwell, 1985), p. 45. This book reprints the Warnock Report on Human Fertilization and Embryology, which was commissioned by the British government for the purpose of recommending legislation concerning surrogacy and other issues. Although the Warnock Report mentions the promotion of altruism as one defense of surrogacy, it strongly condemns the practice overall.

7. John Robertson, "Surrogate Mothers: Not So Novel after All," *Hastings Center Report*, October 1983, pp. 28–34; John Harris, *The Value of Life* (Boston: Routledge and Kegan Paul, 1985).

8. See "No Other Hope for Having a Child," *Time*, 19 January 1987, pp. 50–51. Radin argues that women's traits are also commodified in this practice. See "Market Inalienability," pp. 1932–35.

9. Here I discuss the surrogate industry as it actually exists today. I will consider possible modifications of commercial surrogacy in the final section below.

10. Robert Nozick has objected that my claims about parental love appear to be culture-bound. Do not parents in the Third World, who rely on children to provide for the family subsistence, regard their children as economic goods? In promoting the livelihood of their families, however, such children need not be treated in accordance with market norms—that is, as commodities. In particular, such children usually remain a part of their families, and hence can still be

loved by their parents. But insofar as children are treated according to the norms of modern capitalist markets, this treatment is deplorable wherever it takes place.

11. See Elizabeth Landes and Richard Posner, "The Economics of the Baby Shortage," *Journal of Legal Studies* 7 (1978): 323–48, and Richard Posner, "The Regulation of the Market in Adoptions," *Boston University Law Review* 67 (1987): 59–72.

12. Of course, where children are concerned, it is irrelevant whether these fears are reasonable. One of the greatest fears of children is separation from their parents. Adopted children are already known to suffer from separation anxiety more acutely than children who remain with their natural mothers, for they feel that their original mothers did not love them. In adoption, the fact that the child would be even worse off if the mother did not give it up justifies her severing of ties and can help to rationalize this event to the child. But in the case of commercial surrogacy, the severing of ties is done not for the child's sake, but for the parents' sakes. In the adoption case there are explanations for the mother's action which may quell the child's doubts about being loved which are unavailable in the case of surrogacy.

13. Kay Longcope, "Surrogacy: Two Professionals on Each Side of Issue Give Their Arguments for Prohibition and Regulation," *Boston Globe*, 23 March 1987, pp. 18–19; and Iver Peterson, "Baby M Case: Surrogate Mothers Vent Feelings," *New York Times*, 2 March 1987, pp. B1, B4.

14. Herbert Krimmel, "The Case against Surrogate Parenting," *Hastings Center Report*, October 1983, pp. 35–37.

15. Judge Sorkow made this argument in ruling on the famous case of Baby M. See *In Re Baby M*, 217 N.J. Super 313. Reprinted in *Family Law Reporter* 13 (1987): 2001–30. Chief Justice Wilentz of the New Jersey Supreme Court overruled Sorkow's judgment. See *In the Matter of Baby M*, 109 N.J. 396, 537 A.2d 1227 (1988).

16. Sallyann Payton has observed that the law does not permit the sale of parental rights, only their relinquishment or forced termination by the state, and these acts are subject to Court review for the sake of the child's best interests. But this legal technically does not change the moral implications of the analogy with baby-selling. The mother is still paid to do what she can to relinquish her parental rights and to transfer custody of the child to the father. Whether or not the courts occasionally prevent this from happening, the actions

of the parties express a commercial orientation to children which is degrading and harmful to them. The New Jersey Supreme Court ruled that surrogacy contracts are void precisely because they assign custody without regard to the child's best interests. See *In the Matter of Baby M*, p. 1246.

17. Robertson, "Surrogate Mothers: Not So Novel after All," p. 32; Harris, *The Value of Life*, pp. 144-45.

18. See Philip Parker, "Surrogate Motherhood: The Interaction of Litigation, Legislation and Psychiatry," *International Journal of Law and Psychiatry* 5 (1982): 341-54.

19. The consent-intent rule would not, however, change the fact that commercial surrogacy replaces parental norms with market norms. For the rule itself embodies the market norm which acknowledges only voluntary, contractual relations among people as having moral force. Whereas familial love invites children into a network of unwilled relationships broader than those they have with their parents, the willed contract creates an exclusive relationship between the parents and the child only.

20. I thank Steven Darwall and David Anderson for clarifying my thoughts on this point.

21. I am indebted to Dr. Ezekiel Emanuel for this point.

22. One engages in emotional labor when one is paid to express or repress certain emotions. On the concept of emotional labor and its consequences for workers, see Arlie Hochschild, *The Managed Heart* (Berkeley and Los Angeles: University of California Press, 1983).

23. Noel Keane and Dennis Breo, *The Surrogate Mother* (New York: Everest House, 1981), p. 291; Brophy, "A Surrogate Mother Contract," p. 267. The surrogate's husband is also required to agree to this clause of the contract.

24. One might ask why this argument does not extend to all cases in which one might form an emotional attachment to an object one has contracted to sell. If I sign a contract with you to sell my car to you, can I back out if I decide I am too emotionally attached to it? My argument is based upon the distinctive characteristics of parental love—a mode of valuation which should not be confused with less profound modes of valuation which generate sentimental attachments to things. The degree to which other modes of valuation generate claims to consideration which tell against market norms remains an open question.

25. Corea, *The Mother Machine*, p. 222.

26. Keane and Breo, *The Surrogate Mother*, p. 292.

27. Kay Longcope, "Standing Up for Mary Beth," *Boston Globe*, 5 March 1987, p. 83; Daniel Goleman,

"Motivations of Surrogate Mothers," *New York Times*, 20 January 1987, p. C1; Robertson, "Surrogate Mothers: Not So Novel after All," pp. 30, 34 n. 8. Neither the surrogate mothers themselves nor psychiatrists have been able to predict which women will experience such grief.

28. See Hochschild, *The Managed Heart*, for an important empirical study of the dynamics of commercialized emotional labor.

29. Keane and Breo, *The Surrogate Mother*, pp. 236-37.

30. For one account of how a surrogate mother who came to regret her decision viewed her own moral transformation, see Elizabeth Kane: *Birth Mother: The Story of America's First Legal Surrogate Mother* (San Diego: Harcourt Brace Jovanovich, 1988). I argue below that the implications of commodifying women's labor are not significantly changed even if the contract is unenforceable.

31. Susan Ince, "Inside the Surrogate Industry," in *Test-Tube Women*, ed. Rita Arditti, Ranate Duelli Klein, and Shelley Minden (Boston: Pandora Press, 1984), p. 110.

32. Philip Parker, "Motivation of Surrogate Mothers: Initial Findings," *American Journal of Psychiatry* 140(1983): 117-18.

33. The surrogate broker Noel Keane is remarkably open about reporting the desperate emotional insecurities which shape the lives of so many surrogate mothers, while displaying little sensitivity to the implications of his taking advantage of these motivations to make his business a financial success. See especially Keane and Breo, *The Surrogate Mother*, pp. 247ff.

34. See, for example, the story of the surrogate mother Nancy Barrass in Anne Fleming, "Our Fascination with Baby M," *New York Times Magazine*, 29 March 1987, p. 38.

35. For evidence of these disparate perspectives, see Peterson, "Baby M Case: Surrogate Mothers Vent Feelings," p. B4.

36. The surrogate mother is required to obey all doctor's orders made in the interests of the child's health. (See Brophy, "A Surrogate Mother Contract"; Keane, "The Surrogate Parenting Contract"; and Ince, "Inside the Surrogate Industry.") These orders could include forcing her to give up her job, travel plans, and recreational activities. The doctor could confine her to bed, and order her to submit to surgery and take drugs. One can hardly exercise an autonomous choice over one's health if one could be held in breach of contract and liable for \$35,000 damages for making a decision contrary to the wishes of one's doctor.

37. See Corea, *The Mother Machine*, pp. 227–33, and Christine Overall, *Ethics and Human Reproduction* (Boston: Allen and Unwin, 1987), pp. 122–28. Both emphasize the social conditions which undermine the claim that women choose to be surrogate mothers under conditions of autonomy.
38. Both of these conclusions follow the Warnock commission's recommendations. See Warnock, *A Question of Life*, pp. 43–44, 46–47. Since the surrogate mother is a victim of commercial surrogacy arrangements, she should not be prosecuted for entering into them. And my arguments are directed only against surrogacy as a commercial enterprise.
39. Barbara Cohen, "Surrogate Mothers: Whose Baby Is It?" *American Journal of Law and Medicine* 10 (1984): 282; Peter Singer and Deane Wells, *Making Babies* (New York: Scribner, 1985), pp. 106–7, 111.
40. Harris, *The Value of Life*, pp. 143–44, 156.
41. Singer and Wells support this recommendation in *Making Babies*, pp. 110–11. See also the dissenting opinion of the Warnock commission, *A Question of Life*, pp. 87–89.
42. See Fleming, "Our Fascination with Baby M," for a sensitive discussion of Americans' conflicting attitudes toward surrogate mothers who find they cannot give up their children.
43. *In Re Baby M*, p. 2022. See also Robertson, "Surrogate Mothers: Not So Novel after All," p. 32.
44. The Catholic Church makes this principle the fundamental basis for its own criticism of surrogate motherhood. See Congregation for the Doctrine of the Faith, "Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day," reproduced in *New York Times*, 11 March 1987, pp. A14–A17.

## Egg Donation and Commodification

BONNIE STEINBOCK

Bonnie Steinbock is a professor of philosophy at the State University of New York, Albany. In this essay she addresses the ethical issues raised by egg donation and its commodification. She argues that payment to donors is morally permissible provided the payment is not for the eggs but for the burdens of egg retrieval. She suggests that this distinction will help limit payment and ensure that payment is not made based on the donor's traits or on the number or quality of eggs retrieved.

Both payment for egg donation and payment for surrogacy raise ethical issues. I will address only egg donation, for two reasons. First, more has been written about surrogacy than about egg donation. Second, and more important, the two practices raise very different ethical issues. Surrogacy, or contract pregnancy as some prefer to call it, involves giving birth to a child and then waiving one's rights to custody of that child. In a few

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well-publicized cases, surrogates have changed their minds and attempted to keep the children. This has never, to my knowledge, occurred with egg donation. This is because there is a huge psychological and emotional difference between giving someone else your egg to gestate and deliver a baby, and gestating and delivering a baby yourself and then giving that baby to someone else. Indeed, in most cases, the egg donor does not even know if a child resulted from her donation. While a donor certainly should think about how she will feel about the possibility that there will be a child, or children, genetically linked to her out there in the world, she does not have to contemplate surrendering a child to whom she has given birth. Additionally, a child

born from a surrogate arrangement may feel abandoned by the biological mother, just as an adopted child often does. The feelings of rejection by such children are likely to be compounded by the recognition that the birth mothers conceived them and relinquished them for money. It is implausible that a child conceived through egg donation would feel the same way. Finally, whatever may be wrong with commercial egg donation, it cannot plausibly be characterized as “baby selling.” . . .

### **Noncommercial Gamete Donation**

The Roman Catholic Church opposes gamete (ovum or sperm) donation because of its views on the unity of sexual intercourse and procreation. Sexual intercourse without openness to procreation is wrong, the Church claims (hence its opposition to birth control), but equally so is procreation without sexual intercourse (hence its opposition to most forms of assisted reproduction). Even the “simple case” of in vitro fertilization (IVF), where the husband and wife provide the gametes and the resulting embryos are implanted in the wife’s uterus, is impermissible, according to Catholic teaching. The wrong is compounded in gamete donation, as the introduction of “a third party” violates the unity of marriage. In addition, according to the Rev. Albert Moraczewski, egg donation is demeaning to women. “A donor woman is not really being treated as a person,” he said. “Whether she is paid or acts out of kindness, her egg is being used, so she is not fully treated as a person whose reproductive capacity should be expressed as a result of the love of her husband.” (1)

But why is egg donation demeaning? Presumably blood donation is not demeaning, and does not fail to treat the donor as a person. What is the difference? The answer, according to the Vatican, is that egg donation involves a wrongful use of reproductive capacity. But then to characterize egg donation as demeaning is not to give a reason why it is wrong; rather, egg donation is demeaning because it is wrong. To see egg donation as demeaning, one must accept the principle that reproductive capacity should be exercised only through a sexual act in the context of a loving marriage. And that principle is justified by the supposedly indissolvable unity of

sex, love and procreation. There is nothing inconsistent or incoherent in this view, but it is unlikely to be persuasive to non-Catholics who accept contraception or assisted reproduction.

A different objection to gamete, specifically sperm, donation comes from Daniel Callahan. AID is “fundamentally wrong,” according to Callahan, because a sperm donor is a father, who has all the duties of any other biological father, including rearing responsibilities. Sperm donation, according to Callahan, is as irresponsible as abandoning a woman when she becomes pregnant. He writes: (2)

The only difference between the male who impregnates a woman in the course of sexual liaison and then disappears, and the man who is asked to disappear voluntarily after providing sperm, is that the latter kind of irresponsibility is, so to speak, licensed and legitimated. Indeed, it is treated as a kindly, beneficent action. The effect on the child is of course absolutely identical—an unknown, absent father.

Certainly, it is true that the child born from sperm donation does not know his or her genetic father. But it is not true that these children are fatherless, as is true of most children whose fathers abandon their mothers. They do have fathers—the men who are raising them. Why, one may ask, is it irresponsible to enable an infertile man, who wants very much to parent a child, to become a father? Sperm donors, it may be said, do not evade or abandon their obligations, as do men who abandon women they have impregnated, but rather transfer their rearing rights and duties to others. These others may be men or they may be single women or lesbian couples, who are increasingly using sperm donation. Is it wrong to donate sperm if the resulting child will grow up in a fatherless home? Is this an abandonment of one’s responsibility as a father? In my view, this depends on whether the child can be expected to have a reasonably good life. There is evidence that children in single-parent households are at a disadvantage (since it is usually more stressful to raise a child on one’s own), but growing up in a lesbian family does not appear to have a negative impact on quality of parenting or children’s psychological development. (3) Many lesbian mothers attempt to mitigate the disadvantages of not having

a father by making sure that there are other men in their child's life.

David Benatar (4) acknowledges that "gamete donation is not a unilateral abandonment of responsibility," but rather a transference of responsibility. Nevertheless, Benatar thinks that the responsibility of child rearing is one that should not be transferred, that doing so shows a lack of moral seriousness. Certainly, transferring child-rearing responsibilities without much thought is reprehensible; one thinks of Rousseau, who took five illegitimate children he had with his mistress to an orphanage. But is that what gamete donors do? Sperm and ova are not, after all, children. In my opinion, gamete donors do not give others their children to raise. Rather, they enable people who very much want to have children of their own to do so by providing them with genetic material. A woman who does not have eggs can still experience gestation, birth, and lactation, giving her a biological, if not genetic, connection to her child. In addition, if her husband's sperm is used, he will also have a biological connection to the child....

### **Why Do Women Want to Donate?**

Given the rigors of egg donation, why would a woman who was not undergoing IVF or tubal ligation be willing to undergo egg donation for strangers? Some donors are curious about their own bodies and fertility. They want to know if their eggs are "good." (5) Some have a personal reason for helping, such as having friends or relatives who have struggled with infertility or have undergone miscarriages. Others are attracted by the idea of giving "the gift of life," as the advertisements for egg donors put it. One donor explained it as follows, on a donor website: "I can't even describe how it felt to know that in some small way I helped this couple achieve a huge dream in their life." But while most egg donors are motivated in part by altruistic considerations, most women would not be egg donors for strangers without financial compensation. Many say that egg donation would be impossible if they were not compensated for lost work time, transportation, daycare costs, and the like. However, most donors think that reimbursement for pecuniary expenses alone is not enough. They think that it is only fair that they should

receive reasonable compensation for what they go through in order to provide eggs: the inconvenience, burden, and medical risk they have endured.

### **How Much Payment?**

Compensation has been increasing rapidly over the years. In the mid-1980s, egg donors were paid only about \$250 per cycle. Today, the payment is usually between \$1,500 and \$3,000—depending on the location of the clinic. In an effort to attract donors, some clinics offer substantially more. In 1998, Brooklyn IVF raised its donor compensation from \$2,500 to \$5,000 per cycle to keep pace with St. Barnabas Medical Center in nearby Livingston, New Jersey. "It's obvious why we had to do it," says Susan Lobel, Brooklyn IVF's assistant director. "Most New York area IVF programs have followed suit." (6)

Donors with particular attributes, such as enrollment in an Ivy League college, high SAT scores, physical attractiveness, or athletic or musical ability, have allegedly been offered far larger sums. "The International Fertility Center in Indianapolis, Indiana, for instance, places ads in the *Daily Princetonian* offering Princeton women as much as \$35,000 per cycle. The National Fertility Registry, which, like many egg brokerages, features an online catalogue for couples to browse in, advertises \$35,000 to \$50,000 for Ivy League eggs." (6) In March 2000, an ad appeared in *The Daily Californian* (the campus newspaper for the University of California, Berkeley), which read, "Special Egg Donor Needed," and listed the following criteria for a "preferred donor": "height approximately 5'6" Caucasian, S.A.T. score around 1250 or high A.C.T., college student or graduate under 30, no genetic medical issues." The compensation was listed as \$80,000 "paid to you and/or the charity of your choice." In addition, all related expenses would be paid. Extra compensation was available for someone especially gifted in athletics, science/mathematics or music.

Perhaps the most well-known instance of commercial egg donation is Ron Harris's website, [www.ronsangels.com](http://www.ronsangels.com), which offered models as egg donors, "auctioning their ova via the Internet to would-be parents willing to pay up to \$150,000 in

hopes of having a beautiful child.” (7) A subsequent story suggested that the “egg auction” might just be a publicity stunt to attract people to an erotic website, a claim that a spokesman for Mr. Harris denied. (8) Some infertility experts maintain that the ads offering large sums of money for special donors are not genuine offers, but rather a “bait and switch” tactic to recruit donors. Donors who respond are told that the ad has been filled, but that there are other recipients (offering substantially less money) seeking donors. *The Daily Californian* ad mentioned above specifically stated, “This ad is being placed for a particular client and is not soliciting eggs for a donor bank.” I recently e-mailed the International Infertility Center in Indianapolis, asking them if the fee of \$35,000 mentioned in the news report was actually paid to anyone. They responded that the “high-profile client” on whose behalf they had advertised did not find an ovum donor meeting the requirements, and so no ovum donor was compensated \$35,000 for a cycle. I have not been able to discover if any “special donors” have received the sums in the ads.

Most people would distinguish between reasonable compensation and offering \$30,000 or more to special donors. What explains the negative reaction most people experience when learning of these huge offers? Perhaps we think that people who are so intent on getting superior eggs (or “designer genes”) will be incompetent parents. Instead of anticipating having a child to love, it seems that the couple is focusing on the traits their child will have. They are not satisfied with having a healthy child, which is the reason for genetic screening of donors. Nor is their aim simply to have children who resemble them, something that adoptive parents also usually want. These are reasonable requests, whereas seeking donors from Ivy League schools, with high SATs and athletic ability, indicates something else. The placers of these ads want, and are willing to pay huge sums to get, a “superior” child, and this seems inconsistent with an ideal of unconditional parental love and acceptance.

Moreover, anyone who thinks that it is possible to guarantee that a child will be brilliant, athletic, musically talented, or even blond haired and blue eyed, is likely to be disappointed. According to

several prominent geneticists writing in *The New Republic*, “despite what your high school biology teacher told you, Mendelian rules do not apply even to eye color or hair color.” (9) Even genetic diseases widely considered to follow Mendelian rules, like sickle-cell anemia, may be more or less severe, due to the interaction with other genes in the genome. Predicting or determining non-disease-related traits like intelligence, athletic ability, or musical talent is even less likely, as there are probably thousands of genes that play a role. Finally, the interaction of genes and the environment makes it very difficult to know in advance what phenotypic traits an individual will have. This is not to deny that traits like intelligence or athletic ability have a genetic component, but only to say that they cannot be guaranteed by the choice of an egg donor (who, after all, only provides half the genes). We may well worry about the welfare of a child who fails to live up to parental expectations, after the parents have spent all that money.

The welfare of offspring is a legitimate concern, despite philosophical worries over how to conceptualize it. (10) If commercial egg donation led to poor parenting or had adverse effects on the parent-child relationship, that would be an important moral objection. Yet such an objection might not justify the conclusion that the buying and selling of eggs is morally impermissible, still less that it should be legally banned. For we do not think that procreation is morally permissible only for ideal parents. Nevertheless, concern about effects on parenting and the parent-child relationship fall under the heading of “thick” moral assessments, and may be legitimate.

On the other hand, it is possible that couples who place the ads understand that they cannot determine their children’s traits and that they do not have false expectations. Nevertheless, they might say, they want to give their child an advantage, a better chance at traits likely to help the child in life. It is not that they can only love a tall, brilliant, athletic child, they might say, but rather than they are well aware how advantageous such traits can be. Why, they might ask, if they have the money to spend, should they not use it to give their child the best chance in life? Indeed, some have argued that

prospective parents are morally required to have the best child they can. (11)

The Human Fertilization and Embryology Authority (HFEA) in the U.K. cited “the physical and psychological well-being of children born from egg donation” as a reason to ban all payments, not just large ones, to egg donors. According to one member of HFEA, (12) “Children produced by egg donation could be adversely affected psychologically if they knew that payment had been made as part of their creation.” This seems not only speculative, but implausible. Children may be psychologically harmed if they sense that their parents’ love is contingent on their having certain traits, but why would a child be psychologically harmed by learning that the woman who provided the egg from which he or she was conceived received payment? It seems to me that this concern stems from an inappropriate analogy with commercial surrogacy. Children might well be upset to learn that their biological mothers gave them away for money, but it seems implausible that any child would have similar feelings about an egg donor. This being the case, it is hard to see why children would be affected by whether donors were paid or not.

Another moral objection to these ads is that they are elitist and violate a principle of equality. There is something offensive in the idea that the eggs of Princeton women are worth \$50,000, while the eggs of women at Brooklyn College are worth only \$5,000. (John Arras has jokingly suggested that perhaps *US News & World Report* should include how much their coeds can get for their eggs in their rankings of colleges [personal communication].) Yet it is not clear why we should be offended at the difference in the price put on eggs if we are not offended by differences in employment opportunities or salary.

Some people are disturbed not only by the payment of large sums to egg donors, but by any payment at all. Commercial egg donation is criticized on the grounds that this “commodifies” the human body or “commodifies” reproduction.

### **Commodification**

To commodify something is to give it a market price. That in itself is not a bad thing. We could not

buy our groceries or clothes or the morning paper if they did not have a market price. If some things should not be commodified, we need a rationale for this. This is not always forthcoming. As the guest editors of a recent special issue on commodification in the *Kennedy Institute of Ethics Journal* say, (13) “Unfortunately, a great deal of the talk about ‘commodification’ has been clumsy and sloppy. The term has been used as a magic bullet, as if saying, ‘But that’s commodification!’ is the same as having made an argument.”

The challenge is to distinguish legitimate activities in which the human body or its abilities are used, from those thought to be illegitimate. As Ruth Macklin has put it, (14) “Every service in our economy is sold: academics sell their minds; athletes sell their bodies. . . . If a pretty actress can sell her appearance and skill for television, why should a fecund woman be denied the ability to sell her eggs? Why is one more demeaning than the other?”

Those who tend to oppose commodification typically portray those who are skeptical about its moral wrongness as being enamored of the market, of thinking that freedom of choice is the only or the most important moral value. They say, “. . . there are some categories of human activities that should not be for sale.” (15) But this, even if true, is unhelpful. We want to know *what* things and activities should not be for sale and *why*? Michael Walzer gives voting as an example of a market exchange that should be blocked. Citizens may not sell their votes or vote a certain way for a price. (16) This is so even if the exchange is fully voluntary and even if it makes both parties better off. The reason why votes may not be sold is that this conflicts with the rationale for having the institution of voting in the first place. Voting is intended to express the will of the people in a democracy. Democracy is subverted if votes can be bought.

What we want, then, is a similarly persuasive rationale for the wrongness of selling human body parts. Suzanne Holland attempts to give one. She writes: (17)

For many of us, our sense of the dignity of humanity is fundamentally disturbed by the suggestion that that which bears the marks of personhood can somehow be equated with property. We do not wish

to have certain aspects of that which we associate with our personhood sold off on the market for whatever the market will bear.

Eggs should not be seen as property, according to Holland, because the human body is “inalienable.” But what does this mean? To call rights “inalienable” is to say that they cannot be taken away from us, though Joel Feinberg has argued that we can waive them. (18) If calling the human body “inalienable” means that others cannot use my body or body parts without my permission, that is undeniable. But why does this imply that I may not sell my gametes? If “inalienable” just means “may not be treated like property,” then Holland has not given a reason why eggs are not property, but rather a tautology.

The fact that something is a human body part does not make it obviously wrong to sell it. In the novel *Little Women*, Jo sells her hair to raise money for her father, who is serving as a chaplain in the Union Army. Surely that was not morally wrong of Jo, nor demeaning to her. Indeed, her willingness to part with “her one beauty” is an unselfish and noble gesture. If selling one’s hair is morally permissible, but selling one’s gametes is not, what is the moral difference?

It might be thought that I am missing an obvious point. Selling one’s hair is not wrong because hair is unrelated to sex and reproduction. Selling one’s eggs is akin to selling one’s body in prostitution, and “we all know” that prostitution is wrong. Actually, prostitutes do not literally sell their bodies, since they do not relinquish control. It is more accurate to say that they rent them out, or rather that they perform sexual acts in exchange for money. Most of us believe that this is wrong, but this belief may be due in part to sexual puritanism. Perhaps the distaste we feel for prostitution stems (at least in part) from the way prostitutes have typically been regarded in patriarchal societies—as women of no value, undeserving of respect. Imagine a world in which those who provided sexual services were treated with as much respect as psychotherapists, trainers, and masseurs are in our society. It might be that, under such conditions, prostitution would not be as degrading. But even if this argument is

invalid, there is a vast personal difference between these two types of “selling,” and there is no obvious reason why paying egg donors is incompatible with treating them with respect.

There are two more reasons why selling eggs might be wrong. Providing eggs is both painful and risky. Perhaps offering money to women will lead them to take undue risks, opening up the potential for coercion or exploitation. In addition, some argue that payment for eggs inserts the values of the market into the family. I will consider these objections in turn.

### **The Potential for Coercion or Exploitation**

In its report on *Assisted Reproductive Technologies*, the New York State Task Force made the following recommendation: (19)

Gametes and embryos should not be bought and sold, but gamete and embryo donors should be offered compensation for the time and inconvenience associated with donation. Payments to egg donors should not be so high as to become coercive or so low that they provide inadequate reimbursement for time and inconvenience.

Can offering large sums of money for eggs be seen as coercive? That depends on the theory of coercion that one adopts. (20) In one theory, to coerce is to make a threat: do this or I will make you worse off. The classic example is the highwayman who says, “Your money or your life.” Clearly, potential egg donors are not coerced in this sense, no matter how much money is offered to them. They can turn down the offer and be no worse off than they were.

Perhaps this is too narrow a view of coercion. Perhaps there can be “coercive offers” as well as threats. Consider the following example:

*The Lecherous Millionaire:* Betty’s child will die without expensive surgery, which is not covered by her insurance. Alan, a millionaire, offers to pay for the surgery if Betty will have sex with him.

Alan is not threatening Betty. He will not harm her if she refuses. Yet there is a very real sense in which she has “no choice,” and for this reason we might see the offer as coercive. But even if this is true, and there can be “coercive offers,” does this

apply to egg donation? It might, if the money were offered to terribly poor women whose lives, or the lives of their children, depended on their donating eggs. A woman whose only choice was to give away her eggs or see her child die of starvation might well be seen as the victim of coercion. However, poor women are not usually sought out as egg donors. Typical egg donors are middle-class, often professional, young women. It is simply not true to say that they have no choice but to sell their eggs.

Very large offers of money could be quite tempting to any woman, not just those in desperate need of money. But, as Alan Wertheimer points out, offers are not coercive just because they are tempting. And they are not coercive because they are so good that it would be irrational to refuse. It is not coercive to offer someone a great job at double the salary she is currently earning. (21)

However, if offers of large sums of money are not coercive, they may still be criticized as being "undue inducements." Offering "too much" money may be an attempt to manipulate women into becoming donors. The lure of financial gain may lead them to discount the risks to themselves and to make decisions they will later regret. To take advantage of this is a form of exploitation.

It might be argued that we should not attempt to protect adults from irrational assessments or choices they will later regret, because this is paternalistic. However, paternalism involves preventing people from doing what they want on the grounds that this is in their best interest. It is not paternalistic to refrain from taking advantage of someone's susceptibility to temptation.

Some people have tried to meet the charge of commodification by distinguishing between compensating egg donors for their time, risk, and inconvenience, and payment for their eggs. This distinction has been challenged by several commentators, including Ruth Macklin, who writes, (14) "If there is something suspect about commodifying human reproductive products, it is similarly suspect to commodify human reproductive services." However, I think there are two reasons to distinguish between payment for time, risk, and inconvenience, and payment for eggs. First, if payment is viewed as compensation for the burdens of

egg retrieval, then large payments based on the donor's college, height, or SAT scores would be unjustified. It is as burdensome for a SUNY-Albany student as it is for a Princeton student to go through the egg retrieval process. Additionally, if payment is compensation for the donor's time, risk, and burden, then donors would be compensated regardless of the number or quality of eggs retrieved, whereas this makes no sense if payment is for the product (eggs). Despite Macklin's rejection of the product/service distinction, she makes precisely this recommendation.

If excessive payments exploit donors, so do payments that are too low. Justice would seem to require that the women who go through the rigors of egg retrieval be fairly compensated. Why are only egg donors expected to act altruistically, when everyone else involved in egg donation receives payment? In light of the sacrifices of time, risk, and burden that egg donors make, it seems only fair that they receive enough money to make the sacrifice worthwhile.

### **Other Worries About Exploitation**

Concerns about the exploitation of egg donors are not limited to payment issues. When the New York State Task Force on Life and the Law completed its report on assisted reproductive technologies, (19) one of its findings was that there were serious omissions in the process of gaining informed consent of egg donors. Donors did not always know how strenuous donation would be, or how much time it would take. They often had only the vaguest idea about who would pay their expenses, should there be medical complications stemming from donation. In one study, researchers were told by a number of women that all of their follow-up care was provided free of charge, but two women were billed for medical expenses for follow-up care and medical complications even though both were promised that the clinic would cover these costs:

One woman was promised follow-up care prior to donating, but after the donation, that care was denied. She sought out her own personal physician for a sonogram and had to pay hundreds of dollars out of pocket because she was uninsured at the time. (22)

Another woman fainted at work while taking hormonal injections. She had muscle spasms and started to convulse, and had to stay overnight in the hospital. “The clinic denied that her condition was related to the donation and refused to pay for her hospitalization. She is currently fighting with her own health insurance and worker’s compensation over the \$3500 bill.” (22)

One of the most significant sources of conflict in egg donation is the pressure on health care providers to hyperstimulate the donor to produce the maximum number of oocytes. The more eggs, the better the recipient’s chances at implantation, but the greater the danger to the donor of suffering from hyperstimulation syndrome. (22) One donor who testified before the advisory committee to the New York State Task Force on Life and the Law revealed that one of her cycles had been stopped, but she had no idea that this was due to excessive stimulation, which had posed health risks to her. She thought that the reason so many eggs had been retrieved was that she was “super-fertile.” One of the fertility doctors on the committee said that it was not uncommon for clinics to “flatter” donors in this way, to get them to be repeat donors. Such deceptive treatment of donors is, in my view, a greater source of exploitation, and an area of greater moral concern, than offering payment.

Altruistic egg donation would not necessarily be immune from exploitation. In fact, the true risks and burdens of egg donation might be less likely to be revealed in a voluntary system than in a carefully regulated commercial market, if only because the counseling and screening of donors costs money. Yet altruism can be an appropriate factor. When egg donation imposes little or no extra burden, as in the case of women who are undergoing IVF themselves or women having tubal ligations, there is less reason to compensate women for donating. Altruism in such cases is morally appropriate, as is the case with blood donation, which also involves minimal time and risk. The greater the burdens and risks, the less appropriate is the expectation of altruistic donation.

For some critics, it is not concerns about vulnerable donors that lie at the heart of their objections to commercial egg donation, but rather the effects

on the families that are created, and ultimately on society at large.

### **Threats to Families**

Tom Murray writes: (23)

New reproductive technologies are a challenge to our notions of family because they expose what has been at the core of the family to the vicissitudes of the market. At the heart of our often vague concerns about the impact of new reproductive technologies, such as those about the purchase of human eggs, is our sense that they threaten something valuable about families.

While Murray acknowledges that even noncommercial gamete donation raises “morally relevant difficulties” (presumably those raised by Callahan [2] and Benatar [4], as well as the issue of the introduction of “a third party” into the marital relationship), he thinks it likely that these difficulties are outweighed by the good of creating new parent-child relationships. It is payment that Murray finds morally objectionable. He writes: (23)

If you believe that markets, the values markets exemplify, and the relationships that typify market interactions, celebrate human freedom, and that such freedom is the preeminent good, then none of this should bother you. If, however, you regard families as a sphere distinct from the marketplace, a sphere whose place in human flourishing requires that it be kept free of destructive incursions by the values of the market, paying gamete providers should trouble you.

I think we would all agree that families should be protected from destructive incursions by the values of the market—but which incursions are destructive? Presumably it is okay to pay the people who care for our children: daycare workers, nannies, and babysitters. These transactions, supposedly, do not commercialize families. Also, presumably, there is nothing wrong with paying those who provide fertility treatment: doctors, nurses, receptionists, lawyers, and genetics counselors. So what is it about paying gamete providers that is threatening to families? Murray does not say. One can agree with his view (23) that “thinking of children as property, and of family life as essentially

a series of commercial transactions, is a grievous distortion,” but it is unclear what this has to do with paying gamete donors. Eggs are not children, and buying eggs (or even embryos) is not buying children. Still less is it clear why reasonable compensation to egg providers should turn family life into a series of commercial transactions.

### Incomplete Commodification: A Reasonable Compromise

Is there room for compromise between those who prefer an altruistic system of egg donation and those who think that egg donors should be paid? Suzanne Holland suggests we take an approach she calls “incomplete commodification”: (17)

With respect to gamete donors, an incompletely commodified approach could recognize that donors are contributing to something that can be seen as a social and personal good (remedying infertility), even as they deserve a degree of compensation that constitutes neither a financial burden ([if they are paid] too little) nor a [temptation to undergo] health risk ([if paid] too much). I see no reason not to follow the suggestion of [the] ASRM [American Society for Reproductive Medicine] and cap egg donor compensation at \$5000. . . . Allowing some compensation, but capping it at \$5000, would reduce the competition for eggs and perhaps curb the lure of advertising that is targeted to college students in need of “easy money.”

Not everyone agrees that \$5,000 is appropriate compensation. Mark V. Sauer, a reproductive endocrinologist at Columbia-Presbyterian Medical Center, was “shocked” by the decision of St. Barnabas to double compensation from the community standard of \$2,500 to \$5,000 per cycle: “Even if one considers the time spent in traveling to the local office and waiting for an ultrasound exam to be ‘work,’ donors now will be earning in excess of \$300 per hour. I find it hard to believe that anyone thinks this ‘reasonable compensation’ according to the recommendations of the Ethics Committee of the American Society for Reproductive Medicine.” (24) However, Sauer’s figure apparently takes into consideration only the number of hours spent traveling to and waiting at the clinic, together with the time required for the procedure. It does not consider

compensation for risk or discomfort, or the time that some donors will have to take off from work or classes due to side effects from the drugs they must take. When these factors are considered, reimbursement of \$5,000 may not be an “indecent proposal.” Perhaps if, like Sauer, doctors are worried that (24) “most importantly, and most unfortunately, these expenses will have to be passed on directly to our patients, who are already spending considerable sums of money to seek this procedure,” they might consider reducing their fees.

If compensation were completely banned, few women would agree to be egg donors. Very little egg donation would occur, and this would be unfortunate for those women who cannot have babies any other way. This is part of the justification for paying egg donors; the other part has to do with treating donors fairly. At the same time, legitimate concerns about the psychological welfare of the offspring created, and the potential for exploitation of donors, speaks to the need to limit payments to amounts that are reasonable and fair.

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## Cloning Human Beings: An Assessment of the Ethical Issues Pro and Con

DAN W. BROCK

In this essay Brock reviews the arguments for and against human reproductive cloning. He maintains that there is probably a right to reproductive freedom that covers human cloning, but there could be other rights in conflict with this right, or serious enough harms involved to override it. The possible benefits of human cloning include the ability to relieve infertility, to avoid transmitting serious genetic disease to offspring, and to clone someone (such as a child who died) who had special meaning to individuals. Arguments against the practice include that it violates a right to unique identity or to an open future, that it would cause psychological harm to the later twin, that it would carry unacceptable risks for the clone, and that it would lessen the worth of individuals and diminish respect for human life. Brock finds little merit in the identity and open-future arguments but thinks that human cloning does carry risk of significant harms, although most of the harms that people fear are based on common misconceptions.

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The world of science and the public at large were both shocked and fascinated by the announcement in the journal *Nature* by Ian Wilmut and his colleagues that they had successfully cloned a sheep from a single cell of an adult sheep (Wilmut, 1997). But many were troubled or apparently even horrified at the prospect that cloning of adult humans by

the same process might be possible as well. The response of most scientific and political leaders to the prospect of human cloning, indeed of Dr. Wilmut as well, was of immediate and strong condemnation.

A few more cautious voices were heard both suggesting some possible benefits from the use of human cloning in limited circumstances and questioning its too quick prohibition, but they were a clear minority. A striking feature of these early responses was that their strength and intensity seemed far to outrun the arguments and reasons offered in support of them—they seemed often to be “gut level” emotional reactions rather than considered reflections on the issues. Such reactions should not be simply dismissed, both because they may point us to important considerations otherwise missed and not easily articulated, and because they often have a major impact on public policy. But the formation of public policy should not ignore the moral reasons and arguments that bear on the practice of human cloning—these must be articulated in order to understand and inform people’s more immediate emotional responses. This essay is an effort to articulate, and to evaluate critically, the main moral considerations and arguments for and against human cloning. Though many people’s religious beliefs inform their views on human cloning, and it is often difficult to separate religious from secular positions, I shall restrict myself to arguments and reasons that can be given a clear secular formulation.

On each side of the issue there are no distinct kinds of moral arguments brought forward. On the one hand, some opponents claim that human cloning would violate fundamental moral or human rights, while some proponents argue that its prohibition would violate such rights. While moral and even human rights need not be understood as absolute, they do place moral restrictions on permissible actions that an appeal to a mere balance of benefits over harms cannot justify overriding; for example, the rights of human subjects in research must be respected even if the result is that some potentially beneficial research is more difficult or cannot be done. On the other hand, both opponents and proponents also cite the likely harms and benefits, both to individuals and to society, of the practice. I shall

begin with the arguments in support of permitting human cloning, although with no implication that it is the stronger or weaker position.

### Moral Arguments in Support of Human Cloning

#### Is There a Moral Right to Use Human Cloning?

What moral right might protect at least some access to the use of human cloning? A commitment to individual liberty, such as defended by J. S. Mill, requires that individuals be left free to use human cloning if they so choose and if their doing so does not cause significant harms to others, but liberty is too broad in scope to be an uncontroversial moral right (Mill, 1859; Rhodes, 1995). Human cloning is a means of reproduction (in the most literal sense) and so the most plausible moral right at stake in its use is a right to reproductive freedom or procreative liberty (Robertson, 1994a; Brock, 1994), understood to include both the choice not to reproduce, for example, by means of contraception or abortion, and also the right to reproduce.

The right to reproductive freedom is properly understood to include the right to use various assisted reproductive technologies (ARTs), such as in vitro fertilization (IVF), oocyte donation, and so forth. The reproductive right relevant to human cloning is a negative right, that is, a right to use ARTs without interference by the government or others when made available by a willing provider. The choice of an assisted means of reproduction should be protected by reproductive freedom even when it is not the only means for individuals to reproduce, just as the choice among different means of preventing conception is protected by reproductive freedom. However, the case for permitting the use of a particular means of reproduction is strongest when it is necessary for particular individuals to be able to procreate at all, or to do so without great burdens or harms to themselves or others. In some cases human cloning could be the only means for individuals to procreate while retaining a biological tie to their child, but in other cases different means of procreating might also be possible.

It could be argued that human cloning is not covered by the right to reproductive freedom

because whereas current ARTs and practices covered by that right are remedies for inability to reproduce sexually, human cloning is an entirely new means of reproduction; indeed, its critics see it as more a means of manufacturing humans than of reproduction. Human cloning is a different means of reproduction than sexual reproduction, but it is a means that can serve individuals' interest in reproducing. If it is not protected by the moral right to reproductive freedom, I believe that must be not because it is a new means of reproducing, but instead because it has other objectionable or harmful features; I shall evaluate these other ethical objections to it later.

When individuals have alternative means of procreating, human cloning typically would be chosen because it replicates a particular individual's genome. The reproductive interest in question then is not simply reproduction itself, but a more specific interest in choosing what kind of children to have. The right to reproductive freedom is usually understood to cover at least some choice about the kind of children one will have. Some individuals choose reproductive partners in the hope of producing offspring with desirable traits. Genetic testing of fetuses or preimplantation embryos for genetic disease or abnormality is done to avoid having a child with those diseases or abnormalities. Respect for individual self-determination, which is one of the grounds of a moral right to reproductive freedom, includes respecting individuals' choices about whether to have a child with a condition that will place severe burdens on them, and cause severe burdens to the child itself.

The less a reproductive choice is primarily the determination of one's own life, but primarily the determination of the nature of another, as in the case of human cloning, the more moral weight the interests of that other person, that is the cloned child, should have in decisions that determine its nature (Annas, 1994). But even then parents are typically accorded substantial, but not unlimited, discretion in shaping the persons their children will become, for example, through education and other childrearing decisions. Even if not part of reproductive freedom, the right to raise one's children as one sees fit, within limits mostly determined by the

interests of the children, is also a right to determine within limits what kinds of persons one's children will become. This right includes not just preventing certain diseases or harms to children, but selecting and shaping desirable features and traits in one's children. The use of human cloning is one way to exercise that right.

Public policy and the law now permit prospective parents to conceive, or to carry a conception to term, when there is a significant risk or even certainty that the child will suffer from a serious genetic disease. Even when others think the risk or certainty of genetic disease makes it morally wrong to conceive, or to carry a fetus to term, the parents' right to reproductive freedom permits them to do so. Most possible harms to a cloned child are less serious than the genetic harms with which parents can now permit their offspring to be conceived or born.

I conclude that there is good reason to accept that a right to reproductive freedom presumptively includes both a right to select the means of reproduction, as well as a right to determine what kind of children to have, by use of human cloning. However, the specific reproductive interest of determining what kind of children to have is less weighty than are other reproductive interests and choices whose impact falls more directly and exclusively on the parents rather than the child. Even if a moral right to reproductive freedom protects the use of human cloning, that does not settle the moral issue about human cloning, since there may be other moral rights in conflict with this right, or serious enough harms from human cloning to override the right to use it; this right can be thought of as establishing a serious moral presumption supporting access to human cloning.

### **What Individual or Social Benefits Might Human Cloning Produce?**

#### **Largely Individual Benefits**

The literature on human cloning by nuclear transfer or by embryo splitting contains a few examples of circumstances in which individuals might have good reasons to want to use human cloning. However, human cloning seems not to be the unique answer to any great or pressing human need and its benefits

appear to be limited at most. What are the principal possible benefits of human cloning that might give individuals good reasons to want to use it?

*1. Human cloning would be a new means to relieve the infertility some persons now experience.*

Human cloning would allow women who have no ova or men who have no sperm to produce an offspring that is biologically related to them (Eisenberg, 1976; Robertson, 1994b, 1997; LaBar, 1984). Embryos might also be cloned, by either nuclear transfer or embryo splitting, in order to increase the number of embryos for implantation and improve the chances of successful conception (NABER, 1994). The benefits from human cloning to relieve infertility are greater the more persons there are who cannot overcome their infertility by any other means acceptable to them. I do not know of data on this point, but the numbers who would use cloning for this reason are probably not large.

The large number of children throughout the world possibly available for adoption represents an alternative solution to infertility only if we are prepared to discount as illegitimate the strong desire of many persons, fertile and infertile, for the experience of pregnancy and for having and raising a child biologically related to them. While not important to all infertile (or fertile) individuals, it is important to many and is respected and met through other forms of assisted reproduction that maintain a biological connection when that is possible; that desire does not become illegitimate simply because human cloning would be the best or only means of overcoming an individual's infertility.

*2. Human cloning would enable couples in which one party risks transmitting a serious hereditary disease to an offspring to reproduce without doing so* (Robertson, 1994b). By using donor sperm or egg donation, such hereditary risks can generally be avoided now without the use of human cloning. These procedures may be unacceptable to some couples, however, or at least considered less desirable than human cloning because they introduce a third party's genes into their reproduction instead of giving their offspring only the genes of one of them. Thus, in some cases human cloning could be a reasonable means of preventing genetically transmitted harms to offspring. Here too, we do not

know how many persons would want to use human cloning instead of other means of avoiding the risk of genetic transmission of a disease or of accepting the risk of transmitting the disease, but the numbers again are probably not large.

*3. Human cloning to make a later twin would enable a person to obtain needed organs or tissues for transplantation* (Robertson, 1994b, 1997; Kahn, 1989; Harris, 1992). Human cloning would solve the problem of finding a transplant donor whose organ or tissue is an acceptable match and would eliminate, or drastically reduce, the risk of transplant rejection by the host. The availability of human cloning for this purpose would amount to a form of insurance to enable treatment of certain kinds of medical conditions. Of course, sometimes the medical need would be too urgent to permit waiting for the cloning, gestation, and development that is necessary before tissues or organs can be obtained for transplantation. In other cases, taking an organ also needed by the later twin, such as a heart or a liver, would be impermissible because it would violate the later twin's rights.

Such a practice can be criticized on the ground that it treats the later twin not as a person valued and loved for his or her own sake, as an end in itself in Kantian terms, but simply as a means for benefiting another. This criticism assumes, however, that only this one motive defines the reproduction and the relation of the person to his or her later twin. The well-known case some years ago in California of the Ayalas, who conceived in the hopes of obtaining a source for a bone marrow transplant for their teenage daughter suffering from leukemia, illustrates the mistake in this assumption. They argued that whether or not the child they conceived turned out to be a possible donor for their daughter, they would value and love the child for itself, and treat it as they would treat any other member of their family. That one reason they wanted it, as a possible means to saving their daughter's life, did not preclude their also loving and valuing it for its own sake; in Kantian terms, it was treated as a possible means to saving their daughter, but not *solely as a means*, which is what the Kantian view proscribes.

Indeed, when people have children, whether by sexual means or with the aid of ARTs, their motives

and reasons for doing so are typically many and complex, and include reasons less laudable than obtaining lifesaving medical treatment, such as having someone who needs them, enabling them to live on their own, qualifying for government benefit programs, and so forth. While these are not admirable motives for having children and may not bode well for the child's upbringing and future, public policy does not assess prospective parents' motives and reasons for procreating as a condition of their doing so.

*4. Human cloning would enable individuals to clone someone who had special meaning to them, such as a child who had died* (Robertson, 1994b). There is no denying that if human cloning were available, some individuals would want to use it for this purpose, but their desire usually would be based on a deep confusion. Cloning such a child would not replace the child the parents had loved and lost, but would only create a different child with the same genes. The child they loved and lost was a unique individual who had been shaped by his or her environment and choices, not just his or her genes, and more importantly who had experienced a particular relationship with them. Even if the later cloned child could not only have the same genes but also be subjected to the same environment, which of course is impossible, it would remain a different child than the one they had loved and lost because it would share a different history with them (Thomas, 1974). Cloning the lost child might help the parents accept and move on from their loss, but another already existing sibling or a new child that was not a clone might do this equally well; indeed, it might do so better since the appearance of the cloned later twin would be a constant reminder of the child they had lost. Nevertheless, if human cloning enabled some individuals to clone a person who had special meaning to them and doing so gave them deep satisfaction, that would be a benefit to them even if their reasons for wanting to do so, and the satisfaction they in turn received, were based on a confusion.

#### Largely Social Benefits

*5. Human cloning would enable the duplication of individuals of great talent, genius, character, or other exemplary qualities.* Unlike the first four

reasons for human cloning which appeal to benefits to specific individuals, this reason looks to benefits to the broader society from being able to replicate extraordinary individuals—a Mozart, Einstein, Gandhi, or Schweitzer (Lederberg, 1966; McKinnell, 1979). Much of the appeal of this reason, like much support and opposition to human cloning, rests largely on a confused and false assumption of genetic determinism, that is, that one's genes fully determine what one will become, do, and accomplish. What made Mozart, Einstein, Gandhi, and Schweitzer the extraordinary individuals they were was the confluence of their particular genetic endowments with the environments in which they were raised and lived and the particular historical moments they in different ways seized. Cloning them would produce individuals with the same genetic inheritances (nuclear transfer does not even produce 100 percent genetic identity, although for the sake of exploring the moral issues I have followed the common assumption that it does), but it is not possible to replicate their environments or the historical contexts in which they lived and their greatness flourished. We do not know the degree or specific respects in which any individual's greatness depended on "nature" or "nurture," but we do know that it always depends on an interaction of them both. Cloning could not even replicate individuals' extraordinary capabilities, much less their accomplishments, because these too are the product of their inherited genes and their environments, not of their genes alone.

None of this is to deny that Mozart's and Einstein's extraordinary musical and intellectual capabilities, nor even Gandhi's and Schweitzer's extraordinary moral greatness, were produced in part by their unique genetic inheritances. Cloning them might well produce individuals with exceptional capacities, but we simply do not know how close their clones would be in capacities or accomplishments to the great individuals from whom they were cloned. Even so, the hope for exceptional, even if less and different, accomplishment from cloning such extraordinary individuals might be a reasonable ground for doing so.

Worries here about abuse, however, surface quickly. Whose standards of greatness would be

used to select individuals to be cloned? Who would control use of human cloning technology for the benefit of society or mankind at large? Particular groups, segments of society, or governments might use the technology for their own benefit, under the cover of benefiting society or even mankind at large.

*6. Human cloning and research on human cloning might make possible important advances in scientific knowledge, for example, about human development* (Walters, 1982; Smith, 1983). While important potential advances in scientific or medical knowledge from human cloning or human cloning research have frequently been cited, there are at least three reasons for caution about such claims. First, there is always considerable uncertainty about the nature and importance of the new scientific or medical knowledge to which a dramatic new technology like human cloning will lead; the road to new knowledge is never mapped in advance and takes many unexpected turns. Second, we do not know what new knowledge from human cloning or human cloning research could also be gained by other means that do not have the problematic moral features to which its opponents object. Third, what human cloning research would be compatible with ethical and legal requirements for the use of human subjects in research is complex, controversial, and largely unexplored. Creating human clones solely for the purpose of research would be to use them solely for the benefit of others without their consent, and so unethical. But if and when human cloning was established to be safe and effective, then new scientific knowledge might be obtained from its use for legitimate, nonresearch reasons.

Although there is considerable uncertainty concerning most of human cloning's possible individual and social benefits that I have discussed, and although no doubt it could have other benefits or uses that we cannot yet envisage, I believe it is reasonable to conclude at this time that human cloning does not seem to promise great benefits or uniquely to meet great human needs. Nevertheless, despite these limited benefits, a moral case can be made that freedom to use human cloning is protected by the important moral right to reproductive freedom. I shall turn now to what moral rights might be

violated, or harms produced, by research on or use of human cloning.

### Moral Arguments Against Human Cloning

#### Would the Use of Human Cloning Violate Important Moral Rights?

Many of the immediate condemnations of any possible human cloning following Wilmut's cloning of Dolly claimed that it would violate moral or human rights, but it was usually not specified precisely, or often even at all, what rights would be violated (WHO, 1997). I shall consider two possible candidates for such a right: a right to have a unique identity and a right to ignorance about one's future or to an open future. Claims that cloning denies individuals a unique identity are common, but I shall argue that even if there is a right to a unique identity, it could not be violated by human cloning. The right to ignorance or to an open future has only been explicitly defended, to my knowledge, by two commentators, and in the context of human cloning, only by Hans Jonas; it supports a more promising, but in my view ultimately unsuccessful, argument that human cloning would violate an important moral or human right.

Is there a moral or human right to a unique identity, and if so would it be violated by human cloning? For human cloning to violate a right to a unique identity, the relevant sense of identity would have to be genetic identity, that is, a right to a unique unrepeatable genome. This would be violated by human cloning, but is there any such right? It might be thought that cases of identical twins show there is no such right because no one claims that the moral or human rights of the twins have been violated. However, this consideration is not conclusive (Kass, 1985; NABER, 1994). Only human actions can violate others' rights; outcomes that would constitute a rights violation if deliberately caused by human action are not a rights violation if a result of natural causes. If Arthur deliberately strikes Barry on the head so hard as to cause his death, he violates Barry's right not to be killed; if lightning strikes Cheryl, causing her death, her right not to be killed has not been violated. Thus, the case of twins does not show that there could not be a right to a unique genetic identity.

What is the sense of identity that might plausibly be what each person has a right to have uniquely, that constitutes the special uniqueness of each individual (Macklin 1994; Chadwick 1982)? Even with the same genes, homozygous twins are numerically distinct and not identical, so what is intended must be the various properties and characteristics that make each individual qualitatively unique and different from others. Does having the same genome as another person undermine that unique qualitative identity? Only on the crudest genetic determinism, according to which an individual's genes completely and decisively determine everything else about the individual, all his or her other nongenetic features and properties, together with the entire history or biography that constitutes his or her life. But there is no reason whatever to believe that kind of genetic determinism. Even with the same genes, differences in genetically identical twins' psychological and personal characteristics develop over time together with differences in their life histories, personal relationships, and life choices; sharing an identical genome does not prevent twins from developing distinct and unique personal identities of their own.

We need not pursue whether there is a moral or human right to a unique identity—no such right is found among typical accounts and enumerations of moral or human rights—because even if there is such a right, sharing a genome with another individual as a result of human cloning would not violate it. The idea of the uniqueness, or unique identity, of each person historically predates the development of modern genetics. A unique genome thus could not be the ground of this long-standing belief in the unique human identity of each person.

I turn now to whether human cloning would violate what Hans Jonas called a right to ignorance, or what Joel Feinberg called a right to an open future (Jonas, 1974; Feinberg, 1980). Jonas argued that human cloning in which there is a substantial time gap between the beginning of the lives of the earlier and later twin is fundamentally different from the simultaneous beginning of the lives of homozygous twins that occur in nature. Although contemporaneous twins begin their lives with the same genetic inheritance, they do so at the same time, and so in

ignorance of what the other who shares the same genome will by his or her choices make of his or her life.

A later twin created by human cloning, Jonas argues, knows, or at least believes she knows, too much about herself. For there is already in the world another person, her earlier twin, who from the same genetic starting point has made the life choices that are still in the later twin's future. It will seem that her life has already been lived and played out by another, that her fate is already determined; she will lose the sense of human possibility in freely and spontaneously creating her own future and authentic self. It is tyrannical, Jonas claims, for the earlier twin to try to determine another's fate in this way.

Jonas's objection can be interpreted so as not to assume either a false genetic determinism, or a belief in it. A later twin might grant that he is not determined to follow in his earlier twin's footsteps, but nevertheless the earlier twin's life might always haunt him, standing as an undue influence on his life, and shaping it in ways to which others' lives are not vulnerable. But the force of the objection still seems to rest on the false assumption that having the same genome as his earlier twin unduly restricts his freedom to create a different life and self than the earlier twin's. Moreover, a family environment also importantly shapes children's development, but there is no force to the claim of a younger sibling that the existence of an older sibling raised in that same family is an undue influence on the younger sibling's freedom to make his own life for himself in that environment. Indeed, the younger twin or sibling might gain the benefit of being able to learn from the older twin's or sibling's mistakes.

A closely related argument can be derived from what Joel Feinberg has called a child's right to an open future. This requires that others raising a child not so close off the future possibilities that the child would otherwise have as to eliminate a reasonable range of opportunities for the child autonomously to construct his or her own life. One way this right might be violated is to create a later twin who will believe her future has already been set for her by the choices made and the life lived by her earlier twin.

The central difficulty in these appeals to a right either to ignorance or to an open future is that the right is not violated merely because the later twin is likely to *believe* that his future is already determined, when that belief is clearly false and supported only by the crudest genetic determinism. If we know the later twin will falsely believe that his open future has been taken from him as a result of being cloned, even though in reality it has not, then we know that cloning will cause the twin psychological distress, but not that it will violate his right. Jonas's right to ignorance, and Feinberg's right of a child to an open future, are not violated by human cloning, though they do point to psychological harms that a later twin may be likely to experience and that I will take up later.

Neither a moral or human right to a unique identity, nor one to ignorance and an open future, would be violated by human cloning. There may be other moral or human rights that human cloning would violate, but I do not know what they might be. I turn now to consideration of the harms that human cloning might produce.

### **What Individual or Social Harms Might Human Cloning Produce?**

There are many possible individual or social harms that have been posited by one or another commentator and I shall only try to cover the more plausible and significant of them.

#### **Largely Individual Harms**

1. *Human cloning would produce psychological distress and harm in the later twin.* No doubt knowing the path in life taken by one's earlier twin might often have several bad psychological effects (Callahan, 1993; LaBar, 1984; Macklin, 1994; McCormick, 1993; Studdard, 1978; Rainer, 1978; Verhey, 1994). The later twin might feel, even if mistakenly, that her fate has already been substantially laid out, and so have difficulty freely and spontaneously taking responsibility for and making her own fate and life. The later twin's experience or sense of autonomy and freedom might be substantially diminished, even if in actual fact they are diminished much less than it seems to her. She might have a diminished sense of her own uniqueness and

individuality, even if once again these are in fact diminished little or not at all by having an earlier twin with the same genome. If the later twin is the clone of a particularly exemplary individual, perhaps with some special capabilities and accomplishments, she might experience excessive pressure to reach the very high standards of ability and accomplishment of the earlier twin (Rainer, 1978). These various psychological effects might take a heavy toll on the later twin and be serious burdens to her.

While psychological harms of these kinds from human cloning are certainly possible, and perhaps even likely in some cases, they remain at this point only speculative since we have no experience with human cloning and the creation of earlier and later twins. Nevertheless, if experience with human cloning confirmed that serious and unavoidable psychological harms typically occurred to the later twin, that would be a serious moral reason to avoid the practice. Intuitively at least, psychological burdens and harms seem more likely and more serious for a person who is only one of many identical later twins cloned from one original source, so that the clone might run into another identical twin around every street corner. This prospect could be a good reason to place sharp limits on the number of twins that could be cloned from any one source.

One argument has been used by several commentators to undermine the apparent significance of potential psychological harms to a later twin (Chadwick, 1982; Robertson, 1994b, 1997; Macklin, 1994). The point derives from a general problem, called the nonidentity problem, posed by the philosopher Derek Parfit, although not originally directed to human cloning (Parfit, 1984). Here is the argument. Even if all these psychological burdens from human cloning could not be avoided for any later twin, they are not harms to the twin, and so not reasons not to clone the twin. That is because the only way for the twin to avoid the harms is never to be cloned, and so never to exist at all. But these psychological burdens, hard though they might be, are not so bad as to make the twin's life, all things considered, not worth living. So the later twin is not harmed by being given a life even with these psychological burdens, since the alternative of never existing at all is arguably worse—he or she

never has a worthwhile life—but certainly not better for the twin. And if the later twin is not harmed by having been created with these unavoidable burdens, then how could he or she be wronged by having been created with them? And if the later twin is not wronged, then why is any wrong being done by human cloning? This argument has considerable potential import, for if it is sound it will undermine the apparent moral importance of any bad consequence of human cloning to the later twin that is not so serious as to make the twin's life, all things considered, not worth living.

I defended elsewhere the position regarding the general case of genetically transmitted handicaps, that if one could have a *different* child without comparable burdens (for the case of cloning, by using a different method of reproduction which did not result in a later twin), there is as strong a moral reason to do so as there would be not to cause similar burdens to an already existing child (Brock, 1995). Choosing to create the later twin with serious psychological burdens instead of a different person who would be free of them, without weighty overriding reasons for choosing the former, would be morally irresponsible or wrong, even if doing so does not harm or wrong the later twin who could only exist with the burdens. These issues are too detailed and complex to pursue here and the nonidentity problem remains controversial and not fully resolved, but at the least, the argument for disregarding the psychological burdens to the later twin because he or she could not exist without them is controversial, and in my view mistaken. Such psychological harms, as I shall continue to call them, are speculative, but they should not be disregarded because of the nonidentity problem.

*2. Human cloning procedures would carry unacceptable risks to the clone.* There is no doubt that attempts to clone a human being at the present time would carry unacceptable risks to the clone. Further research on the procedure with animals, as well as research to establish its safety and effectiveness for humans, is clearly necessary before it would be ethical to use the procedure on humans. One risk to the clone is the failure to implant, grow, and develop successfully, but this would involve the embryo's death or destruction long before most people

or the law consider it to be a person with moral or legal protections of its life.

Other risks to the clone are that the procedure in some way goes wrong, or unanticipated harms come to the clone; for example, Harold Varmus, director of the National Institutes of Health, raised the concern that a cell many years old from which a person is cloned could have accumulated genetic mutations during its years in another adult that could give the resulting clone a predisposition to cancer or other diseases of aging (Weiss, 1997). Risks to an ovum donor (if any), a nucleus donor, and a woman who receives the embryo for implantation would likely be ethically acceptable with the informed consent of the involved parties.

I believe it is too soon to say whether unavoidable risks to the clone would make human cloning forever unethical. At a minimum, further research is needed to better define the potential risks to humans. But we should not insist on a standard that requires risks to be lower than those we accept in sexual reproduction, or in other forms of ART.

### Largely Social Harms

*3. Human cloning would lessen the worth of individuals and diminish respect for human life.* Unelaborated claims to this effect were common in the media after the announcement of the cloning of Dolly. Ruth Macklin explored and criticized the claim that human cloning would diminish the value we place on, and our respect for, human life because it would lead to persons being viewed as replaceable (Macklin, 1994). As I have argued concerning a right to a unique identity, only on a confused and indefensible notion of human identity is a person's identity determined solely by his or her genes, and so no individual could be fully replaced by a later clone possessing the same genes. Ordinary people recognize this clearly. For example, parents of a child dying of a fatal disease would find it insensitive and ludicrous to be told they should not grieve for their coming loss because it is possible to replace him by cloning him; it is *their child who is dying* whom they love and value, and that child and his importance to them is not replaceable by a cloned later twin. Even if they would also come to love and value a later twin as much as

they now love and value their child who is dying, that would be to love and value that *different child* for its own sake, not as a replacement for the child they lost. Our relations of love and friendship are with distinct, historically situated individuals with whom over time we have shared experience and our lives, and whose loss to us can never be replaced.

A different version of this worry is that human cloning would result in persons' worth or value seeming diminished because we would come to see persons as able to be manufactured or "handmade." This demystification of the creation of human life would reduce our appreciation and awe of human life and of its natural creation. It would be a mistake, however, to conclude that a person created by human cloning is of less value or is less worthy of respect than one created by sexual reproduction. At least outside of some religious contexts, it is the nature of a being, not how it is created, that is the source of its value and makes it worthy of respect. For many people, gaining a scientific understanding of the truly extraordinary complexity of human reproduction and development increases, instead of decreases, their awe of the process and its product.

A more subtle route by which the value we place on each individual human life might be diminished could come from the use of human cloning with the aim of creating a child with a particular genome, either the genome of another individual especially meaningful to those doing the cloning or an individual with exceptional talents, abilities, and accomplishments. The child then comes to be objectified, valued only as an object and for its genome, or at least for its genome's expected phenotypic expression, and no longer recognized as having the intrinsic equal moral value of all persons, simply as persons. For the moral value and respect due all persons to come to be seen as resting only on the instrumental value of individuals and of their particular qualities to others would be to fundamentally change the moral status properly accorded to persons. Individuals would lose their moral standing as full and equal members of the moral community, replaced by the different instrumental value each has to others.

Such a change in the equal moral value and worth accorded to persons should be avoided at all

costs, but it is far from clear that such a change would result from permitting human cloning. Parents, for example, are quite capable of distinguishing their children's intrinsic value, just as individual persons, from their instrumental value based on their particular qualities or properties. The equal moral value and respect due all persons simply as persons is not incompatible with the different instrumental value of different individuals; Einstein and an untalented physics graduate student have vastly different value as scientists, but share and are entitled to equal moral value and respect as persons. It is a confused mistake to conflate these two kinds of value and respect. If making a large number of clones from one original person would be more likely to foster it, that would be a further reason to limit the number of clones that could be made from one individual.

*4. Human cloning might be used by commercial interests for financial gain.* Both opponents and proponents of human cloning agree that cloned embryos should not be able to be bought and sold. In a science fiction frame of mind, one can imagine commercial interests offering genetically certified and guaranteed embryos for sale, perhaps offering a catalogue of different embryos cloned from individuals with a variety of talents, capacities, and other desirable properties. This would be a fundamental violation of the equal moral respect and dignity owed to all persons, treating them instead as objects to be differentially valued, bought, and sold in the marketplace. Even if embryos are not yet persons at the time they would be purchased or sold, they would be being valued, bought, and sold for the persons they will become. The moral consensus against any commercial market in embryos, cloned or otherwise, should be enforced by law whatever the public policy ultimately is on human cloning.

*5. Human cloning might be used by governments or other groups for immoral and exploitative purposes.* In *Brave New World*, Aldous Huxley imagined cloning individuals who have been engineered with limited abilities and conditioned to do, and to be happy doing, the menial work that society needed done (Huxley, 1932). Selection and control in the creation of people was exercised not in the interests of the persons created, but in the interests

of the society and at the expense of the persons created; nor did it serve individuals' interests in reproduction and parenting. Any use of human cloning for such purposes would exploit the clones solely as means for the benefit of others, and would violate the equal moral respect and dignity they are owed as full moral persons. If human cloning is permitted to go forward, it should be with regulations that would clearly prohibit such immoral exploitation.

Fiction contains even more disturbing or bizarre uses of human cloning, such as Mengel's creation of many clones of Hitler in Ira Levin's *The Boys from Brazil* (Levin, 1976), Woody Allen's science fiction cinematic spoof *Sleeper* in which a dictator's only remaining part, his nose, must be destroyed to keep it from being cloned, and the contemporary science fiction film *Blade Runner*. These nightmare scenarios may be quite improbable, but their impact should not be underestimated on public concern with technologies like human cloning. Regulation of human cloning must assure the public that even such farfetched abuses will not take place.

## Conclusion

Human cloning has until now received little serious and careful ethical attention because it was typically dismissed as science fiction, and it stirs deep, but difficult to articulate, uneasiness and even revulsion in many people. Any ethical assessment of human cloning at this point must be tentative and provisional. Fortunately, the science and technology of human cloning are not yet in hand, and so a public and professional debate is possible without the need for a hasty, precipitate policy response.

The ethical pros and cons of human cloning, as I see them at this time, are sufficiently balanced and uncertain that there is not an ethically decisive case either for or against permitting it or doing it. Access to human cloning can plausibly be brought within a moral right to reproductive freedom, but its potential legitimate uses appear few and do not promise substantial benefits. It is not a central component of the moral right to reproductive freedom and it does not uniquely serve any major or pressing individual or social needs. On the other hand, contrary to the pronouncements of many of its opponents, human cloning seems not to be a violation of moral or

human rights. But it does risk some significant individual or social harms, although most are based on common public confusions about genetic determinism, human identity, and the effects of human cloning. Because most potential harms feared from human cloning remain speculative, they seem insufficient to warrant at this time a complete legal prohibition of either research on or later use of human cloning, if and when its safety and efficacy are established. Legitimate moral concerns about the use and effects of human cloning, however, underline the need for careful public oversight of research on its development, together with a wider public and professional debate and review before cloning is used on human beings.

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## Genetic Choices

We are now in the Genetic Era, a time when the century-old trickle of scientific facts about our genetic selves has given way to a torrent. The rivulet widened suddenly in 1953 when Francis Crick and James Watson discovered that the double helix was the shape of DNA—the chemical compound that encodes the encyclopedic set of instructions for producing and maintaining all living things. It broadened into a flood in 2003 when scientists finally were able to chart the length and breadth of the human genome, determining the exact sequence of a human being's 3 billion letters of DNA code, all grouped into 20,000–25,000 genes. Now scientists are rapidly pinpointing genetic factors that cause or contribute to diseases, developing tests to identify and predict (even before conception) specific human conditions, researching ways to alter genes to effect cures or devise treatments, enabling parents to have control over the genetic makeup of their children, and peering into the future at the power to change profoundly the human genome itself.

At each step, moral questions press in, and they intersect with almost every major ethical concern in this text—paternalism, autonomy, beneficence, rights, confidentiality, abortion, killing, personhood, reproductive technology, justice in providing health care, research ethics, and more. Science has once again outpaced conventional moral understanding as genetics inserts a host of raw, hard questions into our lives: Should genetic testing be used to identify or predict diseases even when no treatment is available? Do carriers of a deadly genetic disease that is likely to be passed on to their children have a duty to warn those children of the risk? Who

should control genetic information about a person, and what is a physician's duty regarding truth-telling and confidentiality? Is it “playing God” to alter someone's genes to treat diseases or prevent them in future generations? Is it wrong for parents to use preconception genetic testing and embryo selection to avoid having a disabled baby? Do these practices discriminate against disabled people? Should genetic technology be used to select a child's gender or other attributes such as eye and hair color and musical or athletic ability? Should eugenics be employed? That is, should genetic knowledge be applied to whole populations in an attempt to improve the human genome?

Such questions could continue for several pages, but let us try to grapple with some of the main ones.

### GENES AND GENOMES

Cells are the fundamental components of every living thing, and DNA (deoxyribonucleic acid) makes up the chemical coding that directs their construction, development, and operation. For nearly all organisms, DNA is the language of the genetic software that runs the cells and ensures the inheritance of traits from one generation to the next. Whether in ants, worms, gazelles, or humans, DNA consists of the same chemical ingredients and has the same molecular architecture: double, parallel strands linked together by chemical crossbars and twisted like a spiral staircase—the classic double helix. Each crossbar is formed by a matching pair of chemical bases, called a base pair. There are only four bases—adenine (A), guanine (G), cytosine (C),

and thymine (T)—yet they constitute the entire “alphabet” of the genetic code. Their order (the DNA sequence) along the strands (ATTCC-GGA, for example) encodes all the instructions required for making and maintaining an organism. As it “reads” the code, a cell constructs, according to the precise specifications, various proteins, which carry out most biological processes and provide almost all of the material for building cells.

An organism’s entire complement of DNA is known as its **genome**. The human genome consists of about 3 billion base pairs, and there is a complete genome in nearly every human cell. (A mouse genome has 2.6 billion base pairs; a fruit fly, 137 million; and an *E. coli* bacterium, 4.6 million.) In a typical human cell, the DNA strands total about six feet, coiled and crammed efficiently into an incredibly small space.

A cell does not “read” the 3 billion base pairs as one long stream of letters but as separate segments, or “words,” of the stream, each segment providing instructions to the cell for manufacturing a customized protein or small group of proteins. These words of genetic code are **genes**, the fundamental units of biological inheritance. The human genome contains 20,000–25,000 genes, which vary in the length of their instructions from hundreds of DNA bases up to 2 million. Each gene has a duplicate, with one copy inherited from the male parent and one from the female parent.

In the cell’s nucleus, the genes are neatly organized—bundled into 46 stringlike molecules known as **chromosomes**. These bundles are arranged into 23 pairs, with 22 of the pairs appearing the same for both males and females, and the twenty-third pair—the sex chromosomes—differing for males and females. Males have both an X and Y chromosome, while females have two X chromosomes.

Through the workings of all this genetic machinery, a human organism is produced and sustained, and a vast share of its characteristics is determined. (Genes have their say, but not necessarily the final say, on how a person turns

out, for he or she is also affected by the incredibly complex interactions between genetic systems and environmental factors.) When the machinery operates properly, the organism thrives. But flaws in the system—mistakes in the genes’ coded instructions—can sometimes lead to devastating disease or disability. Mistakes (mutations or alterations) can arise when the order of bases in a DNA sequence is wrong or when bases have been added, deleted, or duplicated. Occasionally extra genes or chromosomes are added, or essential ones are left out.

Some genetic mutations are acquired—they happen in people randomly or because of exposure to noxious agents such as radiation, chemicals, or cigarette smoke. The exposure disorders can “run in families” not because they are hereditary but because family members are exposed to the same harmful environmental factors. But many mutations are indeed hereditary and are transmitted through families, triggering the same genetic disease in subsequent generations. The genetic errors are responsible for more than 4,000 hereditary diseases.

Unfortunately, the relation between genetic flaws and genetic disease is usually anything but simple. In most cases, genetic diseases arise not from a single gene defect but from many mutations in one or more genes, coupled with a person’s lifestyle habits and environmental influences. Researchers believe that many common disorders such as heart disease, cancer, and diabetes are in this category.

## GENETIC TESTING

Thanks to scientific advances in genetics (most notably the tracing of the human genome sequence by the Human Genome Project), it is now possible to check for genetic disorders by looking for changes in a person’s DNA. This is the power of **genetic testing**, which now includes over two thousand tests designed to detect disease. With a small blood or tissue sample from a patient, clinicians can test for a host of genetic mutations that can unmask a

variety of disorders. The testing is done for several reasons, including:

- *Newborn screening* to uncover genetic diseases for early treatment. Every state mandates some kind of genetic testing for newborns, with some states screening for as many as 30 disorders. The first mandatory genetic testing was for phenylketonuria (PKU), a disorder resulting in profound intellectual disability when not treated early with a special diet.
- *Carrier testing* to determine whether someone is a carrier of a type of genetic disease known as an autosomal recessive disorder. A carrier possesses just one copy of a mutated gene and will not get the disease, but if two carriers together have a child, that child could inherit two copies of the mutated gene (one from each parent) and therefore greatly increase its chances of having the disease. PKU is such a disorder, and so is cystic fibrosis (a life-shortening illness affecting respiratory and gastrointestinal systems), sickle cell disease (a painful, debilitating blood cell disorder), and Tay-Sachs (a devastating metabolic disease usually causing death by age 5).
- *Predictive testing* to find out before any symptoms appear if someone is likely to develop a genetic disease later in life. This kind of testing is often recommended to people who have a family history of a genetic disorder. In a few cases, the testing can predict with high probability that a person will develop a disorder, but usually its implications are much more uncertain. For example, if testing shows that someone has the gene defect responsible for Huntington's disease (a life-shortening disorder causing dementia and physical deterioration), the chances that she will develop the disease are nearly 100 percent. But someone found to have a single copy of the gene mutation linked to venous thrombosis (a blood-clotting disorder) has only a slightly higher risk of getting the disease than the general population.
- *Diagnostic testing* to confirm or rule out a genetic disorder in someone with symptoms.
- *Prenatal testing* to determine if a fetus has genetic abnormalities likely to cause physical or mental impairments. It is performed when there is reason to suspect genetic risk—for example, when the mother is age 35 or older (Down syndrome babies are more likely in this age group), when inherited disorders are evident in family history, or when ancestry or ethnicity suggests a greater chance of particular genetic disorders such as sickle cell and Tay-Sachs. Several prenatal genetic testing procedures are now used, the most common being amniocentesis, which analyzes a sample of amniotic fluid, and chorionic villus sampling (CVS), which tests a few cells from the placenta. Fetuses can now be tested for a long list of genetic disorders causing physical deformities, developmental defects, intellectual disability, deafness, blindness, and death. Often if the news derived from prenatal testing is bad, parents must decide whether to terminate the pregnancy.
- *Preimplantation genetic diagnosis (PGD)* to test embryos produced through in vitro fertilization (IVF) for genetic abnormalities. Typically several embryos are produced in each cycle of IVF. Through PGD, those with genetic defects are screened out and only the mutation-free embryos are transferred to the woman's uterus for implantation. A typical procedure is to remove only one or two cells from a five- to eight-cell embryo for testing. PGD is costly and is usually reserved for cases in which there is a high probability of giving birth to a baby with serious disorders such as Down syndrome or Tay-Sachs disease.

Because genetics is bewilderingly complex, genetic testing itself is laden with complications that erode its usefulness and provoke medical and moral questions. For one thing, genetic tests almost never yield conclusive answers. In most cases, they can give only probabilities of developing a disease. Tests can identify a genetic mutation with certainty but usually can convey only in probabilities what ills that mutation might cause. For example, we can accurately determine that a woman has a mutation in the BRCA1 or BRCA2 gene, and this will tell us not that she will surely develop breast cancer but that she has a greater than 80 percent chance of doing so by age 70. So a positive test result (one identifying a mutation) does not guarantee the development of a genetic disorder. Moreover, though some disorders like Huntington's and Tay-Sachs are caused by mutations in a single gene (and thus are easier to predict), most genetic disorders result from abnormalities in several genes or in interactions between multiple genes and environmental factors. Scientists may not know about all the mutations responsible for a disorder, so available tests may identify only some of them. Or environmental influences later in life may cause mutations that earlier tests miss. So a negative test result (no mutation) does not guarantee a disease-free future.

Even when tests correctly predict a genetic disorder, they usually cannot foretell how severe its symptoms will be or when they will appear. Two people with mutations in the cystic fibrosis gene may differ dramatically in the severity of their respiratory and intestinal problems, and symptoms of Huntington's disease may arise in one person a decade before they appear in another.

Perhaps the most painful fact about genetic testing is that the power to identify and predict genetic disorders has outpaced our ability to do anything about them. We can now test for many diseases—and treat only some of them. We can ascertain that someone has a terrible disorder that has no treatment. Some argue that in such a situation, knowledge is not a blessing but a

curse. A 2002 Harris poll found that 81 percent of adults would likely want a genetic test for a disease that was treatable or otherwise responsive to risk reduction. But only 49 percent would be likely to have the test if there was no known treatment or any other ways to cut risks.<sup>1</sup>

Genetic testing can also take an emotional toll. Though some people find it reassuring or empowering, others do not. After getting their test results, some feel depressed, angry, or frightened. If the testing shows they are at no or low risk of having a disorder, they may be tormented by survivor's guilt. If the news is bad, they may become fatalistic; if the news is good, they may develop a feeling of invulnerability. Either way, they may ignore opportunities to lower their risk (when that's possible), or they may make things worse by behaving recklessly. Though some people who test positive for being carriers take steps to avoid passing on the genetic defect, some also feel ashamed, guilty, or socially stigmatized for being carriers. Along with all these scenarios comes the possibility of family conflicts, for testing can divulge facts not just about the person tested but also about her relatives.

From all these complexities a multitude of ethical issues arise, including the following.

**Personal Knowledge.** Many moral quandaries begin when people suspect they might have a genetic disorder for which testing is available. Should a person choose to be tested when an incurable genetic disease is suspected (and no one else is affected)? This is a question about personal values and worldviews. If a young man suspects he might have a devastating disease like Huntington's (which has no cure and does not affect people until middle age), and he understands that testing could confirm or disconfirm his suspicions, he must decide whether to know or not know his status. In accordance with his values, he may choose to know because he wants to confront life's hazards with his eyes wide open and to exert as much control over his fortunes as he can. Or he may forgo the chance

to learn his fate, seeking instead to live in hope as long as possible without the weight of a terrible diagnosis pressing down on him. This kind of choice is not merely hypothetical: Many symptomless people at risk for Huntington's disease decide not to be tested.

The moral equation changes when others are involved besides the one deciding whether to be tested. Imagine that a 45-year-old woman with grown children comes to believe that she probably has Huntington's disease because she has a family history and is beginning to experience some mild symptoms characteristic of the disease's early stages. If she has the gene mutation responsible for Huntington's, then each of her children has a 50 percent chance of inheriting it and thus having the disease. The average onset of the disorder is 35 to 44 years of age, with death usually occurring 13 to 15 years after that. Symptoms progress to extreme cognitive impairment and motor disability. The question is: Assuming she knows these facts, does she have a moral duty to be tested and, if the test is positive, to tell her children? Or, more generally, do we sometimes have a moral *obligation to know* and then a *duty to warn*?

Some might contend that she has no such obligation since the disease is untreatable. But others would disagree, arguing from the principle that we have a duty to prevent harm to others (especially those with whom we have a special relationship) if we are in a position to do so. Dutifully warned by their mother, the children could choose to be tested themselves and perhaps avoid transmitting the disorder to another generation by not having children or by using reproductive technology. In any case, the children could better arrange their lives to take the genetic facts into account, avoiding the harm of decisions made in ignorance.<sup>2</sup>

Often in genetic testing cases, people view the main ethical issue as a conflict between the duty to prevent harm to others and the principle of autonomy (typically construed as involving a right to privacy). Consider the case of three 20-something siblings, one of whom, Maria, has

been diagnosed with Wilson's disease, an inherited metabolic disorder causing liver dysfunction and serious psychiatric problems. Wilson's is an autosomal recessive disorder, and since Maria definitely has it, her siblings each possess a one in four chance of also having it. Effective treatment is possible if it is started before symptoms appear. So far the siblings show no symptoms, and they are unaware that Wilson's has affected their family. Maria understands that her siblings could possibly be spared a dreadful disease if they are tested and treated early. But she is ashamed of her condition, especially the psychiatric symptoms, and insists that her privacy be respected and that her diagnosis not be disclosed to any of her relatives.

According to any plausible view of the principle of autonomy, Maria should be permitted to make choices affecting her own life, and her privacy should be respected. But many would assume that she also has an obligation to prevent harm—specifically, a duty to warn her siblings of the danger posed by Wilson's disease. Assuming this description of the ethical parameters is correct, which duty makes a stronger demand on Maria? Many would argue that the duty to prevent harm is stronger. Respect for autonomy is not absolute; we may—and often should—violate someone's autonomy to prevent harm to others. But some would say that autonomy is supreme or that we have no obligation at all to prevent harm, arguing that we do have a duty not to directly *harm* others but not a duty to *save* others.

**Paternalism, Autonomy, and Confidentiality.** Dilemmas of genetic knowledge also afflict clinicians—most sharply when the duty to maintain patient confidentiality clashes with a duty to warn family members of serious genetic peril. In Maria's case, a physician is caught in the middle, duty-bound to respect her privacy yet seeing clearly the harm that could befall her siblings if they are not told the very thing that Maria wants to keep secret. The law has been equivocal about disclosure of medical

information against the patient's will, though some legal cases suggest that physicians may have a duty to warn people who are likely to be seriously harmed. A few physicians have been sued for their failure to inform relatives about genetic risks. Some physicians argue that breaching confidentiality may be morally permissible if the harm done by keeping silent outweighs the harm done by revealing private information about the patient. Others insist on strict adherence to a policy of nondisclosure. (Professional codes of ethics also differ on this issue.) But whatever view physicians take, they are likely to try to get around the dilemma by urging patients to warn their own family members.

In genetic testing, as in so many other areas of medicine, the principles of beneficence and autonomy collide, and the extent of physician paternalism is a live issue. For example, physicians have debated whether they should reveal to a patient the results of a genetic test showing that he or she is at high risk for an unpreventable, untreatable disease. They wonder if doing so is really in the patient's best interests. The question is especially keen when genetic testing targeted at one disorder incidentally uncovers a danger of falling prey to another—as when the APOE gene test for coronary heart disease shows a very high risk of eventually having Alzheimer's disease. The main argument against revealing this additional (and possibly unwanted) information is that it will not benefit the patient (because there is no way to prevent or treat Alzheimer's) and will cause the patient psychological harm. But many reject this view as strongly paternalistic and argue that the principle of autonomy gives patients the right to know their medical condition, including the results of genetic tests—even if the news is upsetting.

The same sorts of arguments are offered on the question of whether the public availability of genetic tests should be restricted. Most people can probably see the wisdom in restricting access to genetic tests that yield misleading, confusing,

or otherwise unhelpful information. (Many genetic tests are like this and are useful only when combined with family history.) But some physicians favor restricting access to genetic tests for more paternalistic reasons, arguing that genetic self-knowledge causes psychological harms such as depression, anxiety, and panic or that patients cannot understand the complexities and implications of genetic information. Those who disagree with this view maintain that there is no reason to think that most patients will be psychologically wrecked by learning the truth about their genetic risks, that patient autonomy trumps any such concerns, and that the complexity of medical information is usually not considered an adequate justification for overriding patient autonomy.

Many people welcome the chance to discover the facts about their genetic predispositions, but others think they have good reasons to conceal such information or to decline testing altogether. Their wariness is prompted by the possibility of **genetic discrimination**, the use of genetic information by employers, insurance companies, and others to discriminate against or stigmatize people. Many fear that employers may use genetic information to decide whether to hire or fire them, weeding out those who may be healthy now but at risk for future diseases that could reduce productivity. They are also afraid that to cut costs, insurance companies will deny them health coverage or cancel it because genetic tests suggest a likelihood of eventual illness. These possibilities have left some people reluctant to undergo genetic testing because the results could be used as evidence against them, and this reluctance has been reinforced by some documented cases of genetic discrimination. Until recently, no comprehensive federal law addressed genetic discrimination, while state laws were inconsistent and limited in their approach to the issue. In 2008 the Genetic Information Nondiscrimination Act was signed into law, prohibiting genetic discrimination by either insurance companies or employers and barring them from requesting genetic tests.

The main ethical concern here is justice, whether people are being treated fairly. Employers and insurers have a plausible interest in controlling the costs of doing business, but can this interest legitimately include granting economic benefits to some people and not to others merely because of a difference in genes? Is it morally permissible to discriminate against people in this way because of factors over which they have no control? Can it be right to discriminate against people who are now healthy but may someday be unhealthy? If this type of discrimination is legitimate, for what genetic mutations and conditions would it be appropriate? In most cases, the chances that specific mutations will result in a particular disease are difficult or impossible to gauge. Is it acceptable to discriminate against people when the basis for that discrimination is so dubious?

**Reproductive Decisions.** The possibility of detecting genetic mutations in a fetus or in an embryo inspires both hope and anguish—the hope of avoiding birth impairments, the anguish of moral conflict. The moral issues arise primarily because prenatal testing is coupled with the option of abortion (called *selective* when done to avoid impairments), and PGD entails embryo selection. In nearly every case, selective abortion and embryo selection are the only options for avoiding the birth of a severely impaired baby. Once a genetic mutation is discovered, there is little or nothing that can be done to correct the mutation or the disorder. Those opposed to all abortions and the screening or destruction of embryos will judge these procedures morally impermissible, and they may see no wrong in permitting the birth of children with serious abnormalities. But many think that abortion and embryo selection may be justified when used to avoid having babies with such terrible defects.

A typical statement of the latter view is that it would be wrong not to prevent devastating diseases or disabilities in a child. Explaining exactly why a failure to prevent defects would be

wrong, however, is not as easy as it might seem. We could say that failing to prevent an impairment is wrong because the child would be better off if the impairment were prevented, but philosophers have thought this notion incoherent. Bioethicist Dan W. Brock explains:

The difficulty is that it would *not* be better for the person with the handicap to have had it prevented since that can only be done by preventing him from ever having existed at all; preventing the handicap would deny the individual a worthwhile, although handicapped, life. . . . But if [a mother's] failing to prevent the handicap has not made her child worse off, then failing to prevent the handicap does not harm her child. And if she does not harm her child by not preventing its handicap, then why does she wrong her child morally by failing to do so?<sup>3</sup>

Philosophers have responded to this incoherence problem by arguing that even if failing to prevent a serious disability does not wrong the child, the failure is still morally wrong for other reasons—for example, because it contributes to overall suffering in the world or because it treats children unfairly by disregarding their legitimate interests in having a decent chance at a good life.

A common charge against genetic testing to prevent birth impairments is that it amounts to disrespect or discrimination against people with disabilities. Some critics are adamantly opposed to testing, claiming that its purpose is to eliminate an entire class of people (the disabled), which puts genetic testing in the same moral category as heinous attempts to eradicate whole races of people. Even if not discriminatory, others say, genetic testing is meant to prevent the existence of the disabled and make possible the existence of the normal, and that fact sends a message of disrespect to people now living with disabilities. The message is that it would be better if disabled people did not exist.

Genetic testing is discriminatory if it involves violating people's rights, and it is disrespectful if it entails an attitude of contempt or condescension. But some bioethicists have insisted that

discrimination or disrespect for persons is not entailed by genetic testing. For example:

Much of what is involved in equality of respect is compatible with screening. Aiming for the conception and birth of normal people, for instance, is perfectly compatible with insisting that the rights of disabled people are fully respected and with seeing them as equals. Medical treatment presupposes that health is better than sickness, but those who believe in it treat sick people as their equals.<sup>4</sup>

It has also been argued that anti-testing attitudes themselves have unsavory moral implications. Jeff McMahan points out that the critics of testing believe that “it is wrong for people to try to avoid having a disabled child and to have a non-disabled child instead.” But this seems to imply that an action that most think is wrong must be permissible:

[I]f it is morally *mandatory* to *allow* oneself to have a disabled child rather than to try, through screening, to have a child who would not be disabled, then it must be at least *permissible* to *cause* oneself to have a disabled rather than a non-disabled child.<sup>5</sup>

Yet most of us think it wrong deliberately to cause a disabled child to exist instead of a healthy child.

Even if we grant that embryo or prenatal testing is permissible, its use still raises a range of moral concerns. If a fetus has the gene for Huntington’s disease, it is almost certain to suffer from the disease as an adult. The probability of being affected is extremely high, so we might conclude that testing (and possibly a selective abortion) is justified. But what if the chances of being affected are lower or uncertain (as is the case with the BRCA1 or BRCA2 gene)? Would abortion or embryo selection be justified? Would it be permissible if the odds of having the disease were low but the suffering it could cause was horrendous? Some diseases predicted by testing are late-onset (Huntington’s and Alzheimer’s, for instance); a person could live a satisfying life for decades before having symptoms. Is selective abortion permissible in

such cases? Would it be permissible if the suffering at the end of life was likely to overshadow whatever happiness occurs earlier? Some predicted disorders are mild or treatable. Would parents have an obligation to screen out embryos with such disorders? Would it at least be permissible for parents to do so?

## GENE THERAPY

After deciphering the vast codex of the human genome and peering into the rich patterning of genes, humans have taken the next, seemingly inevitable, step: to try to repair the genetic flaws they see. This incredible repair work is known as **gene therapy** (also referred to as genetic engineering), the manipulation of someone’s genetic material to prevent or treat disease. It is an attempt to alter the workings of cells. Currently there are five main ways to do this, as explained by the American Society of Gene and Cell Therapy:

**Gene addition** involves inserting a new copy of a gene into the target cells to produce more of a protein. Most often, a modified virus such as adeno-associated virus (AAV) is used to carry the gene into the cells. . . .

**Gene correction** can be achieved by modifying part of a gene using recently developed gene editing technology (e.g., CRISPR/cas9, TALEN, or ZFN) to remove repeated or faulty elements of a gene, or to replace a damaged or dysfunctional region of DNA. The goal of gene correction is to produce a protein that functions in a normal manner instead of in a way that contributes to disease. . . .

**Gene silencing** prevents the production of a specific protein by targeting messenger RNA (mRNA; an intermediate required for protein expression from a gene) for degradation so that no protein is produced. . . .

**Reprogramming** involves adding one or more genes to cells of a specific type to change the characteristics of those cells. This technique is particularly powerful in tissues where multiple

cell types exist and the disease is caused by dysfunction in one type of cells. . . .

**Cell elimination** strategies are typically used to destroy malignant (cancerous) tumor cells, but can also be used to target overgrowth of benign (non-cancerous) tumor cells. Tumor cells can be eliminated via the introduction of “suicide genes,” which enter the tumor cells and release a prodrug that induces cell death in those cells. Viruses can be engineered to have an affinity for tumor cells. These oncotropic viruses can carry therapeutic genes to increase toxicity to tumor cells, stimulate the immune system to attack the tumor, or inhibit the growth of blood vessels that supply the tumor with nutrients.<sup>10</sup>

To date, most uses of gene therapy have been of the first kind, the insertion of a normal copy of a gene into cells to do the job that defective or absent genes should be doing. But delivering a gene to a cell is tricky and usually must be done with a carrier, or vector, such as a virus. Viruses can seek out particular cells and transfer pieces of DNA into them. Scientists put this natural talent of viruses to work by inactivating their harmful characteristics and modifying them to carry particular genes into designated cells. The genes can then induce the production of the proteins needed for normal functioning. A good example of this approach is the treatment of hemophilia (hemophilia A and B), a disorder that puts people at risk of bleeding to death because of impaired blood-clotting. The problem is caused by mutations in the genes that manufacture the proteins necessary for clotting (called blood-clotting factors), resulting in deficiencies of the proteins. In both animals and humans, scientists have used viruses to transfer normal copies of these genes into cells, enabling the genes to start producing the blood-clotting factors. The therapy has worked in animals and has shown promise in humans.

Gene therapy is of two types: somatic cell and germ-line cell. The former involves altering genes in a person’s somatic (body) cells, such as liver or muscle cells, to treat an existing disorder.

The alterations can help the person suffering from the disease but are not inheritable—they cannot be passed on to the person’s offspring. They affect the person’s genome but not the genomes of subsequent generations. The other type of gene therapy entails modifying genes in germ-line cells (egg and sperm cells) and zygotes—and these alterations are inheritable. Currently the scientific focus is on somatic-cell gene therapy, with most research evaluating treatments for cancer, heart disease, and infectious diseases. Gene therapy in germ-line cells is not yet feasible. But the ability to manipulate germ-line cells evokes both the dream of eradicating mutations from future generations (and thus permanently banishing particular disorders) and the nightmare of fabricating “designer” babies or introducing horrible errors into the human genome.

For scientists, physicians, and policymakers, the potential of gene therapy to effect cures is too great to ignore, so research will likely continue (and expand) indefinitely. But devising effective gene therapies is extremely difficult, and they can pose risks to patients. To develop any kind of effective gene therapy, scientists have to solve several technical problems. Chief among them are the difficulty of controlling viruses to accurately deliver genes to cells, the risk of virus carriers causing disease or provoking a harmful immune system response, and the complexity of treating disorders generated by multiple genes (such as diabetes, arthritis, heart diseases, and Alzheimer’s). For these and other reasons, the field is still experimental, with hundreds of gene therapy studies in progress all over the world but few or no therapies approved for routine use. So far, scientific studies demonstrating success in using gene therapy have been intriguing and encouraging but preliminary. But there is little doubt among experts that safe and effective gene therapies (at least the somatic-cell kind) will be devised in the next few years.

In 1990 researchers conducted the first federally approved study of gene therapy, treating a 4-year-old girl suffering from adenosine deaminase (ADA)

## Fact File Genetic Testing for Cancer Risk

Particular inherited changes, or variants, in a person's genes are associated with an increased risk of developing cancer, and more and more of these variants can be identified through testing. According to the National Cancer Institute, "Testing whether someone carries a harmful variant in one of these genes can confirm whether a condition is, indeed, the result of an inherited syndrome. Genetic testing is also done to determine whether family members who have not (yet) developed a cancer have inherited the same variant as a family member who is known to carry a harmful (cancer susceptibility predisposing) variant." The NCI's answers to some common questions:

### **Does someone who inherits a cancer susceptibility variant always get cancer?**

No. Even if a cancer susceptibility variant is present in a family, it does not necessarily mean that everyone who inherits the variant will develop cancer. Several factors influence whether a given person with the variant will actually develop cancer. . . .

### **What genetic tests are available for cancer risk assessment?**

More than 50 hereditary cancer syndromes have been described. . . . Most of these are caused by harmful variants that are inherited in an autosomal dominant fashion—that is, a single altered copy of the gene inherited from one parent is enough to increase a person's chance of developing cancer. For most of these syndromes, genetic tests for harmful variants are available.

Tests are also available for several inherited genetic variants that are not associated with named syndromes but have been found to increase cancer risk. Examples include inherited variants in PALB2 (associated with increased risks of breast and pancreatic cancers), CHEK2 (breast and colorectal cancers), BRIP1 (ovarian cancer), and RAD51C and RAD51D (ovarian cancer).

### **Who should consider genetic testing for cancer risk?**

People who are concerned about whether their family history puts them at risk for cancer should consult with a genetic counselor. The features of a person's personal or family medical history that, particularly in combination, may suggest a hereditary cancer syndrome include:

- Cancer was diagnosed at an unusually young age
- Several different types of cancer occurred in the same person
- Cancer in both organs in a set of paired organs, such as both kidneys or both breasts
- Several first-degree relatives (the parents, siblings, or children of an individual) have the same type of cancer (for example, a mother, daughter, and sisters with breast cancer); family members with breast or ovarian cancer; family members with colon cancer and endometrial cancer
- Unusual cases of a specific cancer type (for example, breast cancer in a man)
- The presence of birth defects that are known to be associated with inherited cancer syndromes, such as certain noncancerous (benign) skin growths and skeletal abnormalities associated with neurofibromatosis type I.
- Being a member of a racial or ethnic group that is known to have an increased risk of having a certain inherited cancer susceptibility syndrome and having one or more of the above features as well
- Several family members with cancer

(continued)

### **Can at-home or direct-to-consumer genetic tests be used to test for cancer risk?**

An increasing number of companies offer at-home genetic testing, also known as direct-to-consumer (DTC) genetic testing. People collect a saliva sample or a mouth swab themselves and submit the sample through the mail. They learn about the test results on a secure website, by mail, or over the phone....

DTC genetic testing for cancer risk often involves the analysis of common inherited genetic variants that, individually, are generally associated with only a minor increase in risk. Even when added together, all the known common variants associated with a particular cancer type account for only a small portion of a person's risk of that cancer. Genetic tests based on these common variants have not yet been found to help patients and their care providers make health care decisions and, therefore, they are not a part of recommended clinical practice.\*

\*National Cancer Institute, "Genetic Testing for Inherited Cancer Susceptibility Syndromes," March 15, 2019, Genetic Testing Fact Sheet—National Cancer Institute.

deficiency, a life-shortening disorder of severely weakened immunity. A normal gene generates ADA, an enzyme crucial to a healthy immune system, but in the girl the gene was missing, leaving her without any defense against life-threatening infections. Using a virus carrier, the researchers delivered the normal ADA gene to the girl's immune cells, hoping that it would produce the needed enzyme. The treatment worked. Her immune system soon began to function normally and did so for years.

Since that promising experiment, there have also been disappointments—and lessons to learn about the risks involved in gene therapy. In 1999 18-year-old Jesse Gelsinger experienced multiple organ failures and died during gene therapy to treat ornithine transcarboxylase deficiency (OTCD). The ultimate cause of death was traced back to his immune system's devastating reaction to the virus carrier. A few years later scientists used gene therapy to treat children with severe combined immunodeficiency (SCID), an intractable disorder that usually results in death by the age of 1. Amazingly, most of the children were cured. But two of these developed a condition like leukemia, so in 2003 the Food and Drug Administration (FDA) temporarily suspended clinical trials using these

procedures. Later the trials resumed with closer FDA oversight and a greater appreciation among scientists generally of the inherent risks and the curative possibilities of gene therapy.

As you might suspect, many moral questions about gene therapy center on its potential for harm and help. In somatic-cell gene therapy, the risks and benefits of using the technology have become the primary moral concern, spurred on by much soul-searching after the early clinical mistakes. Regulatory agencies and review boards have sprung up to oversee clinical trials and to ensure an acceptable balance of risks and benefits for study subjects. The prevailing view is that if such steps are taken to minimize harm, and if the potential benefits are substantial, somatic-cell therapy is morally permissible.

Germ-line therapy is a different matter. The safety concerns surrounding the technology are so worrisome that, at least in its current immature stage, it is generally thought to be morally unacceptable. The main problem is that scientists do not yet fully understand the likely ramifications of refashioning the genetic machinery of germ-line cells. The addition or modification of genes might make a condition worse or prevent one disease but cause others that are more severe. The result could be catastrophic or fatal

to a child born of such engineering, and the calamities could happen at birth or years later. Worse, the resulting disorders could be passed on to future children. The nightmare scenario is that the genetic changes are inherited by many people, and the human genome itself is altered for the worse. These unknowns have compelled scientists not to renounce this research but to proceed with extreme caution and to forgo clinical trials until the genetics of germ-line cells is better understood.

Many moral arguments for and against gene therapy—perhaps the most controversial ones—do not appeal to the possibility of harm from the procedure itself, or they work from the assumption that the safety and effectiveness of gene therapy will eventually be established. Those arguments in favor of applying gene therapy (in either form) mirror many of those made for reproductive technology and genetic testing: If it is within our power to correct genetic flaws and thereby prevent or cure diseases, aren't we obligated to do so? If gene therapy offers us the chance to prevent harm to future people, don't we have a duty to try? If the principle of autonomy (or reproductive liberty) grants us the freedom to reproduce or not reproduce, doesn't it also give us the right to decide whether our offspring will have a disability or disease?

The responses to these views should also sound familiar: Reproductive freedom has limits, and germ-line therapy crosses the line; the manipulation or destruction of embryos that may occur in germ-line therapy shows disrespect for human life; and gene therapy (especially germ-line) disrespects or discriminates against people with disabilities.

Some argue that gene therapy should not be permitted because it amounts to *eugenics*, the deliberate attempt to improve the genetic makeup of humans by manipulating reproduction. The word calls up images of the Nazi drive to racial purity through mandatory sterilization of undesirables as well as the early twentieth-century programs in the United States to forcibly sterilize criminals, "imbeciles," and other

"defective persons." Such misdeeds are morally objectionable for several reasons, most notably because they violate people's autonomy, the central feature of state-sponsored coercion. But the term *eugenics* is broad, covering a range of practices that are not necessarily coercive and that have been called eugenics of either a *negative* or *positive* kind. Negative eugenics is thought to involve the prevention or treatment of diseases, typically through genetic testing, embryo selection, selective abortion, or germ-line therapy. By this definition, prenatal screening—which is a matter of public policy and generally considered morally permissible—is a type of negative eugenics. Positive eugenics is said to include attempts to improve on normal functions. It seeks not repair, but enhancement. Theoretically through germ-line therapy, parents could produce children who are smarter, taller, or more resistant to certain diseases than normal children are. Such enhancements are controversial, even though they may not be technically possible for many years.

The idea of a distinction between repair and enhancement is prominent in moral debates because some argue that the former is morally obligatory while the latter is not. That is, we may have a duty to use gene therapy to treat Tay-Sachs disease or cystic fibrosis, but not to give a child an abnormally long life or a super immune system. Several bioethicists reject this view. For example, John Harris:

[S]uppose genes coding for repair enzymes which would not only repair radiation damage or damage by other environmental pollutants but would also prolong healthy life expectancy could be inserted into humans. Again, would it be permissible to let people continue suffering such damage when they could be protected against it? Would it in short be OK to let them suffer?

It is not normal for the human organism to be self-repairing in this way; this must be eugenic if anything is. But if available, its use would surely, like penicillin before it, be more than merely [permissible].

... There is in short no moral difference between attempts to cure dysfunction and attempts to enhance function where the enhancement protects life or health.<sup>6</sup>

Others insist that there is indeed a clear difference between the two, asserting that gene therapy is moral if it is intended to ensure or restore normal functions, but immoral if it is aimed at enhancing functions beyond normal. Their strongest objection to genetic enhancement is that it would lead to the most flagrant kind of social injustice. As Walter Glannon argues,

The main moral concern about genetic enhancement of physical and mental traits is that it would give some people an unfair advantage over others with respect to competitive goods like beauty, sociability, and intelligence.... Enhancement would be unfair because only those who could afford the technology would have access to it, and many people are financially worse off than others through no fault of their own. Insofar as the possession of these goods gives some people an advantage over others in careers, income, and social status, the competitive nature of these goods suggests that there would be no limit to the benefits that improvements to physical and mental capacities would yield to those fortunate enough to avail themselves of the technology.<sup>7</sup>

## STEM CELLS

There are over 200 different kinds of cells in the human body—muscle cells, blood cells, skin cells, nerve cells, and more. Yet all these cell types arise from just one sort of cell present in the early embryo, or blastocyst, five days after fertilization and before implantation in the uterus. These early cells are undifferentiated, having no specialized function as the other kinds of cells do; but they are also *pluripotent*, which means they are able to *become* differentiated, to turn into any of the body's specialty cells. They number only 30 or so inside the blastocyst, which is no larger than the dot on this

letter *i*. Under normal conditions, they quickly differentiate into the various cell types. But when they are extracted from the blastocyst and nurtured in culture dishes, they can remain undifferentiated and retain their power to transform into any kind of cell, while replicating themselves continuously without limit. At this point they are *embryonic stem cells*. Because they can reproduce indefinitely, creating replicating cell lines, just a few of them are needed to generate a large supply.

Other stem cells in the developed human—*adult stem cells*—stand ever ready to differentiate themselves to replace worn out or damaged cells, constantly renewing and repairing the body's parts. Adult stem cells generate new bone, cartilage, skin, muscle, blood, and many other tissues. But their potential to produce diverse kinds of cells is constrained—unlike the nearly unbounded powers of differentiation found in embryonic stem cells.

It is this regenerative potential of stem cells (especially the embryonic kind) that has excited so much scientific and medical interest. Researchers have found that by getting stem cells to differentiate into particular kinds of cells, new cells and tissues can be generated to treat diseases and injuries characterized by a lack of functioning cell types. The therapeutic possibilities include Parkinson's disease, diabetes, heart disease, Alzheimer's, stroke, spinal cord injuries, burns, and arthritis. For example, type I diabetes occurs for lack of the cells that produce insulin, but scientists think it may be possible to prod embryonic stem cells into becoming insulin-producing cells and then to transplant those cells into patients with diabetes. On another front, researchers are now investigating the possibility of using stem cells to generate new heart muscle tissue to transplant to damaged hearts. These and many other stem-cell investigations are preliminary and may not yield effective treatments for years, and so far the established stem-cell therapies are few (only blood and skin cell transplants). But the amazing potential for treatments and cures of

## Fact File New Developments in Gene Therapy

The U.S. Food and Drug Administration (FDA) has approved only a few gene therapy products for sale in the United States. But hundreds of gene therapy clinical trials are now testing the safety and effectiveness of treatments for a wide range of conditions. Here are some of the promising developments.

- **Chronic pain.** March 10, 2021. A gene therapy for chronic pain could offer a safer, non-addictive alternative to opioids. Researchers have developed the new therapy, which works by temporarily repressing a gene involved in sensing pain. It increased pain tolerance in mice, lowered their sensitivity to pain and provided months of pain relief without causing numbness. . . . The gene therapy could be used to treat a broad range of chronic pain conditions, from lower back pain to rare neuropathic pain disorders—conditions for which opioid painkillers are the current standard of care.
- **Immune deficiency in infants and children.** May 11, 2021. An investigational gene therapy can safely restore the immune systems of infants and children who have a rare, life-threatening inherited immunodeficiency disorder, according to research supported in part by the National Institutes of Health. The researchers found that 48 of 50 children who received the gene therapy retained their replenished immune system function two to three years later and did not require additional treatments for their condition, known as severe combined immunodeficiency due to adenosine deaminase deficiency, or ADA-SCID.
- **Alzheimer's disease.** May 4, 2021. Researchers at University of California San Diego School of Medicine, with colleagues elsewhere, have used gene therapy to prevent learning and memory loss in a mouse model of Alzheimer's disease (AD), a key step toward eventually testing the approach in humans with the neurodegenerative disease.
- **Childhood blindness.** April 19, 2021. A new gene therapy for one of the most common forms of congenital blindness was safe and improved patients' vision, according to initial data from a clinical trial led by researchers at the Scheie Eye Institute in the Perelman School of Medicine at the University of Pennsylvania. The therapy delivers working copies of GUCY2D to the eyes of patients who have severe vision impairments caused by mutations in the gene.
- **Angelman syndrome.** October 21, 2020. Babies born with a faulty maternal copy of the UBE3A gene will develop Angelman syndrome, a severe neurodevelopmental disorder with no cure and limited treatments. Now, for the first time, scientists at the UNC School of Medicine show that gene editing and gene therapy techniques can be used to restore UBE3A in human neuron cultures and treat deficits in an animal model of Angelman syndrome. This work . . . lays important groundwork for a long-lasting treatment or cure for this debilitating disease, as well as a therapeutic path forward for other single-gene disorders.\*

\*From "Gene Therapy News," Science Daily, May 19, 2021, Gene Therapy News—ScienceDaily.

seemingly unstoppable diseases spurs on the research, raises the stakes, and makes debates about halting stem-cell research all the more volatile.

Most of the moral controversy over embryonic stem cells has focused on their source. The main source is, of course, embryos (blastocysts), which are inevitably destroyed in the process of

retrieving the cells. The majority of the embryos are produced through IVF used in the treatment of infertility. IVF involves the production of multiple blastocysts, only some of which are eventually implanted in the uterus. The leftover blastocysts are frozen, and some that are neither implanted nor discarded may be used to extract stem cells. Another possibility is the use of IVF to create blastocysts specifically for stem-cell extraction in research—an option that is much more controversial than using the surplus blastocysts. Beyond the blastocyst stage there is one more stem-cell source: Researchers have been able to derive embryonic stem cells from fetuses obtained after elective abortions.

It is possible—but not yet technically feasible—to derive embryonic stem cells from blastocysts produced through what has been called *research* (or *therapeutic cloning*). Many distinguish this kind of cloning-for-research-purposes from *reproductive cloning*, which aims at the live birth of a baby. In both forms, the underlying method is the same: Replace the nucleus of an egg cell with the nucleus of an ordinary somatic cell (a skin cell, for example) from an adult and then stimulate this reconstructed cell to start cell division and growth into a blastocyst. In research cloning, stem cells would be derived from the blastocyst; in reproductive cloning, the blastocyst would be implanted in the uterus to continue the reproductive process to birth. An advantage of research cloning is that body tissues derived from the stem cells would be genetically matched to the nucleus donor, so the new tissues could be used to treat the donor with less risk of tissue rejection by the donor's body. To date, no one has extracted human embryonic stem cells from cloned embryos successfully, but judging from research in animals, the feat eventually will be accomplished.

In the United States the availability of embryonic stem cells for research has been influenced heavily by existing laws and policies. A law enacted in 1995 bans the use of federal funds for any research involving the destruction of human

embryos—a significant restriction since federal money drives an enormous portion of biomedical research. In 2001 President George W. Bush declared that no federal funding may support research that obtains stem cells by destroying embryos, although research may continue on the few existing stem-cell lines previously derived.

In March 2009 President Barack Obama issued an executive order that revoked the Bush restrictions and made way for a new policy allowing the National Institutes of Health to “support and conduct responsible, scientifically worthy human stem cell research, including human embryonic stem cell research.”

In 2007 a scientific breakthrough looked like it might solve the stem-cell source problem. Scientists announced that they were able to genetically reprogram ordinary human skin cells to take on the characteristics of embryonic stem cells. The findings seemed to promise an abundant future supply of embryonic stem cells for research without destroying embryos or using embryos already deceased. Many commentators immediately declared that science had finally ended the stem-cell debates that it began. Scientists everywhere welcomed the news of the breakthrough, but many also thought it premature to proclaim embryo research superfluous. They pointed out that it is not yet known whether the new engineered stem cells are as versatile, safe, or hearty as stem cells derived from embryos. They therefore favored pursuing, at least for now, both paths simultaneously.

Whether or not public disputes about embryonic stem cells subside, the underlying moral issues remain. The core question is this: Is it morally permissible to destroy human embryos in a search for cures? For those who believe that embryos have the moral status of persons, the answer must be no (just as it would be on the issue of abortion). The same goes for those who think using embryos as a source of stem cells shows disrespect for human life by reducing it to a mere commodity. In either case, people who grant embryos this special moral status are

likely to argue that destroying them cannot be justified by any potential medical and scientific benefits. Some who take this view insist that just using or benefiting from stem cells previously derived from embryos or aborted fetuses is also impermissible. But to be involved in this way is to participate, however indirectly, in the immoral act of destroying innocent human life.

At the other end of the moral spectrum are those who maintain that blastocysts have no moral status at all and should be treated like any other human cell. They therefore contend that the use of embryos in stem-cell research is permissible, especially since it promises to help alleviate much human suffering. Their main concerns are the safety, integrity, and usefulness of the research and the resulting therapies.

For many who adopt intermediate positions, early embryos have less than full moral status but are still deserving of some respect. Stem-cell research using embryos is therefore morally acceptable—within limits. Bonnie Steinbock, for example, takes this view:

Lacking the kinds of ends that persons have, embryos cannot be given the respect that is due to persons. Nevertheless, they have a significance and moral value that other bodily tissues do not have because they are “potent symbols of human life.” . . . We show respect for human embryos by not using them in unimportant or frivolous ways, say, to teach high school biology or to make cosmetics or jewelry. However, respect for embryos does not require refraining from research likely to have significant benefits, such as treating disease and prolonging life.<sup>8</sup>

Some stake out some middle ground in the stem-cell debate in other ways. They may argue that mining stem cells from embryos is objectionable but that manipulating already available stem-cell lines is not. Or that taking stem cells from aborted fetuses or from embryos left over after reproductive IVF is permissible but that using embryos created for research through IVF or therapeutic cloning is wrong. Or that using IVF embryos, created originally for whatever

reason, is moral but that generating embryos for stem-cell extraction through any kind of cloning is immoral.

### APPLYING MAJOR THEORIES

The moral theories that have been applied to familiar ethical problems for generations also do work in the epoch of genetic testing and intervention. A utilitarian perspective is likely to favor genetic testing and gene therapy if they tend to promote the general welfare. A utilitarian might say that tests providing useful information about people's genetic risks are probably beneficial overall, though benefits must be weighed against the harm that can result from misleading test results, genetic discrimination, and breaches of doctor-patient confidentiality. She almost certainly would argue that prenatal testing and PGD (combined with selective abortion and embryo selection) are morally acceptable because they can prevent devastating diseases and disabilities in children as well as emotional or economic suffering in families. Gene therapy (both somatic and germ-line cell) is likely to be viewed in the same way—morally permissible if its benefits outweigh its risks. The utilitarian also would not hesitate to employ positive eugenics if altering the human genome would, on balance, increase human happiness and ease suffering. She would probably sanction the therapeutic use of embryonic stem cells (derived from any source) as long as there was a net benefit to society.

A natural law theorist might view some forms of genetic testing (newborn screening and predictive testing, for example) as morally acceptable ways to gain knowledge about health risks and to guide treatment. But a theorist in the Roman Catholic tradition would in most instances object to prenatal testing and PGD because they usually lead directly to selective abortion and embryo selection—clear violations of the unborn's right to life. Natural law theory would seem to countenance somatic-cell gene therapy because the aims are therapeutic, like conventional medical treatment. But germ-line

## CLASSIC CASE FILE

## The Kingsburys

Increasing numbers of prospective parents are choosing to use PGD to screen their embryos for genetic diseases. In the past, many would-be parents who requested PGD knew this: They had a particular gene mutation, there was a good chance of passing it to their offspring, any child with the mutation is almost certain to develop the disease, and the disease is devastating and untreatable. The horrors in this category include cystic fibrosis, Huntington's disease, and Tay-Sachs. Now some couples in similar situations are taking PGD a step further: They are using it to screen for disorders that have much less than 100 percent probability of arising and that in many cases respond to treatment. The Kingsburys were among the first to face such a choice.

In their quest to have children, Chad and Colby Kingsbury were up against some dire genetic facts. Chad had inherited a genetic defect that causes a form of colon cancer—a disease that had already taken his mother and her two brothers, afflicted his cousin, and could very well soon affect him. For anyone with the mutation, the chances of having colon cancer are 20 times greater than normal. The disease generally appears in middle age, and most people can survive it if it's treated early. There is a 50 percent probability that any child of Chad's will inherit the mutation.

The Kingsburys understood these risks and knew that PGD could eliminate them. But there were other factors to weigh. PGD involves culling defective embryos (which are likely to be destroyed) and deliberately selecting those that are genetically acceptable. Is such a procedure morally permissible

when the disorder to be avoided is not invariably lethal, not guaranteed to arise, and not likely to develop, if at all, until middle age?

As reported in the *New York Times*, to opt for PGD,

[The Kingsburys] had to overcome their own misgivings about meddling with nature. They had to listen to the religious concerns of Mr. Kingsbury's family and to the insistence of Ms. Kingsbury's that the expense and physical demands of in vitro fertilization were not worth it, given that the couple could probably get pregnant without it. They had to stop asking themselves the unanswerable question of whether a cure would be found by the time their child grew up. . . . It took them two months to make the decision.<sup>9</sup>

In the end they chose PGD, and a healthy baby girl, Chloe, was the result. She will not get—and her children will not inherit from her—the kind of colon cancer that has ravaged Chad Kingsbury's family.

He says that he and his wife made the right decision: "I couldn't imagine them telling me my daughter has cancer when I could have stopped it."

Many people object to PGD and the embryo selection that it entails, arguing that it is morally equivalent to abortion, that it amounts to arrogant interference in natural processes, that it is eugenics run amok to create "designer babies," and that it demonstrates disrespect for people with disabilities. Nevertheless, the use of PGD is likely to increase—and to be applied to an ever-widening range of diseases with varying degrees of severity.

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gene therapy as a tool of positive eugenics would probably be condemned as contrary to nature. Research using stem cells derived from embryos would be considered immoral because it involves destroying innocent human life.

The Kantian notions of autonomy and of persons as ends-in-themselves support the right of patients to know (or not to know) the results of genetic tests, to have those results guarded according to rules of privacy and confidentiality,

and to be treated fairly without fear of genetic discrimination. If by Kantian lights an embryo is a person, then destroying it after genetic testing may be impermissible. It's possible, however, to construe Kant as allowing the destruction of this person-embryo on the grounds that preventing its future suffering could actually be an act of respect for its personhood. Likewise, positive eugenics could be seen through Kantian eyes as a way to improve human life while leaving personhood untouched.

#### KEY TERMS

chromosome  
eugenics  
gene  
gene therapy  
genetic discrimination  
genetic testing  
genome

#### SUMMARY

DNA makes up the chemical coding that directs the development and operation of cells, the fundamental components of every organism. Genes, the basic units of biological inheritance, are discrete segments of DNA strands. Genes in turn are organized into 46 chromosomes, arranged in 23 pairs. According to the instructions written in genes, a human organism is produced and sustained, and a large portion of its characteristics is determined. Mistakes, or mutations, in the DNA coding can lead to a variety of diseases and conditions, some of them grave.

Genetic testing involves procedures to check for genetic disorders by looking for changes in a person's DNA. Common forms of testing include newborn screening; carrier, predictive, diagnostic, and prenatal testing; and preimplantation genetic diagnosis (PGD). Genetic tests rarely yield certain predictions. For several reasons, a positive test result does not guarantee the presence of a disorder, and a negative test result does not ensure its absence. Unfortunately, our ability to detect diseases through genetic testing has outstripped our power to treat

many of them. Many moral questions that arise from genetic testing are about duties to warn family members when an inherited disorder is discovered, the obligation of physicians regarding patient autonomy and confidentiality, the permissibility of genetic discrimination, and the morality of using testing to avoid causing seriously disabled persons to exist.

Gene therapy is the manipulation of someone's genetic material to prevent or treat disease. The somatic-cell type involves altering genes in a person's body cells; the germ-line type entails modifying genes in egg and sperm cells and zygotes. Ethical issues concern the medical risks and benefits of the therapy, duties to use the procedures to prevent suffering, reproductive freedom, and the morality of practicing positive genetics.

Embryonic stem cells can be derived from blastocysts, aborted fetuses, research cloning, and—apparently—genetically engineered somatic cells. The core issue regarding them is whether it is morally permissible to destroy them in a search for cures. Those who assign personhood status to embryos say no. Those who reject that view may grant embryos no special status at all, or they may say that embryos are not persons but are still worthy of some respect. In either case, embryonic stem-cell research is thought to be permissible.

## Cases for Evaluation

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### CASE I

#### Selecting Babies

(*TimesOnline*)—A British couple have won the right to test embryos for a gene that leads to high cholesterol levels and an increased risk of heart attacks, *The Times* has learnt.

The decision by the fertility watchdog will reopen controversy over the ethics of designer babies, as it allows doctors to screen embryos for a condition that is treatable with drugs and can be influenced by lifestyle as well as genes.

While the procedure is designed to detect a rare version of a disease called familial hypercholesterolaemia

(FH), which often kills children before puberty, it will also identify a milder form that can be controlled by drugs and diet.

Critics argue that the test will allow couples to destroy embryos that would have had a good chance of becoming children with fulfilling and reasonably healthy lives.

The test will also create an unprecedented moral dilemma for some couples, as it could show that they have produced no embryos completely unaffected by the disease. This would force them to decide whether to implant embryos that they know have a genetic risk of premature heart disease and death, or to throw them away and deny them a chance of life.

Britain's first licence to test embryos for FH will be awarded next week to Paul Serhal, of University College Hospital in London, by the Human Fertilisation and Embryology Authority (HFEA).

Its decision breaks new ground because it permits Mr. Serhal to screen out not only the severe form of the condition but also the milder type, which is usually treatable.

Embryo screening has previously been approved only for disorders in which a gene invariably causes a serious disease, or for conditions such as breast cancer in which mutations carry an 80 percent lifetime risk.

FH occurs in two forms. The more common version, heterozygous FH, affects 1 in 500 people. It is caused by a single mutated gene, which raises cholesterol and thus the risk of hardened arteries, heart disease, and stroke. It can usually be managed with statin drugs and diet.

One in 250,000 people inherits two defective copies of the gene and develops homozygous FH, which is much more serious. Sufferers show severely elevated cholesterol from the age of 5, and can suffer angina by 6 or 7. Many die in childhood, and most have suffered at least one heart attack by the end of their twenties.

Mr. Serhal's patients, who are in their thirties, both have the milder heterozygous FH. They discovered their status only when they had a daughter, now 5, with the homozygous form, and they also have an unaffected son.

They said yesterday that they were delighted. "We had no idea that we both carried a gene for high cholesterol until the double gene was expressed in our

first child. We are very lucky that our child has responded so well to the very high-dose drug regime. We have been led to understand that other children with the same double gene may not be so lucky." . . .

Mr. Serhal said: "This obnoxious disease can cause cardiovascular accidents at a very young age. Ideally, we will find embryos with no FH genes, but it is possible we will not and it will be up to the patients to choose. Some people would think twice about using embryos that they know have a risky gene, and others would say you shouldn't screen out a condition that can be managed so people can live with it. It will be an awkward choice."\*

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*Is it wrong for parents to screen out embryos with disorders that are treatable? What about embryos that will probably—not certainly—develop a serious disease? Or those that will develop a fatal disease only in middle age? Is it morally permissible to cause persons to exist who are severely disabled and likely to suffer horribly throughout their lives? Give reasons for your answer.*

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\*Mark Henderson, "Designer Baby Fear over Heart Gene Test," TimesOnline, December 15, 2007, <http://www.timesonline.co.uk/tol/news/uk/science/article3054249.ece?>

## CASE 2

### Causing Deaf Children

(*New Scientist*)—A few years ago, a lesbian couple in the U.S. sparked controversy when they chose a deaf sperm donor to ensure their children, like them, would be deaf. Now it appears that some would-be parents are resorting to pre-implantation genetic diagnosis (PGD) to achieve the same thing, by selecting and implanting embryos that will develop into deaf children.

This comes from a survey by the Genetics and Public Policy Center in Washington DC on how PGD is being used in the U.S.

Deep inside the report is this paragraph: "Some prospective parents have sought PGD to select an embryo for the presence of a particular disease or disability, such as deafness, in order that the child would share that characteristic with the parents.

Three percent of IVF-PGD clinics report having provided PGD to couples who seek to use PGD in this manner.”

It is not clear how many, if any, children have been born after embryo selection for a disability, or which disabilities have been selected for. I asked Susannah Baruch, the lead author of the GPPC report, who told me that the team does not have any more details.

So let's do the sums: Since the survey included 137 IVF-PGD clinics, 3% means 4 couples at least, more if you assume some of the 200 clinics who did not respond to the survey have also provided this service. And since the success rate of IVF is roughly 30%, even if each couple made only one attempt at least one child must have been born with a designer disability, most likely deafness, with the help of PGD.\*

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*Is it right to deliberately cause a child to be deaf and thereby limit her opportunities in life? If so, why? If not, why not? Should medical authorities or the government restrict the use of IVF and PGD to selecting only healthy embryos? If both prospective parents have inherited deafness, there is a high probability that their child will be deaf. So their failing to use IVF/PGD to select healthy embryos would almost guarantee a deaf baby. Is such a failure morally wrong? If so, is deliberately selecting impaired embryos equally wrong? Explain.*

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\*Michael Le Page, “Designer Deafness,” *New Scientist*, September 29, 2006.

### CASE 3

### Cosmetic Embryo Selection

(*London Telegraph*)—Embryos are to be screened for a cosmetic defect for the first time in a British clinic.

Doctors have been given permission to create a baby free from a genetic disorder which would have caused the child to have a severe squint.

The Bridge Centre family clinic, in London, has been licensed to treat a businessman and his wife to create the baby. Both the businessman and his father suffer from the condition, which causes the eyes only to look downwards or sideways.

Critics have said that the permission is another step on the road to creating only perfect-looking babies in the laboratory.

The licence was granted by the Human Fertilisation and Embryology Authority (HFEA) to Prof. Gedis Grudzinskas, who believes the landmark ruling marks a shift away from granting licences only for life-threatening conditions.

He said: “We will increasingly see the use of embryo screening for severe cosmetic conditions.”

He added that he would seek to screen for any genetic factor at all that would cause a family severe distress.

When asked if he would screen embryos for factors like hair colour, he said: “If there is a cosmetic aspect to an individual case I would assess it on its merits. [Hair colour] can be a cause of bullying which can lead to suicide. With the agreement of the HFEA, I would do it. If a parent suffered from asthma, and it was possible to detect the genetic factor for this, I would do it. It all depends on the family’s distress.”

He argued that a baby born with the squint condition, congenital fibrosis of the extramacular muscles, would have to undergo several potentially dangerous operations from a young age. . . .

If successful, the screening could be the first case in the world where doctors have been able to select embryos without the condition. . . .

Until last year screening was restricted to life-threatening conditions such as cystic fibrosis or fatal blood disorders.\*

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*Should prospective parents be permitted to screen their embryos for cosmetic reasons? Is there a moral difference between embryo selection against severe disabilities and embryo selection against cosmetic imperfections that cause the child to suffer psychological distress or social discrimination? Is embryo selection for cosmetic reasons a form of discrimination or disrespect for people with disabilities or imperfections? Explain your answers.*

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\*Roland Hancock, “Clinic to Weed Out Embryos with a Squint,” *Telegraph.co.uk*, July 5, 2007, <http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2007/05/07/nbaboy07.xml>.

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## READINGS

## Genetics and Reproductive Risk: Can Having Children Be Immoral?

LAURA M. PURDY

Purdy contends that it is morally wrong to “reproduce when we know there is a high risk of transmitting a serious disease or defect.” This conclusion is based on the judgment that we have an obligation to provide each child with “something like a minimally satisfying life.”

Is it morally permissible for me to have children?<sup>1</sup> A decision to procreate is surely one of the most significant decisions a person can make. So it would seem that it ought not to be made without some moral soul-searching.

There are many reasons why one might hesitate to bring children into this world if one is concerned about their welfare. Some are rather general, like the deteriorating environment or the prospect of poverty. Others have a narrower focus, like continuing civil war in Ireland, or the lack of essential social support for child rearing persons in the United States. Still others may be relevant only to individuals at risk of passing harmful diseases to their offspring.

There are many causes of misery in this world, and most of them are unrelated to genetic disease. In the general scheme of things, human misery is most efficiently reduced by concentrating on noxious social and political arrangements. Nonetheless, we shouldn’t ignore preventable harm just because it is confined to a relatively small corner of life. So the question arises: can it be wrong to have a child because of genetic risk factors?<sup>2</sup>

Unsurprisingly, most of the debate about this issue has focused on prenatal screening and abortion: much useful information about a given fetus can be made available by recourse to prenatal testing. This fact has meant that moral questions about reproduction have become entwined with abortion

politics, to the detriment of both. The abortion connection has made it especially difficult to think about whether it is wrong to prevent a child from coming into being since doing so might involve what many people see as wrongful killing; yet there is no necessary link between the two. Clearly, the existence of genetically compromised children can be prevented not only by aborting already existing fetuses but also by preventing conception in the first place.

Worse yet, many discussions simply assume a particular view of abortion, without any recognition of other possible positions and the difference they make in how people understand the issues. For example, those who object to aborting fetuses with genetic problems often argue that doing so would undermine our conviction that all humans are in some important sense equal.<sup>3</sup> However, this position rests on the assumption that conception marks the point at which humans are endowed with a right to life. So aborting fetuses with genetic problems looks morally the same as killing “imperfect” people without their consent.

This position raises two separate issues. One pertains to the legitimacy of different views on abortion. Despite the conviction of many abortion activists to the contrary, I believe that ethically respectable views can be found on different sides of the debate, including one that sees fetuses as developing humans without any serious moral claim on continued life. There is no space here to address the details, and doing so would be once again to fall into the trap of letting the abortion question

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swallow up all others. Fortunately, this issue need not be resolved here. However, opponents of abortion need to face the fact that many thoughtful individuals do not *see* fetuses as moral persons. It follows that their reasoning process and hence the implications of their decisions are radically different from those envisioned by opponents of prenatal screening and abortion. So where the latter see genetic abortion as murdering people who just don't measure up, the former see it as a way to prevent the development of persons who are more likely to live miserable lives. This is consistent with a world view that values persons equally and holds that each deserves high quality life. Some of those who object to genetic abortion appear to be oblivious to these psychological and logical facts. It follows that the nightmare scenarios they paint for us are beside the point: many people simply do not share the assumptions that make them plausible.

How are these points relevant to my discussion? My primary concern here is to argue that conception can sometimes be morally wrong on grounds of genetic risk, although this judgment will not apply to those who accept the moral legitimacy of abortion and are willing to employ prenatal screening and selective abortion. If my case is solid, then those who oppose abortion must be especially careful not to conceive in certain cases, as they are, of course, free to follow their conscience about abortion. Those like myself who do not see abortion as murder have more ways to prevent birth.

### Huntington's Disease

There is always some possibility that reproduction will result in a child with a serious disease or handicap. Genetic counselors can help individuals determine whether they are at unusual risk, and, as the Human Genome Project rolls on, their knowledge will increase by quantum leaps. As this knowledge becomes available, I believe we ought to use it to determine whether possible children are at risk *before* they are conceived.

I want in this paper to defend the thesis that it is morally wrong to reproduce when we know there is a high risk of transmitting a serious disease or defect. This thesis holds that some reproductive acts are wrong, and my argument puts the burden of

proof on those who disagree with it to show why its conclusions can be overridden. Hence it denies that people should be free to reproduce mindless of the consequences.<sup>4</sup> However, as moral argument, it should be taken as a proposal for further debate and discussion. It is not, by itself, an argument in favor of legal prohibitions of reproduction.<sup>5</sup>

There is a huge range of genetic diseases. Some are quickly lethal; others kill more slowly, if at all. Some are mainly physical, some mainly mental; others impair both kinds of function. Some interfere tremendously with normal functioning, others less. Some are painful, some are not. There seems to be considerable agreement that rapidly lethal diseases, especially those, like Tay-Sachs, accompanied by painful deterioration, should be prevented even at the cost of abortion. Conversely, there seems to be substantial agreement that relatively trivial problems, especially cosmetic ones, would not be legitimate grounds for abortion.<sup>6</sup> In short, there are cases ranging from low risk of mild disease or disability to high risk of serious disease or disability. Although it is difficult to decide where the duty to refrain from procreation becomes compelling, I believe that there are some clear cases. I have chosen to focus on Huntington's Disease to illustrate the kinds of concrete issues such decisions entail. However, the arguments presented here are also relevant to many other genetic diseases.<sup>7</sup>

The symptoms of Huntington's Disease usually begin between the ages of thirty and fifty. It happens this way:

Onset is insidious. Personality changes (obstinacy, moodiness, lack of initiative) frequently antedate or accompany the involuntary choreic movements. These usually appear first in the face, neck, and arms, and are jerky, irregular, and stretching in character. Contractions of the facial muscles result in grimaces; those of the respiratory muscles, lips, and tongue lead to hesitating, explosive speech. Irregular movements of the trunk are present; the gait is shuffling and dancing. Tendon reflexes are increased. . . . Some patients display a fatuous euphoria; others are spiteful, irascible, destructive, and violent. Paranoid reactions are common. Poverty of thought and impairment of attention, memory, and judgment occur. As the disease progresses, walking becomes impossible, swallowing

difficult, and dementia profound. Suicide is not uncommon.<sup>8</sup>

The illness lasts about fifteen years, terminating in death.

Huntington's Disease is an autosomal dominant disease, meaning that it is caused by a single defective gene located on a non-sex chromosome. It is passed from one generation to the next via affected individuals. Each child of such an affected person has a fifty percent risk of inheriting the gene and thus of eventually developing the disease, even if he or she was born before the parent's disease was evident.<sup>9</sup>

Until recently, Huntington's Disease was especially problematic because most affected individuals did not know whether they had the gene for the disease until well into their childbearing years. So they had to decide about childbearing before knowing whether they could transmit the disease or not. If, in time, they did not develop symptoms of the disease, then their children could know they were not at risk for the disease. If unfortunately they did develop symptoms, then each of their children could know there was a fifty percent chance that they, too, had inherited the gene. In both cases, the children faced a period of prolonged anxiety as to whether they would develop the disease. Then, in the 1980s, thanks in part to an energetic campaign by Nancy Wexler, a genetic marker was found that, in certain circumstances, could tell people with a relatively high degree of probability whether or not they had the gene for the disease.<sup>10</sup> Finally, in March 1993, the defective gene itself was discovered.<sup>11</sup> Now individuals can find out whether they carry the gene for the disease, and prenatal screening can tell us whether a given fetus has inherited it. These technological developments change the moral scene substantially.

How serious are the risks involved in Huntington's Disease? Geneticists often think a ten percent risk is high.<sup>12</sup> But risk assessment also depends on what is at stake: the worse the possible outcome the more undesirable an otherwise small risk seems. In medicine, as elsewhere, people may regard the same result quite differently. But for devastating diseases like Huntington's this part of the

judgment should be unproblematic: no one wants a loved one to suffer in this way.<sup>13</sup>

There may still be considerable disagreement about the acceptability of a given risk. So it would be difficult in many circumstances to say how we should respond to a particular risk. Nevertheless, there are good grounds for a conservative approach, for it is reasonable to take special precautions to avoid very bad consequences, even if the risk is small. But the possible consequences here are very bad: a child who may inherit Huntington's Disease has a much greater than average chance of being subjected to severe and prolonged suffering. And it is one thing to risk one's own welfare, but quite another to do so for others and without their consent.

Is this judgment about Huntington's Disease really defensible? People appear to have quite different opinions. Optimists argue that a child born into a family afflicted with Huntington's Disease has a reasonable chance of living a satisfactory life. After all, even children born of an afflicted parent still have a fifty percent chance of escaping the disease. And even if afflicted themselves, such people will probably enjoy some thirty years of healthy life before symptoms appear. It is also possible, although not at all likely, that some might not mind the symptoms caused by the disease. Optimists can point to diseased persons who have lived fruitful lives, as well as those who seem genuinely glad to be alive. One is Rick Donohue, a sufferer from the Joseph family disease: "You know, if my mom hadn't had me, I wouldn't be here for the life I have had. So there is a good possibility I will have children."<sup>14</sup> Optimists therefore conclude that it would be a shame if these persons had not lived.

Pessimists concede some of these facts, but take a less sanguine view of them. They think a fifty percent risk of serious disease like Huntington's appallingly high. They suspect that many children born into afflicted families are liable to spend their youth in dreadful anticipation and fear of the disease. They expect that the disease, if it appears, will be perceived as a tragic and painful end to a blighted life. They point out that Rick Donohue is still young, and has not experienced the full horror of his sickness. It is also well-known that some young persons have such a dilated sense of time that they can

hardly envision themselves at thirty or forty, so the prospect of pain at that age is unreal to them.<sup>15</sup>

More empirical research on the psychology and life history of sufferers and potential sufferers is clearly needed to decide whether optimists or pessimists have a more accurate picture of the experiences of individuals at risk. But given that some will surely realize pessimists' worst fears, it seems unfair to conclude that the pleasures of these who deal best with the situation simply cancel out the suffering of those others when that suffering could be avoided altogether.

I think that these points indicate that the morality of procreation in situations like this demands further investigation. I propose to do this by looking first at the position of the possible child, then at that of the potential parent.

### Possible Children and Potential Parents

The first task in treating the problem from the child's point of view is to find a way of referring to possible future offspring without seeming to confer some sort of morally significant existence upon them. I will follow the convention of calling children who might be born in the future but who are not now conceived "possible" children, offspring, individuals, or persons.

Now, what claims about children or possible children are relevant to the morality of childbearing in the circumstances being considered? Of primary importance is the judgment that we ought to try to provide every child with something like a minimally satisfying life. I am not altogether sure how best to formulate this standard but I want clearly to reject the view that it is morally permissible to conceive individuals so long as we do not expect them to be so miserable that they wish they were dead.<sup>16</sup> I believe that this kind of moral minimalism is thoroughly unsatisfactory and that not many people would really want to live in a world where it was the prevailing standard. Its lure is that it puts few demands on us, but its price is the scant attention it pays to human well-being.

How might the judgment that we have a duty to try to provide a minimally satisfying life for our children be justified? It could, I think, be derived fairly straightforwardly from either utilitarian or

contractarian theories of justice, although there is no space here for discussion of the details. The net result of such analysis would be the conclusion that neglecting this duty would create unnecessary unhappiness or unfair disadvantage for some persons.

Of course, this line of reasoning confronts us with the need to spell out what is meant by "minimally satisfying" and what a standard based on this concept would require of us. Conceptions of a minimally satisfying life vary tremendously among societies and also within them. De rigueur in some circles are private music lessons and trips to Europe, while in others providing eight years of schooling is a major accomplishment. But there is no need to consider this complication at length here since we are concerned only with health as a prerequisite for a minimally satisfying life. Thus, as we draw out what such a standard might require of us, it seems reasonable to retreat to the more limited claim that parents should try to ensure something like normal health for their children. It might be thought that even this moderate claim is unsatisfactory since in some places debilitating conditions are the norm, but one could circumvent this objection by saying that parents ought to try to provide for their children health normal for that culture, even though it may be inadequate if measured by some outside standard.<sup>17</sup> This conservative position would still justify efforts to avoid the birth of children at risk for Huntington's Disease and other serious genetic diseases in virtually all societies.<sup>18</sup>

This view is reinforced by the following considerations. Given that possible children do not presently exist as actual individuals, they do not have a right to be brought into existence, and hence no one is maltreated by measures to avoid the conception of a possible person. Therefore, the conservative course that avoids the conception of those who would not be expected to enjoy a minimally satisfying life is at present the only fair course of action. The alternative is a laissez-faire approach which brings into existence the lucky, but only at the expense of the unlucky. Notice that attempting to avoid the creation of the unlucky does not necessarily lead to *fewer* people being brought into being; the question boils down to taking steps to bring

those with better prospects into existence, instead of those with worse ones.

I have so far argued that if people with Huntington's Disease are unlikely to live minimally satisfying lives, then those who might pass it on should not have genetically related children. This is consonant with the principle that the greater the danger of serious problems, the stronger the duty to avoid them. But this principle is in conflict with what people think of as the right to reproduce. How might one decide which should take precedence?

Expecting people to forego having genetically related children might seem to demand too great a sacrifice of them. But before reaching that conclusion we need to ask what is really at stake. One reason for wanting children is to experience family life, including love, companionship, watching kids grow, sharing their pains and triumphs, and helping to form members of the next generation. Other reasons emphasize the validation of parents as individuals within a continuous family line, children as a source of immortality, or perhaps even the gratification of producing partial replicas of oneself. Children may also be desired in an effort to prove that one is an adult, to try to cement a marriage or to benefit parents economically.

Are there alternative ways of satisfying these desires? Adoption or new reproductive technologies can fulfil many of them without passing on known genetic defects. Replacements for sperm have been available for many years via artificial insemination by donor. More recently, egg donation, sometimes in combination with contract pregnancy,<sup>19</sup> has been used to provide eggs for women who prefer not to use their own. Eventually it may be possible to clone individual humans, although that now seems a long way off. All of these approaches to avoiding the use of particular genetic material are controversial and have generated much debate. I believe that tenable moral versions of each do exist.<sup>20</sup>

None of these methods permits people to extend both genetic lines, or realize the desire for immortality or for children who resemble both parents; nor is it clear that such alternatives will necessarily succeed in proving that one is an adult, cementing a marriage, or providing economic benefits. Yet, many people feel these desires strongly. Now, I am

sympathetic to William James's dictum regarding desires: "Take any demand, however slight, which any creature, however weak, may make. Ought it not, for its own sole sake be satisfied? If not, prove why not."<sup>21</sup> Thus a world where more desires are satisfied is generally better than one where fewer are. However, not all desires can be legitimately satisfied since, as James suggests, there may be good reasons—such as the conflict of duty and desire—why some should be overruled.

Fortunately, further scrutiny of the situation reveals that there are good reasons why people should attempt—with appropriate social support—to talk themselves out of the desires in question or to consider novel ways of fulfilling them. Wanting to see the genetic line continued is not particularly rational when it brings a sinister legacy of illness and death. The desire for immortality cannot really be satisfied anyway, and people need to face the fact that what really matters is how they behave in their own lifetime. And finally, the desire for children who physically resemble one is understandable, but basically narcissistic, and its fulfillment cannot be guaranteed even by normal reproduction. There are other ways of proving one is an adult, and other ways of cementing marriages—and children don't necessarily do either. Children, especially prematurely ill children, may not provide the expected economic benefits anyway. Nongenetically related children may also provide benefits similar to those that would have been provided by genetically related ones, and expected economic benefit is, in many cases, a morally questionable reason for having children.

Before the advent of reliable genetic testing, the options of people in Huntington's families were cruelly limited. On the one hand, they could have children, but at the risk of eventual crippling illness and death for them. On the other, they could refrain from childbearing, sparing their possible children from significant risk of inheriting this disease, perhaps frustrating intense desires to procreate—only to discover, in some cases that their sacrifice was unnecessary because they did not develop the disease. Or they could attempt to adopt or try new reproductive approaches.

Reliable genetic testing has opened up new possibilities. Those at risk who wish to have children

can get tested. If they test positive, they know their possible children are at risk. Those who are opposed to abortion must be especially careful to avoid conception if they are to behave responsibly. Those not opposed to abortion can responsibly conceive children, but only if they are willing to test each fetus and abort those who carry the gene. If individuals at risk test negative, they are home free.

What about those who cannot face the test for themselves? They can do prenatal testing and abort fetuses who carry the defective gene. A clearly positive test also implies that the parent is affected, although negative tests do not rule out that possibility. Prenatal testing can thus bring knowledge that enables one to avoid passing the disease to others, but only, in some cases, at the cost of coming to know with certainty that one will indeed develop the disease. This situation raises with peculiar force the question of whether parental responsibility requires people to get tested.

Some people think that we should recognize a right "not to know." It seems to me that such a right could be defended only where ignorance does not put others at serious risk. So if people are prepared to forego genetically related children, they need not get tested. But if they want genetically related children then they must do whatever is necessary to ensure that affected babies are not the result. There is, after all, something inconsistent about the claim that one has a right to be shielded from the truth, even if the price is to risk inflicting on one's children the same dread disease one cannot even face in oneself.

In sum, until we can be assured that Huntington's Disease does not prevent people from living a minimally satisfying life, individuals at risk for the disease have a moral duty to try not to bring affected babies into this world. There are now enough options available so that this duty needn't frustrate their reasonable desires. Society has a corresponding duty to facilitate moral behavior on the part of individuals. Such support ranges from the narrow and concrete (like making sure that medical testing and counseling is available to all) to the more general social environment that guarantees that all pregnancies are voluntary, that pronatalism is eradicated, and that women are treated with respect regardless of the reproductive options they choose.

#### NOTES

1. This paper is loosely based on "Genetic Diseases: Can Having Children Be Immoral?" originally published in *Genetics Now*, ed. John L. Buckley (Washington, DC: University Press of America, 1978) and subsequently anthologized in a number of medical ethics texts. Thanks to Thomas Mappes and David DeGrazia for their helpful suggestions about updating the paper.
2. I focus on genetic considerations, although with the advent of AIDS the scope of the general question here could be expanded. There are two reasons for sticking to this relatively narrow formulation. One is that dealing with a smaller chunk of the problem may help us think more clearly, while realizing that some conclusions may nonetheless be relevant to the larger problem. The other is the peculiar capacity of some genetic problems to affect ever more individuals in the future.
3. For example, see Leon Kass, "Implications of Prenatal Diagnosis for the Human Right to Life," *Ethical Issues in Human Genetics*, eds. Bruce Hilton et al. (New York: Plenum Press, 1973).
4. This is, of course, a very broad thesis. I defend an even broader version in "Loving Future People," *Reproduction, Ethics and the Law*, ed. Joan Callahan (Bloomington: Indiana University Press, forthcoming).
5. Why would we want to resist legal enforcement of every moral conclusion? First, legal action has many costs, costs not necessarily worth paying in particular cases. Second, legal enforcement would tend to take the matter in question out of the realm of debate and treat it as settled. But in many cases, especially where mores or technology is rapidly evolving, we don't want that to happen. Third, legal enforcement would undermine individual freedom and decision-making capacity. In some cases, the ends envisioned are important enough to warrant putting up with these disadvantages, but that remains to be shown in each case.
6. Those who do not see fetuses as moral persons with a right to life may nonetheless hold that abortion is justifiable in these cases. I argue at some length elsewhere that lesser defects can cause great suffering. Once we are clear that there is nothing discriminatory about failing to conceive particular possible individuals, it makes sense, other things being equal, to avoid the prospect of such pain if we can. Naturally, other things rarely are equal. In the first place, many problems go undiscovered until a baby is born. Secondly, there are often substantial costs associated with screening programs. Thirdly, although women

should be encouraged to consider the moral dimensions of routine pregnancy, we do not want it to be so fraught with tension that it becomes a miserable experience. (See “Loving Future People.”)

7. It should be noted that failing to conceive a single individual can affect many lives: in 1916, nine hundred and sixty-two cases could be traced from six seventeenth-century arrivals in America. See Gordon Rattray Taylor, *The Biological Time Bomb* (New York, 1968), p. 176.

8. *The Merck Manual* (Rahway, NJ: Merck, 1972), pp. 1363, 1346. We now know that the age of onset and severity of the disease is related to the number of abnormal replications of the glutamine code on the abnormal gene. See Andrew Revkin, “Hunting Down Huntington’s,” *Discover*, December 1993, p. 108.

9. Hymie Gordon, “Genetic Counseling,” *JAMA*, Vol. 217, n. 9 (August 30, 1971), p. 1346.

10. See Revkin, “Hunting Down Huntington’s,” pp. 99–108.

11. “Gene for Huntington’s Disease Discovered,” *Human Genome News*, Vol. 5, n. 1 (May 1993), p. 5.

12. Charles Smith, Susan Holloway, and Alan E. H. Emery, “Individuals at Risk in Families—Genetic Disease,” *Journal of Medical Genetics*, Vol. 8 (1971), p. 453.

13. To try to separate the issue of the gravity of the disease from the existence of a given individual, compare this situation with how we would assess a parent who neglected to vaccinate an existing child against a hypothetical viral version of Huntington’s.

14. *The New York Times*, September 30, 1975, p. 1, col. 6. The Joseph family disease is similar to Huntington’s Disease except that symptoms start appearing in the twenties. Rick Donohue was in his early twenties at the time he made this statement.

15. I have talked to college students who believe that they will have lived fully and be ready to die at those

ages. It is astonishing how one’s perspective changes over time, and how ages that one once associated with senility and physical collapse come to seem the prime of human life.

16. The view I am rejecting has been forcefully articulated by Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1984). For more discussion, see “Loving Future People.”

17. I have some qualms about this response since I fear that some human groups are so badly off that it might still be wrong for them to procreate, even if that would mean great changes in their cultures. But this is a complicated issue that needs its own investigation.

18. Again, a troubling exception might be the isolated Venezuelan group Nancy Wexler found where, because of in-breeding, a large proportion of the population is affected by Huntington’s. See Revkin, “Hunting Down Huntington’s.”

19. Or surrogacy, as it has been popularly known. I think that “contract pregnancy” is more accurate and more respectful of women. Eggs can be provided either by a woman who also gestates the fetus or by a third party.

20. The most powerful objections to new reproductive technologies and arrangements concern possible bad consequences for women. However, I do not think that the arguments against them on these grounds have yet shown the dangers to be as great as some believe. So although it is perhaps true that new reproductive technologies and arrangements shouldn’t be used lightly, avoiding the conceptions discussed here is well worth the risk. For a series of viewpoints on this issue, including my own “Another Look at Contract Pregnancy,” see Helen B. Holmes, *Issues in Reproductive Technology I: An Anthology* (New York: Garland Press, 1992).

21. *Essays in Pragmatism*, ed. A. Castell (New York, 1948), p. 73.

## The Morality of Screening for Disability

JEFF McMAHAN

McMahan examines arguments against using screening technologies such as PGD to avoid giving birth to a disabled child. The most common objections are that screening and selection are discriminatory, diminish human diversity, cause disabled people social harms, and express a hurtful view toward them. McMahan says these objections imply that “it is wrong for people to try to avoid having a disabled child and to have a non-disabled child instead.” This view in turn implies that it must be at least permissible to cause oneself to have a disabled rather than a nondisabled child. But, he argues, it is wrong to deliberately cause a disabled child to exist instead of a healthy child; therefore, we must reject some or all of the objections against testing.

My topic is the morality of using screening technologies to enable potential parents to avoid having a disabled child. The relevant techniques include preconception genetic and non-genetic testing of potential parents, preimplantation genetic diagnosis (PGD), and prenatal screening with the option of abortion. Many people use these techniques and are grateful to have them. Others, however, object to their use, even when abortion is not an issue. The most common objections can be grouped into four basic types.

First, the opponents of screening and selection urge that these practices are perniciously discriminatory, in that their aim is to rid the world of people of a certain type, people who have increasingly come to share a sense of collective identity and solidarity. Some might even argue that for society to endorse and support screening for disability is analogous to promoting efforts to prevent the births of people of a particular racial group.

Second, the practices of screening and selection are not just detrimental to the disabled as a group but may also be harmful to individual disabled people in various ways. They may, for example, reinforce or seem to legitimize forms of

discrimination against existing disabled people. And, if effective, they also reduce the *number* of disabled people, thereby making each disabled person a bit more unusual and a bit more isolated. The reduction in numbers may, in addition, diminish the visibility and political power of disabled people generally.

Third, it is often held that a reduction in the number of disabled people would have an adverse effect on human diversity. To eliminate the disabled would be to eliminate a type of human being who makes a unique contribution to the world. For the disabled themselves, and indeed their mere presence among the rest of us, teach valuable lessons about respect for difference, about the nobility of achievement in the face of grave obstacles, and even about the value of life and what makes a life worth living.

Fourth, it is often held that practices of screening and selection express a view of disabled people that is hurtful to existing disabled people. Efforts to prevent disabled people from existing are said to express such views as that disabled people ought not to exist, that it is bad if disabled people exist, or at least worse than if normal people exist, that disabled people are not worth the burdens they impose on their parents and on the wider society, and so on. Screening and selection, in other words, seem to say to existing disabled people: The rest of us are trying to prevent the existence of other people like you.

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One can respond to these objections to screening and selection, as some of the speakers at this conference have done, by appealing to rights of individual liberty. One could grant that the practices are objectionable for the reasons given but argue that those reasons are overridden by rights to reproductive freedom and by the benefits to those who are able to exercise those rights. But I want to advance a reason for scepticism about the force of the objections themselves.

The objections do of course express serious and legitimate concerns, concerns that must be addressed in appropriate ways. But I will argue that they're insufficiently strong to show that screening and selection are wrong or should be prohibited. For if they were taken to show that, they would also have implications beyond the practices of screening and selection. They would also imply the permissibility of certain types of action that most people believe are impermissible.

Consider this hypothetical example: Suppose there is a drug that has a complex set of effects. It is an aphrodisiac that enhances a woman's pleasure during sexual intercourse. But it also increases fertility by inducing ovulation. If ovulation has recently occurred naturally, this drug causes destruction of the egg that is present in one of the fallopian tubes but also causes a new and different egg to be released from the ovaries. In addition, however, it has a very high probability of damaging the new egg in a way that will cause any child conceived through the fertilization of that egg to be disabled. The disability caused by the drug is, let us suppose, one that many potential parents seek to avoid through screening. But it is also, like virtually all disabilities, not so bad as to make life not worth living. Suppose that a woman takes this drug primarily to increase her pleasure but also with the thought that it may increase the probability of conception—for she wants to have a child. She is aware that the drug is likely to cause her to have a disabled child but she is eager for pleasure and reflects that it might be rather nice to have a child who might be more dependent than children usually are. Although she does not know it, she has in fact just ovulated naturally so the drug destroys and replaces the egg that was already present but also

damages the new egg, thereby causing the child she conceives to be disabled.

Note that because the drug causes the woman's ovaries to release a new egg, the disabled child she conceives is a different individual from the child she would have had if she hadn't taken the drug.

Many people think that this woman's action is morally wrong. It is wrong to cause the existence of a disabled child rather than a child without a disability, just for the sake of one's own sexual pleasure. There are, of course, some who think that rights to reproductive freedom make it permissible to choose to have a disabled child just as they also make it permissible to try to avoid having a disabled child. But most of us do not share that view. Most of us think that if it would be wrong to cause an already born child to become disabled, and if it would be wrong to cause a future child to be disabled through the infliction of prenatal injury, it should also be wrong to cause a disabled child to exist rather than a child without a disability.

There are of course differences. Whether they are morally significant and if so to what extent, are matters to which I will return shortly. For the moment, the important point to notice is that if the arguments I cited earlier show that screening and selection are wrong, they should also show that the action of the woman who takes the aphrodisiac is permissible. This is because if it is morally *mandatory* to allow oneself to have a disabled child rather than to try, through screening, to have a child who would not be disabled, then it must be at least *permissible* to cause oneself to have a disabled rather than a non-disabled child.

Let me try to explain this in greater detail. If it is wrong for the woman to take the aphrodisiac, that must be because there is a moral objection to voluntarily having a disabled child—an objection that's strong enough to make it wrong to cause oneself, by otherwise permissible means, to have a disabled rather than a non-disabled child. But if there is such an objection, it must surely be strong enough to make it at least permissible for people to try, by morally acceptable means, to avoid having a disabled child and to have a non-disabled child instead, and to make it impermissible for others to prevent them from making this attempt.

Yet the critics of screening believe not only that it is wrong for people to try to avoid having a disabled child and to have a non-disabled child instead, but even that it is permissible for others to prevent them from having a non-disabled rather than a disabled child. It would be inconsistent for these critics to condemn the woman in this example for causing herself to have a disabled rather than a non-disabled child and to condemn those who try to cause themselves *not* to have a disabled rather than a non-disabled child.

The crucial premise here is that if it would be morally objectionable to try to *prevent* a certain outcome, and permissible to deprive people of the means of preventing that outcome, then it ought to be permissible to *cause* that outcome, provided one does so by otherwise permissible means.

Note also that if we were to assert publicly that it would be wrong for this woman to do what would cause her to have a disabled child rather than a non-disabled child, or if we were to attempt to prevent her from taking the drug—for example, by making the drug illegal on the ground that it causes “birth defects”—our action would be vulnerable to the same objections that opponents of screening and selection urge against those practices.

If, for example, we were publicly to state the reasons why it would be objectionable for the woman to take the drug—that the disabled child’s life might be likely to contain more hardship and less good than the life of a non-disabled child, that provision for the disabled child’s special needs would involve greater social costs, and so on—the evaluations of disability and of disabled people that might be thought to be implicit in these claims could be deeply hurtful to existing disabled people, and if we were to prevent this woman and others from being able to take the drug, this would reduce the number of disabled people relative to the number there would otherwise have been, thereby threatening the collective identity and political power of existing disabled people.

In short, the arguments of the opponents of screening seem to imply not only that it would be permissible for the woman to take the aphrodisiac, thereby causing herself to have a disabled child, but also that it would be wrong even to voice objections to her action.

Some opponents of screening and selection may be willing to accept these implications. They might argue that there are relevant differences between causing oneself to have a disabled child rather than a different non-disabled child and causing an existing individual to be disabled. For example, in the latter case but not the former, there is a victim, someone for whom one’s act is worse. So there are objections to causing an existing individual to be disabled that do not apply to merely causing a disabled person to exist, and to assert these objections merely expresses the view that it can be worse to be disabled than not to be, which seems unobjectionable, since it does not imply any view of disabled people themselves. Screening and selection, by contrast, are held to express a pernicious and degrading view of disabled people.

Thus, opponents of screening and selection typically think that they can draw the line between action by a woman that may cause her to conceive a child who will be disabled and, for example, action taken by a pregnant woman that injures her fetus, causing it to be disabled when it otherwise would not have been. But in fact many people, especially among the disabled themselves, contend that it is no worse to be disabled than not to be. They claim that disabilities are “neutral” traits. So, for example, Harriet McBryde Johnson (2003), a disabled lawyer, emphatically repudiates the “unexamined assumption that disabled people are inherently ‘worse off,’ that we ‘suffer,’ that we have lesser ‘prospects of a happy life.’”

The view that it is not bad to be disabled, apart from any ill effects caused by social discrimination, would be very difficult to sustain if it implied that to cause a person to become disabled would not harm that person, or that it is irrational to be averse to becoming disabled. But in fact those who claim that it is not bad in itself to *be* disabled can accept without inconsistency that it can be bad to *become* disabled. They can appeal to the *transition costs*. It is bad to become disabled because this can involve loss and discontinuity, requiring that one abandon certain goals and projects and adapt to the pursuit of different ones instead. It is these effects that make it rational to fear becoming disabled and they are a major part of the explanation of why it is wrong to

cause someone to become disabled. The other major part is that the causation of disability involves a violation of the victim's autonomy.

But notice that these considerations do not count against causing disability through prenatal injury. For congenital disability does not have transition costs, and fetuses are not autonomous.

It seems, therefore, that opponents of screening and selection who also claim that it is not worse to be disabled have no basis for objecting to the infliction of prenatal injury that causes congenital disability. Moreover, to object to the infliction of disabling prenatal injury or to enact measures to prevent it would seem to express a negative view of disability and perhaps of the disabled themselves. At a minimum, it expresses the view that it is bad to be disabled, or at least worse than not to be disabled. And, if effective, efforts to prevent disabling prenatal injury would have other effects comparable to those of prohibiting or restricting screening for disability and selection, such as reducing the number of disabled people who would be born, thereby also threatening the sense of collective identity and solidarity among the disabled as well as diminishing their visibility and political power. Finally, prevention of prenatal injury would also threaten human diversity. It would deprive those who would have had contact with the person if he had been disabled of the unique benefits that disabled people offer to others.

So for those opponents of selection who also hold that it is not a harm or misfortune to be disabled, it seems that there are not only no reasons to object to the infliction of disabling prenatal injury but even positive reasons not to object to it and not to try to prevent it.

Suppose there were an aphrodisiac that would greatly enhance a woman's pleasure during sex but would, if taken during pregnancy, injure the fetus in a way that would cause it to be congenitally severely disabled. Those who oppose screening and selection for the reasons I cited earlier and who also hold that it is not bad in itself to be disabled are logically committed by their own arguments to accept that it would be permissible for a pregnant woman to take this aphrodisiac just to increase her own pleasure, and they are further committed to accept

that it would be wrong to try to prevent the woman from taking the aphrodisiac or even to criticize her for doing so.

If we think that these conclusions are mistaken, which they surely are, we must reject some part of the case against screening and selection.

I will conclude by briefly suggesting a more positive way of addressing the concerns of those who oppose screening and selection. My sense is that the chief worry of those opposed to screening and selection has to do with the expressive effects of these practices. The worry is, as I noted earlier, that these practices give social expression to a negative view of disabled people, thereby reinforcing other forms of discrimination against them.

But notice that it is usually only people who have not had a disabled child who are averse to doing so. Those people who actually have a disabled child tend overwhelmingly to be glad that they had the particular child they had. If any child they might have had would have been disabled, they tend to prefer having had their actual disabled child to having had no child at all. If they could have had a non-disabled child but it would have been a different child, they tend to prefer their actual disabled child. Of course, what they would usually most prefer is that their actual child had not been disabled. But it is almost invariably the case that any action that would have enabled them to avoid having a disabled child would have caused them to have a different child. When the parents appreciate this fact, they cease to wish that anything had been different in the past, and focus their hopes on the possibility of a cure.

In short, most people who currently have or have had a disabled child in the past do not regret having done so. They are, instead, glad to have had their actual child and frequently testify to the special joy and illumination afforded by being bound to a disabled child. This very different evaluation of having a disabled child by those who actually have experience of it is no less rational and no less authoritative than the evaluation that many people make prospectively that it would be bad or worse to have a disabled child.

We could therefore try to offset any negative expressive effects of screening and selection by giving public expression to these different and equally

valid evaluations. I do not have any suggestions for how we might do this. That's a matter for specialists in public policy, not philosophers. But the crucial point is that it would be morally and strategically better for disabled people and their advocates to focus their efforts on positive proposals of this sort rather than to stigmatize and to seek to restrict or suppress practices such as screening and selection. By crusading against screening and selection, they

risk making themselves appear to the wider public as fanatics bent on imposing harmful restrictions on others. That would certainly not serve the cause of obtaining justice for the disabled.

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## Genetic Dilemmas and the Child's Right to an Open Future

DENA S. DAVIS

Davis explores whether genetic counselors—who are fiercely committed to respecting the autonomy of their patients—are duty bound to respect the requests of parents who want help in deliberately producing children with disabilities. She focuses on the example of deaf parents who would like their children to be deaf. She concludes that counselors should not participate in purposely creating deaf children, for such a result would violate a child's right to an open future.

The profession of genetic counseling is strongly characterized by a respect for patient autonomy that is greater than in almost any other area of medicine. When moral challenges arise in the clinical practice of genetics, they tend to be understood as conflicts between the obligation to respect patient autonomy and other ethical norms, such as doing good and avoiding harm. Thus, a typical counseling dilemma exists when a person who has been tested and found to be carrying the gene for Tay-Sachs disease refuses to share that information with siblings and other relatives despite the clear benefits to them of having that knowledge, or when a family member declines to participate in a testing protocol necessary to help another member discover his or her genetic status.

From Dena S. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27, no. 2 (1997): 7–15.

This way of looking at moral issues in genetic counseling often leaves both the counselors and commentators frustrated, for two reasons. First, by elevating respect for patient autonomy above all other values, it may be difficult to give proper weight to other factors, such as human suffering. Second, by privileging patient autonomy and by defining the patient as the person or couple who has come for counseling, there seems no "space" in which to give proper attention to the moral claims of the future child who is the endpoint of many counseling interactions.

These difficulties have been highlighted of late by the surfacing of a new kind of genetic counseling request: parents with certain disabilities who seek help in trying to assure that they will have a child who shares their disability. The two reported instances are in families affected by achondroplasia (dwarfism) and by hereditary deafness. This essay will focus on deafness.

Such requests are understandably troubling to genetic counselors. Deeply committed to the principle of giving clients value-free information with which to make their own choices, most counselors nonetheless make certain assumptions about health and disability—for example, that it is preferable to be a hearing person rather than a deaf person. Thus, counselors typically talk of the “risk” of having a child with a particular genetic condition. Counselors may have learned (sometimes with great difficulty) to respect clients’ decisions not to find out if their fetus has a certain condition or not to abort a fetus which carries a genetic disability. But to respect a parental value system that not only favors what most of us consider to be a disability, but actively expresses that preference by attempting to have a child with the condition, is “the ultimate test of nondirective counseling.”<sup>1</sup>

To describe the challenge primarily as one that pits beneficence (concern for the child’s quality of life) against autonomy (concern for the parents’ right to decide about these matters) makes for obvious difficulties. These are two very different values, and comparing and weighing them invites the proverbial analogy of “apples and oranges.” After all, the perennial critique of a principle-based ethics is that it offers few suggestions for ranking principles when duties conflict. Further, beneficence and respect for autonomy are values that will always exist in some tension within genetic counseling. For all the reasons I list below, counselors are committed to the primacy of patient autonomy and therefore to nondirective counseling. But surely, most or all of them are drawn to the field because they want to help people avoid or at least mitigate suffering.

Faced with the ethical challenge of parents who wish to ensure children who have a disability, I suggest a different way to look at this problem. Thinking this problem through in the way I suggest will shed light on some related topics in genetics as well, such as sex selection. I propose that, rather than conceiving this as a conflict between autonomy and beneficence, we recast it as a conflict between parental autonomy and the child’s future autonomy: what Joel Feinberg has called “the child’s right to an open future.”

## New Challenges

The Code of Ethics of the National Society of Genetic Counselors states that its members strive to:

- Respect their clients’ beliefs, cultural traditions, inclinations, circumstances, and feelings.
- Enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.<sup>2</sup>

Considering the uncertain and stochastic nature of genetic counseling, and especially in light of the difficulty physicians experience in sharing uncertainty with patients, it is remarkable that medical geneticists have hewed so strongly to an ethic of patient autonomy. This phenomenon can be explained by at least five factors: the desire to disassociate themselves as strongly as possible from the discredited eugenics movement;<sup>3</sup> an equally strong desire to avoid the label of “abortionist,” a realistic fear if counselors are perceived as advocates for abortion of genetically damaged fetuses;<sup>4</sup> the fact that few treatments are available for genetic diseases (p. 29); an awareness of the intensely private nature of reproductive decisions; and the fact that genetic decisions can have major consequences for entire families.<sup>5</sup> As one counselor was quoted, “I am not going to be taking that baby home—they will.”<sup>6</sup>

The commitment to patient autonomy faces new challenges with the advances arising from the Human Genome Project. The example of hereditary deafness is reported by Walter E. Nance, who writes:

It turns out that some deaf couples feel threatened by the prospect of having a hearing child and would actually prefer to have a deaf child. The knowledge that we will soon acquire [due to the Human Genome Project] will, of course, provide us with the technology that could be used to assist such couples in achieving their goals. This, in turn, could lead to the ultimate test of nondirective counseling. Does adherence to the concept of nondirective counseling actually require that we assist such a couple in terminating a pregnancy with a hearing child or is this nonsense?<sup>7</sup>

Several issues must be unpacked here. First, I question Nance's depiction of deaf parents as feeling "threatened" by the prospect of a hearing child. From Nance's own depiction of the deaf people he encounters, it is at least as likely that deaf parents feel that a deaf child would fit into their family better, especially if the parents themselves are "deaf of deaf" or if they already have one or more deaf children. Or perhaps the parents feel that Deafness (I use the capital "D," as Deaf people do, to signify Deafness as a culture) is an asset—tough at times but worthwhile in the end—like belonging to a racial or religious minority.

Second, I want to avoid the issue of abortion by discussing the issue of "deliberately producing a deaf child" as distinct from the question of achieving that end by aborting a hearing fetus. The latter topic is important, but it falls outside the purview of this paper. I will focus on the scenario where a deaf child is produced without recourse to abortion. We can imagine a situation in the near future where eggs or sperm can be scrutinized for the relevant trait before fertilization, or the present situation in which preimplantation genetic diagnosis after in vitro fertilization allows specialists to examine the genetic makeup of the very early embryo before it is implanted.

Imagine a Deaf couple approaching a genetic counselor. The couple's goals are to learn more about the cause(s) of their own deafness, and, if possible, to maximize the chance that any pregnancy they embark upon will result in a Deaf child. Let us suppose that the couple falls into the 50 percent of clients whose Deafness has a genetic origin.<sup>8</sup> The genetic counselor who adheres strictly to the tenets of client autonomy will respond by helping the couple to explore the ways in which they can achieve their goal: a Deaf baby. But as Nance's depiction of this scenario suggests, the counselor may well feel extremely uneasy about her role here. It is one thing to support a couple's decision to take their chances and "let Nature take its course," but to treat as a goal what is commonly considered to be a risk may be more pressure than the value-neutral ethos can bear. What is needed is a principled argument against such assistance. This refusal need not rise to a legal prohibition, but could become part of

the ethical norms and standard of care for the counseling profession.<sup>9</sup>

The path I see out of this dilemma relies on two steps. First, we remind ourselves why client autonomy is such a powerful norm in genetic counseling. Clients come to genetic counselors with questions that are simultaneously of the greatest magnitude and of the greatest intimacy. Clients not only have the right to bring their own values to bear on these questions, but in the end they must do so because they—and their children—will live with the consequences. As the President's Commission said in its 1983 report on Screening and Counseling for Genetic Conditions:

The silence of the law on many areas of individual choice reflects the value this country places on pluralism. Nowhere is the need for freedom to pursue divergent conceptions of the good more deeply felt than in decisions concerning reproduction. It would be a cruel irony, therefore, if technological advances undertaken in the name of providing information to expand the range of individual choices resulted in unanticipated social pressures to pursue a particular course of action. Someone who feels compelled to undergo screening or to make particular reproductive choices at the urging of health care professionals or others or as a result of implicit social pressure is deprived of the choice-enhancing benefits of the new advances. The Commission recommends that those who counsel patients and those who educate the public about genetics should not only emphasize the importance of preserving choice but also do their utmost to safeguard the choices of those they serve.<sup>10</sup>

Now let us take this value of respect for autonomy and put it on both sides of the dilemma. Why is it morally problematic to seek to produce a child who is deaf? Being deaf does not cause one physical pain or shorten one's life span, two obvious conditions which it would be *prima facie* immoral to produce in another person. Deaf people might (or might not) be less happy on average than hearing people, but that is arguably a function of societal prejudice. The primary argument against deliberately seeking to produce deaf children is that it violates the child's own autonomy and narrows the scope of her choices when she grows up; in other words, it violates her right to an "open future."

### The Child's Right to an Open Future

Joel Feinberg begins his discussion of children's rights by noticing that rights can ordinarily be divided into four kinds. First, there are rights that adults and children have in common (the right not to be killed, for example). Then, there are rights that are generally possessed only by children (or by "childlike" adults). These "dependency-rights," as Feinberg calls them, derive from the child's dependence on others for such basics as food, shelter, and protection. Third, there are rights that can only be exercised by adults (or at least by children approaching adulthood), for example, the free exercise of religion. Finally, there are rights that Feinberg calls "rights-in-trust," rights which are to be "saved for the child until he is an adult." These rights can be violated by adults now, in ways that cut off the possibility that the child, when it achieves adulthood, can exercise them. A striking example is the right to reproduce. A young child cannot physically exercise that right, and a teenager might lack the legal and moral grounds on which to assert such a right. But clearly the child, when he or she attains adulthood, will have that right, and therefore the child now has the right not to be sterilized, so that the child may exercise that right in the future. Rights in this category include a long list: virtually all the important rights we believe adults have, but which must be protected now to be exercised later. Grouped together, they constitute what Feinberg calls "the child's right to an open future."<sup>11</sup>

Feinberg illustrates this concept with two examples. The first is that of the Jehovah's Witness child who needs a blood transfusion to save his life but whose parents object on religious grounds. In this case, the parents' right to act upon their religious beliefs and to raise their family within the religion of their choice conflicts with the child's right to live to adulthood and to make his own life-or-death decisions. As the Supreme Court said in another (and less defensible) case involving Jehovah's Witnesses:

Parents may be free to become martyrs themselves. But it does not follow that they are free in identical circumstances to make martyrs of their children before they have reached the age of full and legal discretion when they can make that decision for themselves.<sup>12</sup>

The second example is more controversial. In 1972, in a famous Supreme Court case, a group of Old Order Amish argued that they should be exempt from Wisconsin's requirement that all children attend school until they are either sixteen years old or graduate from high school.<sup>13</sup> The Amish didn't have to send their children to public school, of course; they were free to create a private school of their own liking. But they framed the issue in the starker manner: to send their children to any school, past eighth grade, would be antithetical to their religion and their way of life, and might even result in the death of their culture.

The case was framed as a freedom of religion claim on the one hand, and the state's right to insist on an educated citizenry on the other. And within that frame, the Amish won. First, they were able to persuade the Court that sending their children to school after eighth grade would potentially destroy their community, because it

takes them away from their community, physically and emotionally, during the crucial and formative adolescent period. During this period, the children must acquire Amish attitudes favoring manual work and self-reliance and the specific skills needed to perform the adult role of an Amish farmer or housewife. In the Amish belief higher learning tends to develop values they reject as influences that alienate man from God. (p. 211)

Second, the Amish argued that the state's concerns—that children be prepared to participate in the political and economic life of the state—did not apply in this case. The Court listened favorably to expert witnesses who explained that the Amish system of home-based vocational training—learning from your parent—worked well for that community, that the community itself was prosperous, and that few Amish were likely to end up unemployed. The Court said:

the value of all education must be assessed in terms of its capacity to prepare the child for life. It is one thing to say that compulsory education for a year or two beyond the eighth grade may be necessary when its goal is the preparation of the child for life in modern society as the majority live, but it is quite another if the goal of education can be viewed as the preparation of the child for life in the separated

agrarian community that is the keystone of the Amish faith. (p. 222)

What only a few justices saw was that the children themselves were largely ignored in this argument. The Amish wanted to preserve their way of life. The state of Wisconsin wanted to make sure that its citizens could vote wisely and make a living. No justice squarely faced the question of whether the liberal democratic state owes all its citizens, especially children, a right to a basic education that can serve as a building block if the child decides later in life that she wishes to become an astronaut, a play-wright, or perhaps to join the army. As we constantly hear from politicians and educators, without a high school diploma one's future is virtually closed. By denying them a high school education or its equivalent, parents are virtually ensuring that their children will remain housewives and agricultural laborers. Even if the children agree, is that a choice parents ought to be allowed to make for them?

From my perspective, the case was decided wrongly. If Wisconsin had good reasons for settling on high school graduation or age sixteen as the legal minimum to which children are entitled then I think that the Amish children were entitled to that minimum as well, despite their parents' objections. In deciding the issue primarily on grounds that the Amish were not likely to create problems for the state if allowed to keep their children out of school, the Court reflected a rather minimalist form of liberalism. In fact, the abiding interest of this case for many political philosophers lies in the deep conflict it highlights between two different concepts of liberalism: commitment to autonomy and commitment to diversity. William Galston, for example, argues that:

A standard liberal view (or hope) is that these two principles go together and complement one another: the exercise of autonomy yields diversity, while the fact of diversity protects and nourishes autonomy. By contrast, my . . . view is that these principles do not always, perhaps even do not usually, cohere; that in practice, they point in quite different directions in currently disputed areas such as education. . . . Specifically: the decision to throw state power behind the promotion of individual

autonomy can weaken or undermine individuals and groups that do not and cannot organize their affairs in accordance with that principle without undermining the deepest sources of their identity.<sup>14</sup>

Galston claims that "properly understood, liberalism is about the protection of diversity, not the valorization of choice. To place an ideal of autonomous choice . . . at the core of liberalism is in fact to narrow the range of possibilities available within liberal societies" (p. 523).

One can see this conflict quite sharply if one returns to the work of John Stuart Mill. On the one hand, there is probably no philosopher who gives more weight to the value of individual choice than does Mill. In *On Liberty*, he claims that the very measure of a human being is the extent to which he makes life choices for himself, free of societal pressure:

The human faculties of perception, judgment, discriminative feeling, mental activity, and even moral preference, are exercised only in making a choice. He who does anything because it is the custom makes no choice.<sup>15</sup>

Mill would abhor a situation like that of the Amish communities in *Yoder*, which unabashedly want to give their children as few choices as possible. But, on the other hand, it is clear from both common sense and from Mill's own statements that in order for people to have choices about the pattern of their lives (and to be inspired to create new patterns) there must be more than one type of community available to them. To quote Mill again, "There is no reason that all human existence should be constructed on some one or some small number of patterns" (p. 64). As we look at the last three centuries of American history, we see what an important role different community "patterns" have played, from the Shakers to the Mormons to Bronson Alcott's *Fruitlands* to the communal experiments of the 1960s. If those patterns are to exhibit the full range of human endeavor and experiment, they must include communities that are distinctly anti-liberal. Not only does the panoply of widely different communities enrich our culture, but it also provides a welcome for those who do not fit into the mainstream. As Mill says, "A man cannot get a coat or pair of shoes to fit him

unless they are either made to his measure, or he has a whole warehouseful to choose from: and is it easier to fit him with a life than with a coat[?]" (p. 64). Some of us are geniuses who make our lives to "fit our measure," others are happy enough to fit into the mainstream, but for others, the availability of a "warehouseful" of choices increases the possibility of finding a good fit. And for some, a good fit means an authoritarian community based on tradition, where one is freed from the necessity of choice. Thus Galston is correct in pointing to the paradox: if the goal of a liberal democracy is to actively promote something like the greatest number of choices for the greatest number of individuals, this seems to entail hostility toward narrow-choice communities like the Amish. But if the Amish, because of that hostility, fail to flourish, there will be fewer choices available to all.

The compromise I promote is that a liberal state must tolerate even those communities most unsympathetic to the liberal value of individual choice. However, this tolerance must exist within a limiting context, which is the right of individuals to choose which communities they wish to join and to leave if they have a mind to. Even Galston begins with the presumption that society must "defend . . . the liberty not to be coerced into, or trapped within, ways of life. Accordingly, the state must safeguard the ability of individuals to shift allegiances and cross boundaries."<sup>16</sup> Thus, I argue that the autonomy of the individual is ethically prior to the autonomy of the group. Both ideals have powerful claims on us, but when group rights would extinguish the abilities of the individuals within them to make their own life choices, then the liberal state must support the individual against the group. This is especially crucial when the individual at issue is a child, who is particularly vulnerable to adult coercion and therefore has particular claims on our protection.

Unfortunately, it is precisely where children are concerned that groups are understandably most jealous of their prerogatives to guide and make decisions. The Amish are an example of a group guarding its ability to shape the lives of its children; Deaf parents wishing to ensure Deaf children are an example of families pursuing the same goals. Of course, groups and families ought to—in fact, they

must—strive to shape the values and lives of the children in their care, not to do so leads to social and individual pathology. But when that shaping takes the form of a radically narrow range of choices available to the child when she grows up, when it impinges substantially on the child's right to an open future, then liberalism requires us to intervene to support the child's future ability to make her own choices about which of the many diverse visions of life she wishes to embrace.

But I concede one problem with this point of view. As a liberal who believes that the state should not dictate notions of "the good life," Feinberg believes that the state must be neutral about the goals of education, skewing the question neither in favor of the Amish lifestyle nor in favor of the "modern," technological life most Americans accept. The goal of education is to allow the child to make up its own mind from the widest array of options; the best education is the one which gives the child the most open future. A neutral decision would assume only that education should equip the child with the knowledge and skills that will help him choose whichever sort of life best fits his native endowment and matured disposition. It should send him out into the adult world with as many open opportunities as possible, thus maximizing his chances for self-fulfillment.<sup>17</sup>

The problem here is that an education which gave a child this array of choices would quite possibly make it impossible for her to choose to remain Old Order Amish. Her "native endowment and matured disposition" might now have taken her away from the kind of personality and habits that would make Amish life pleasant. Even if she envies the peace, warmth, and security that a life of tradition offers, she may find it impossible to turn her back on "the world," and return to her lost innocence. To quote the Amish, she may have failed irreversibly to "acquire Amish attitudes" during "the crucial and formative adolescent period." This problem raises two issues. First, those of us who would make arguments based on the child's right to an open future need to be clear and appropriately humble about what we are offering. Insisting on a child's right to a high school education may open a future wider than she otherwise could have dreamed, but it also

may foreclose one possible future: as a contented member of the Amish community. Second, if the Amish are correct in saying that taking their children out of school at grade eight is crucial for the child's development into a member of the Amish community, then there is no "impartial" stance for the state to take. The state may well be impartial about whether the "better life" is to be found within or without the Amish community, but it cannot act in an impartial fashion. Both forcing the parents to send their children to school or exempting them from the requirement has likely consequences for the child's continued existence within the community when she grows up and is able to make a choice. Feinberg seeks to avoid this second problem by claiming that the neutral state would act to

let all influences . . . work equally on the child, to open up all possibilities to him, without itself influencing him toward one or another of these. In that way, it can be hoped that the chief determining factor in the grown child's choice of a vocation and life-style will be his own governing values, talents, and propensities. (pp. 134–35)

The problem with this is that, as I understand the Amish way of life, being Amish is precisely not to make one's life choices on the basis of one's own "talents and propensities," but to subordinate those individual leanings to the traditions of the group. If one discovers within oneself a strong passion and talent for jazz dancing, one ought to suppress it, not nurture it.

### **Is Creating a Deaf Child a Moral Harm?**

Now, as we return to the example of the couple who wish to ensure that they bear only deaf children, we have to confront two distinctly different issues. The first is, in what sense is it ever possible to do harm by giving birth to a child who would otherwise not have been born at all? The second is whether being deaf rather than hearing is in fact a harm.

The first issue has been well rehearsed elsewhere.<sup>18</sup> The problem is, how can it be said that one has harmed a child by bringing it into the world with a disability, when the only other choice was for the child not to have existed at all? In the case of a child whose life is arguably not worth living, one

can say that life itself is a cruelty to the child. But when a child is born in less than ideal circumstances, or is partially disabled in ways that do not entail tremendous suffering, there seems no way to argue that the child herself has been harmed. This may appear to entail the conclusion, counter to our common moral sense, that therefore no harm has been done. "A wrong action must be bad for someone, but [a] choice to create [a] child with its handicap is bad for no one."<sup>19</sup>

All commentators agree that there is no purely logical way out of what Dan Brock calls the "wrongful handicap" conundrum (p. 272). However, most commentators also agree that one can still support a moral critique of the parents' decision. Bonnie Steinbock and Ron McClamrock argue for a principle of "parental responsibility" by which being a good parent entails refraining from bringing a child into the world when one cannot give it "even a decent chance at a good life."<sup>20</sup> Brock, following Parfit, distinguishes same person from same number choices. In same person choices, the same person exists in each of the alternative courses of action the agent chooses, but the person may exist more or less harmed. In same number choices, "the choice affects who, which child, will exist."<sup>21</sup> Brock claims that moral harms can exist in both instances, despite the fact that in same number choices the moral harm cannot be tied to a specific person. Brock generates the following principle:

Individuals are morally required not to let any possible child . . . for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child . . . for whose welfare they would be responsible will not experience serious suffering or limited opportunity. (pp. 272–73)

While agreeing with Brock, Steinbock, and others, I locate the moral harm differently, at least with respect to disabled persons wishing to reproduce themselves in the form of a disabled child. Deliberately creating a child who will be forced irreversibly into the parents' notion of "the good life" violates the Kantian principle of treating each person as an end in herself and never as a means only. All parenthood exists as a balance between

fulfillment of parental hopes and values and the individual flowering of the actual child in his or her own direction. The decision to have a child is never made for the sake of the child—for no child then exists. We choose to have children for myriad reasons, but before the child is conceived those reasons can only be self-regarding. The child is a means to our ends: a certain kind of joy and pride, continuing the family name, fulfilling religious or societal expectations, and so on. But morally the child is first and foremost an end in herself. Good parenthood requires a balance between having a child for our own sakes and being open to the moral reality that the child will exist for her own sake, with her own talents and weaknesses, propensities and interests, and with her own life to make. Parental practices that close exits virtually forever are insufficiently attentive to the child as end in herself. By closing off the child's right to an open future, they define the child as an entity who exists to fulfill parental hopes and dreams, not her own.

Having evaded the snares of the wrongful handicap conundrum, we must tackle the second problem: is being deaf a harm? At first glance, this might appear as a silly question. Ethically, we would certainly include destroying someone's hearing under the rubric of "harm"; legally, one could undoubtedly receive compensation if one were rendered deaf through someone else's negligence. Many Deaf people, however, have recently been claiming that Deafness is better understood as a cultural identity than as a disability. Particularly in the wake of the Deaf President Now revolution at Gallaudet University in 1988, Deaf people have been asserting their claims not merely to equal access (through increased technology) but also to equal respect as a cultural minority. As one (hearing) reporter noted:

So strong is the feeling of cultural solidarity that many deaf parents cheer on discovering that their baby is deaf. Pondering such a scene, a hearing person can experience a kind of vertigo. The surprise is not simply the unfamiliarity of the views; it is that, as in a surrealist painting, jarring notions are presented as if they were commonplace.<sup>22</sup>

From this perspective, the use of cochlear implants to enable deaf children to hear, or the

abortion of deaf fetuses, is characterized as "genocide."<sup>23</sup> Deaf pride advocates point out that as Deaf people they lack the ability to hear, but they also have many positive gains: a cohesive community, a rich cultural heritage built around the various residential schools, a growing body of drama, poetry, and other artistic traditions, and, of course, what makes all this possible, American Sign Language.<sup>24</sup> Roslyn Rosen, the president of the National Association of the Deaf, is Deaf, the daughter of Deaf parents, and the mother of Deaf children. "I'm happy with who I am," she says, "and I don't want to be 'fixed.' Would an Italian-American rather be a WASP? In our society everyone agrees that whites have an easier time than blacks. But do you think a black person would undergo operations to become white?"<sup>25</sup>

On the other side of the argument is evidence that deafness is a very serious disability. Deaf people have incomes thirty to forty percent below the national average.<sup>26</sup> The state of education for the deaf is unacceptable by anyone's standards; the typical deaf student graduates from high school unable to read a newspaper.<sup>27</sup>

However, one could also point to the lower incomes and inadequate state of education among some racial and ethnic minorities in our country, a situation we do not (or at least ought not) try to ameliorate by eradicating minorities. Deaf advocates often cite the work of Nora Ellen Groce, whose oral history of Martha's Vineyard, *Everyone Here Spoke Sign Language*, tells a fascinating story. For over two hundred years, ending in the middle of the twentieth century, the Vineyard experienced a degree of hereditary deafness exponentially higher than that of the mainland. Although the number of deaf people was low in noncomparative terms (one in 155), the result was a community in which deaf people participated fully in the political and social life of the island, had an economic prosperity on par with their neighbors, and communicated easily with the hearing population, for "everyone here spoke sign language." So endemic was sign language for the general population of the island that hearing islanders often exploited its unique properties even in the absence of deaf people. Old-timers told Groce stories of spouses communicating

through sign language when they were outdoors and did not want to raise their voices against the wind. Or men might turn away and finish a “dirty” joke in sign when a woman walked into the general store. At church, deaf parishioners gave their testimony in sign.

As one Deaf activist said, in a comment that could have been directly related to the Vineyard experience, “When Gorbachev visited the U.S., he used an interpreter to talk to the President. Was Gorbachev disabled?”<sup>28</sup> Further, one might argue that, since it is impossible to eradicate deafness completely even if that were a worthy goal, the cause of deaf equality is better served when parents who are proud to be Deaf deliberately have Deaf children who augment and strengthen the existing population. Many of the problems that deaf people experience are the result of being born, without advance warning, to hearing parents. When there is no reason to anticipate the birth of a deaf child, it is often months or years before the child is correctly diagnosed. Meanwhile, she is growing up in a world devoid of language, unable even to communicate with her parents. When the diagnosis is made, her parents first must deal with the emotional shock, and then sort through the plethora of conflicting advice on how best to raise and educate their child. Most probably, they have never met anyone who is deaf. If they choose the route recommended by most Deaf activists and raise their child with sign language, it will take the parents years to learn the language. Meanwhile, their child has missed out on the crucial development of language at the developmentally appropriate time, a lack that is associated with poor reading skills and other problems later (p. 43).

Further, even the most accepting of hearing parents often feel locked in conflict with the Deaf community over who knows what is best for their child. If Deafness truly is a culture rather than a disability, then raising a deaf child is somewhat like white parents trying to raise a black child in contemporary America (with a background chorus of black activists telling them that they can’t possibly make a good job of it!). Residential schools, for example, which can be part of the family culture for a Deaf couple, can be seen by hearing parents as

Dickensian nightmares or, worse, as a “cultlike” experience in which their children will be lost to them forever.

By contrast, deaf children born to Deaf parents learn language (sign) at the same age as hearing children. They are welcomed into their families and inculcated into Deaf culture in the same way as any other children. Perhaps for these reasons, by all accounts the Deaf of Deaf are the acknowledged leaders of the Deaf Pride movement, and the academic *crème de la crème*. In evaluating the choice parents make who deliberately ensure that they have Deaf children, we must remember that the statistics and descriptions of deaf life in America are largely reflective of the experience of deaf children born to hearing parents, who make up the vast majority of deaf people today.

But if Deafness is a culture rather than a disability, it is an exceedingly narrow one. One factor that does not seem clear is the extent to which children raised with American Sign Language as their first language ever will be completely comfortable with the written word. (Sign language itself has no written analogue and has a completely different grammatical structure from English.) At present, the conflicted and politicized state of education for the deaf, along with the many hours spent (some would say “wasted”) on attempting to teach deaf children oral skills, makes it impossible to know what is to blame for the dismal reading and writing skills of the average deaf person. Some deaf children who are raised with sign language from birth do become skilled readers. But there is reason to question whether a deaf child may have very limited access to the wealth of literature, drama, and poetry that liberals would like to consider every child’s birthright.

Although Deaf activists rightly show how many occupations are open to them with only minor technological adjustments, the range of occupations will always be inherently limited. It is not likely that the world will become as Martha’s Vineyard, where everyone knew sign. A prelingually deafened person not only cannot hear, but in most instances cannot speak well enough to be understood. This narrow choice of vocation is not only a harm in its own sake but also is likely to continue to

lead to lower standards of living. (Certainly one reason why the Vineyard deaf were as prosperous as their neighbors was that farming and fishing were just about the only occupations available.)

### **Either Way, a Moral Harm**

If deafness is considered a disability, one that substantially narrows a child's career, marriage, and cultural options in the future, then deliberately creating a deaf child counts as a moral harm. If Deafness is considered a culture, as Deaf activists would have us agree, then deliberately creating a Deaf child who will have only very limited options to move outside of that culture, also counts as a moral harm. A decision, made before a child is even born, that confines her forever to a narrow group of people and a limited choice of careers, so violates the child's right to an open future that no genetic counseling team should acquiesce in it. The very value of autonomy that grounds the ethics of genetic counseling should preclude assisting parents in a project that so dramatically narrows the autonomy of the child to be.

### **Coda**

Although I rest my case at this point, I want to sketch out some further ramifications of my argument. Are there other, less obvious, ways in which genetic knowledge and manipulation can interfere with the child's right to an open future?

The notion of the child's right to an open future can help in confronting the question of whether to test children for adult-onset genetic diseases, for example Huntington disease.<sup>29</sup> It is well known that the vast majority of adults at risk for Huntington disease choose not to be tested. However, it is not uncommon for parents to request that their children be tested; their goals may be to set their minds at rest, to plan for the future, and so on. On one account, parental authority to make medical decisions suggests that clinicians should accede to these requests (after proper counseling about possible risks). A better account, in my opinion, protects the child's right to an open future by preserving into adulthood his own choice to decide whether his life is better lived with that knowledge or without.<sup>30</sup>

Finally, a provocative argument can be made that sex selection can be deleterious to the child's right to an open future. I am ignoring here all the more obvious arguments against sex selection, even when accomplished without abortion. Rather, I suspect that parents who choose the sex of their offspring are more likely to have gender-specific expectations for those children, expectations that subtly limit the child's own individual flowering. The more we are able to control our children's characteristics (and the more time, energy, and money we invest in the outcome), the more invested we will become in our hopes and dreams for them. It is easy to sympathize with some of the reasons why parents might want to ensure a girl or boy. People who already have one or two children of one sex can hardly be faulted for wanting to "balance" their families by having one of each. And yet, this ought to be discouraged. If I spent a great deal of time and energy to get a boy in the hope of having a football player in the family, I think I would be less likely to accept it with good grace if the boy hated sports and spent all his spare time at the piano. If I insisted on having a girl because I believed that as a grandparent I would be more likely to have close contact with the children of a daughter than of a son, I think I would find it much harder to raise a girl who saw motherhood as a choice rather than as a foregone conclusion. Parents whose preferences are compelling enough for them to take active steps to control the outcome, must, logically, be committed to certain strong gender role expectations. If they want a girl that badly, whether they are hoping for a Miss America or the next Catherine McKinnon, they are likely to make it difficult for the actual child to resist their expectations and to follow her own bent.

### **NOTES**

1. Walter E. Nance, "Parables," in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, ed. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine De Gruyter, 1993), p. 92.
2. National Society of Genetic Counselors, Code of Ethics, reprinted in *Prescribing Our Future*, pp. 169–71.
3. James R. Sorenson, "Genetic Counseling: Values That Have Mattered," *Prescribing Our Future*, p. 11;

- Arthur L. Caplan, "The Ethics of Genetic Counseling," *Prescribing Our Future*, p. 161.
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## Disowning Knowledge: Issues in Genetic Testing

ROBERT WACHBROIT

Wachbroit considers whether physicians are justified in limiting patients' access to certain kinds of genetic tests or test results. He argues that sometimes such restrictions can be justified on scientific grounds, but too often they represent a "resurgent paternalism" in which physicians make nonmedical judgments out of concern that genetic information might cause social or psychological harm to patients. We should respect people's decisions to know—as well as their decisions not to know.

Last fall in Chicago, at a conference sponsored by the Alzheimer's Association and the National Institute on Aging, doctors and researchers met to discuss an ethical dilemma that has grown increasingly familiar as advances in diagnostic techniques outstrip the therapeutic abilities of the medical profession. The meeting focused on the use of a medical test for a particular heart condition—a test that can also, in some cases, predict with 90 percent accuracy whether someone will develop Alzheimer's disease by the age of 80. Should patients tested for the heart condition be told of their risk of contracting Alzheimer's disease, when there is little if anything medicine at present can do to prevent or ameliorate the condition?

Some people, including many of those attending the meeting, believe that the answer to this question is no: if the information is of little therapeutic value, it's of little value to the patient as well. It is wrong to burden the patient with troubling news when there is little or nothing that the physician can do about it.

At this stage in the history of medical practice, we may well be surprised to encounter such a response. Over the past few decades there has been an intense effort to articulate and defend a person's right to be informed of his or her medical condition. Not so long ago, this right was not widely acknowledged. Health professionals generally

assumed that, in the case of certain diseases, patients didn't really want to know. Moreover, even if they did want to, they wouldn't really understand the diagnosis; and even if they did want to know and could understand, they would be so psychologically harmed by the information that the result would likely be, if not suicide, then a clinical depression that would interfere with any sort of available care. Over the years the arguments attempting to defend this medical paternalism have been carefully examined and successfully undermined. The very idea of health professionals deciding whether a patient should know his or her medical condition is now routinely criticized in bioethics courses. Nonetheless, the advent of genetic testing appears to have provoked a resurgence of paternalistic thinking, especially in those cases where doctors can detect the genetic condition associated with a particular disease but are as yet unable to prevent or treat that disease.

The association between a genetic condition and a disease, and so the type of information a genetic test reveals, is subject to considerable variation. With results from the test for a specific mutation at the tip of chromosome 4, we can predict with near certainty whether an individual will suffer from Huntington's disease, a severe late-onset neurological disorder, but we can't yet tell when the disease will occur. With information from the test for mutations of the BRCA1 gene, we can, in particular situations, conclude that an individual has a susceptibility to a specific type of breast cancer, but we don't yet know what other conditions must be in place to trigger this susceptibility. With

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information from the test discussed in Chicago—a test that detects the presence of the apolipoprotein E genotype—we can, in particular situations, conclude that an individual is at an increased risk of contracting Alzheimer's disease, but there is still some controversy about the relative importance of this risk factor.

Recent concern has largely focused on these last two tests. At the Chicago meeting, the issue was the disclosure of certain additional information from a test already administered. In other cases, professional organizations, as well as some advocacy groups, have proposed limits on the very availability of certain genetic tests. It is argued that tests for certain conditions should be restricted to research settings for the time being and not offered routinely or to all.

Are these proposals based on medical paternalism? Or can restrictions on genetic testing be defended on other grounds? I wish to examine possible justifications for limiting testing, distinguishing between those that are paternalistic and those that are not. I shall then consider the reasons and responsibilities that might influence patients in deciding whether to be tested or to receive genetic information.

### **Grounds for Restrictions**

A discussion of reasons for restricting genetic testing should begin by acknowledging that there is no *right* to genetic testing. A right to be informed of test results (assuming that such a right exists) would not entail a right to *be* tested. And a "right to health care" (in the usual ways that phrase is understood) is not taken to include a right to have every diagnostic test, including genetic tests, performed. But though there is no right to genetic testing, a decision to withhold or restrict certain tests should be based on good public reasons (as opposed to private, economic reasons). This is especially true in the case of genetic tests, since in many cases genetic testing facilities, e.g., those connected with teaching hospitals, are supported, directly or indirectly, with public funds.

Reasons for restricting certain kinds of genetic tests can be divided into two broad categories.

One set of reasons focuses on the *time and resources* that would be lost by the inappropriate use of genetic testing. Given the current state of knowledge, the results obtained from certain tests may include such a high number of false-positives or false-negatives, or be so difficult to interpret, that performing these tests would be a waste of the health professional's or laboratory's time, diverting resources from tests that are diagnostically more useful. For example, research has revealed a large number of possible mutations in BRCA1. Unless a woman's family history implicates a particular mutation in the occurrence of breast cancer, there is no point in testing her for that mutation; whatever the test result may be, it will not be interpretable. Thus, a decision not to offer BRCA1 testing to all women would be defensible on the grounds that widespread testing would needlessly draw upon society's limited resources of expertise and technology. Where the best available evidence shows that a given procedure would yield no meaningful information, it is entirely appropriate, so the argument goes, to restrict that procedure.

The second set of grounds for restricting the availability of genetic tests focuses on claims about the *social or psychological harms* that individuals might suffer from knowing their test results, where these harms are not offset by any corresponding medical benefit. Indeed, in many cases these harms are considered to be so palpable and the medical benefits so clearly nonexistent that it is assumed people would not want to know their genetic condition even if they had the opportunity.

One widely cited harm of knowing one's genetic condition arises from the prospect of discrimination in employment or insurance coverage. Someone with a known genetic condition indicating a susceptibility to breast cancer might be denied a job or a promotion, or denied health or life insurance, because she is regarded as a health risk and therefore as too great an economic risk. This concern about discrimination chiefly provides a reason why *third parties* should not be given access to an individual's genetic information. Yet an individual may well decide to forgo this information in order to maintain deniability. For example, suppose an

insurance contract requires the individual to tell all she knows about her genetic condition, so that discovering that any information was withheld would constitute grounds for dismissing later claims. A person in this situation might well decide to remain ignorant, since she can't be penalized for withholding information she doesn't have.

However, a person can maintain ignorance of her genetic condition only up to a point, since genetic tests are not the only source of information about that condition. Standard family medical histories can sometimes tell a good deal, and claiming ignorance of this history may not be possible. If an individual suffers from Huntington's disease, then his or her children have a 50 percent probability of contracting it as well. If a woman's sister, mother, and aunt suffer from breast cancer, then it is likely that the woman is at greater risk than the general population of contracting breast cancer herself. Furthermore, genetic information is not always bad news. Someone who appears to be at risk for a certain disease because of her family history could discover, and so presumably assure an employer or insurer, that she is in fact not at risk because her test result was negative. Nevertheless, we should acknowledge that there can be perverse incentives to be ignorant, especially in the absence of appropriate laws regarding "genetic discrimination" or regulations regarding insurance and preexisting conditions.

A completely different harm that is associated with genetic information has to do with the psychological burden of knowing. Indeed, one writer refers to such information as "toxic knowledge." Unlike concerns about employment discrimination or insurance, fears about the burden of knowing speak directly to the question of the desirability of self-knowledge. For some people, the discovery that they have a genetic condition that places them at an especially high risk of suffering certain diseases could so depress them that the quality, joy, and purpose of their lives would evaporate. Moreover, even if the results of a genetic test were negative, some people might experience the reaction commonly known as "survivor's guilt," as they contemplate the prospects of their less fortunate siblings or other relatives.

The applicability of this reason will vary from person to person. Some people might be able to handle bad news calmly and move on, while others might become irrevocably incapacitated. We are individuals in how we each deal with the disappointments and tragedies in our lives. Genetic knowledge might be extremely toxic for one individual but less so for another. Presumably however, if a person does raise this issue in his own case, it probably applies.

### Deciding for the Patient

It is this last set of reasons, when invoked to justify limits on the availability of genetic testing, that suggests a resurgent paternalism with respect to medical information. They involve explicit judgments by medical professionals about what would be good for the patient, where the "good" (i.e., the avoidance of certain social and psychological harms) extends beyond matters of medical expertise. Whatever force they may have as reasons an *individual* might give for not wanting to know genetic information, their persuasiveness weakens considerably when they are offered by third parties as reasons for restrictions on genetic testing. While certain people might be psychologically devastated by their test results, there is no evidence to support the assumption that most people will be so devastated; indeed, such an assumption flies in the face of our commonsense knowledge of people's differences. Similarly, the likelihood that people will confront employment discrimination or insurance problems, and the seriousness with which they regard such a prospect, will vary with circumstances. It is therefore paternalistic to cite these concerns as grounds for restricting genetic testing.

The same can be said of arguments that the results of genetic tests are too complex or ambiguous for patients to understand. Test results may identify risk factors rather than yield predictions; the information may consist of probabilities rather than certainties. In other medical contexts, however, the complexity of information is not accepted as an excuse for taking decisions out of the patient's hands. For example, we require physicians to obtain informed consent before they engage in an intervention. However complex the relevant

information might be, usefully communicating it to the patient is a challenge to which the professional must rise.

A rejection of the paternalistic arguments does not yield the conclusion that all genetic tests should be available to the public. As we have seen, restrictions on the availability of certain genetic tests, or of any medical procedure, need not be based on paternalism. For example, none of these comments affects the legitimacy or persuasiveness of the scientific reasons for restricting certain tests.

Unfortunately, some of the professional organizations and advocacy groups seeking to restrict genetic testing have allowed an admixture of paternalism to enter into what would otherwise be sound scientific arguments. Instead of simply pointing out that a test for BRCA1 mutations can yield no useful information about most women, they express worries about the “fear” and “panic” that widespread testing might provoke. The first objection to indiscriminate testing is valid; the second is not. By including arguments that would in other contexts be rejected as unwarranted medical paternalism, these organizations have inadvertently ceded the moral high ground to the for-profit laboratories that have rushed in to perform these tests. Whether the labs can provide testing with the appropriate care and counseling is an open question. But efforts to regulate or even comment upon their services are likely to be ineffectual so long as the laboratories can self-righteously affirm the patient’s “right to know” against the paternalism of their critics.

Similarly, when the researchers in Chicago tried to formulate a policy regarding the disclosure of test results, paternalistic assumptions clouded the issue. It was agreed that a cardiac test yielding information about the risk of Alzheimer’s disease poses an ethical problem for the physician, who must either inform patients of their condition or withhold that information. But there is another alternative: the physician can tell patients, before testing for one condition, that information about another condition will be available. Whether or not to be informed becomes the patient’s decision. Indeed, this option is standard in communicating the results of various medical tests, including

results where disease is not at issue. The obstetrician performing amniocentesis doesn’t typically agonize over whether to inform the couple of the fetus’s sex. The couple are simply asked whether they want to know. And in our society at this time, the patient’s desire to know or not to know is taken to settle the matter.

### **A Responsibility to Know**

It is mainly those who wish to know their genetic condition who are likely to object to paternalistic restrictions on genetic testing. We cannot assume, however, that most people would fall into this category. In one recent study, only 43 percent of research subjects who were offered the BRCA1 test agreed to have it performed. Many who refused the test cited the concerns about employment and insurance that I have already described, while others pointed to the psychological distress that knowledge might bring.

If the challenge to medical paternalism is based on the notion that people should be free to make their own choices with respect to information, then in general the decision not to know should be as fully respected as the decision *to* know. No one would be in favor of frog-marching people to a genetics lab, having them tested, and then compelling them to listen to the results. The widely acknowledged right people have to refuse treatment surely includes a right to refuse diagnostic tests. If some people simply don’t want their decisions about how they live their lives to depend upon genetic information, it would seem that they have no reason, and certainly no obligation, to know.

Nevertheless, there are many circumstances in which people might have a moral responsibility to know—a responsibility that grows out of their professional or personal obligations. The case for professional obligations, though limited, is fairly clear. The same reasoning that supports drug testing of individuals in particular professions—air traffic controller, train conductor, airline pilot—also supports claiming that these individuals have an obligation to know their genetic information. If an individual might have a condition that, if manifested, would interfere with his job performance in such a way as to endanger other people, that person

has an obligation to know and monitor that condition, whether he wants to or not.

Since most of us are not employed in such professions, however, this obligation attaches to relatively few people. Moreover, most genetic conditions are unlikely to have an impact on the safety of other people. It is difficult to argue that an airline pilot's refusal to know whether she is at special risk of contracting breast cancer would endanger the lives of the passengers.

The ways in which personal obligations may generate a responsibility to know one's genetic condition have not been given comparable attention, even though they are more widely applicable. Most of us are enmeshed in a network of personal obligations and commitments—to families, dependents, loved ones. In many cases, with information about our medical condition, we can more effectively discharge our obligations, or at least avoid measures that, under the circumstances, may be futile. Consider the case of a 50-year-old parent of minor children who refuses to know whether he is at high risk of contracting Alzheimer's disease within the next ten years. His refusal to know might be irresponsible; it might amount to a failure to engage fully in the (not just financial) planning that is part of a parent's commitment to his children. Whether one has a moral responsibility to know one's genetic

condition, and the strength of that responsibility, will depend upon the particulars of the situation. In all likelihood, however, a person's *responsibility* to know will not depend upon the strength of his or her *desire* to know or not to know.

The idea of having a responsibility to know can seem jarring at first. We are drawn to a picture of an individual, faced with the prospect of knowing, weighing how that knowledge would affect her personally. The thought that someone ought to know seems to go against our cultural assumptions, as if such an obligation were an unwelcome interference in the private relationship a person has with her own life. The problem with this picture of solitary individuals contemplating whether to know about their future is that it fits so few of us.

How should the responsibility of knowing be balanced against the possible burden and cost of knowing? There is probably little of use that can be said at this level of generality, since much will depend on the circumstances. The 50-year-old who has minor children, by birth or adoption, is in a different situation from the footloose 20-year-old. In any event it should be clear that if we are to make responsible decisions about accepting or refusing medical information, we must begin by acknowledging that these decisions affect others as well as ourselves.

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## The Non-Identity Problem and Genetic Harms— The Case of Wrongful Handicaps

DAN W. BROCK

In this essay Brock scrutinizes the claim that it would be wrong not to prevent devastating genetic diseases or disabilities in a child. Some have held that failing to prevent an impairment is wrong because the child would be better off if the impairment were prevented. But Brock finds this view incoherent, arguing on logical grounds that a failure to prevent a serious disability cannot in fact *wrong the child*. He maintains instead that although failing to prevent a serious disability does not wrong the child, it is nevertheless wrong for "non-person-affecting" reasons.

The world-wide Human Genome Project (HGP) will produce information permitting genetic screening for an increasing number of genetic diseases and genetically based increased susceptibilities to diseases and other harmful conditions. In the foreseeable future, the capacities for preconception and prenatal screening for these diseases and conditions will almost certainly far outstrip our capacities for genetic therapy to correct for the harmful genes and their effects. The vast majority of decisions faced by prospective parents, consequently, will be whether to screen for particular genetic risks and/or conditions and when they are found to be present, whether to avoid conception or to terminate a pregnancy. Moreover, the vast majority of genetic risks that will be subject to screening will not be for diseases or conditions incompatible with life worth living—wrongful life cases—but rather for diseases and conditions sufficiently less severe or grave as to be compatible with having a life worth living. These genetic conditions and diseases will take different forms and many factors will affect the moral case for preventing them. But there is a systematic objection to all preconception wrongful handicap cases which must be resolved to clear the way for judgment about specific cases.

To fix attention on the general sort of case and problem in question, which is not restricted to the context of genetic disease, let us alter slightly a case of Derek Parfit's, call it case P<sub>1</sub>, in which a woman is told by her physician that she should not attempt to become pregnant now because she has a condition that would be highly likely to result in mild retardation in her child.<sup>1</sup> Her condition is easily and fully treatable by taking a quite safe medication for one month. If she takes the medication and delays becoming pregnant for two months, there is every reason to expect that she will have a normal child. Because she is impatient to begin a family she refuses to wait, gets pregnant now, and gives birth to a child who is mildly retarded. In common sense moral views, the woman in case P<sub>1</sub> acts wrongly, and in particular wrongs her child, by not preventing its handicap for such a morally trivial reason. Most people would likely say that her action in P<sub>1</sub> is no different morally than if she failed to take the medicine in a case, P<sub>2</sub>, identical to P<sub>1</sub> except that the

condition is discovered, and so the medicine must be taken, after conception and when she is already pregnant, or if, in a case, P<sub>3</sub>, she failed to provide a similar medication to her born child, in each case necessary to prevent a comparable degree of mental retardation to her child. On what Derek Parfit has called the “no difference” view, the view of common sense morality that he endorses, her failure to employ the medication to prevent her child’s mental retardation would be equally and seriously wrong in each of the three cases. But her action in P<sub>1</sub>, which is analogous in relevant respects to genetic screening to prevent handicaps, has a special feature that makes it not so easily shown to be wrong as common sense morality might suppose.

In wrongful handicap cases such as this, the person's handicap leaves him with a worthwhile life, a life that is better than no life at all. The philosophical problem, as noted earlier, is how this judgment is compatible with the common view that it would be wrong not to prevent the handicap. The difficulty is that it would *not* be better for the person with the handicap to have had it prevented since that can only be done by preventing him from ever having existed at all; preventing the handicap would deny the individual a worthwhile, although handicapped, life. The handicap could be prevented either by conceiving at a different time and/or under different circumstances, in which case a different child would be conceived, or by terminating the pregnancy, in which case this child never comes into existence and a different child may or may not be conceived instead. None of those possible means of preventing the handicap would be better for the child with the handicap—all would deny him or her a worthwhile life. But if the mother's failing to prevent the handicap has not made her child worse off, then failing to prevent the handicap does not harm her child. And if she does not harm her child by not preventing its handicap, then why does she wrong her child morally by failing to do so? How could making her child better off by giving it a life worth living, albeit a life with a significant handicap, wrong it? A wrong action must be bad for someone, but her choice to create her child with its handicap is bad for no one. So actions with effects for a child that would constitute seriously wrongful child

abuse if done to an existing child are no harm, and so no wrong, if done to a child when they are inextricable from the choice to bring that child into existence with a worthwhile life. This argument threatens to undermine common and firmly held moral judgments, as well as public policy measures, concerning prevention of such handicaps to children.

Some philosophers accept the implications of this argument and hold that in choices of whether a particular individual will be brought into existence, only the interests of actual persons, not the interests of possible persons, which here means the individual whose existence is in question, are relevant to the choice.<sup>2</sup> So in case P1 above, the effects on the parents and the broader society, such as the greater childrearing costs and difficulties of having the mildly retarded child instead of taking the medication and having a normal child two months later are relevant to the decision; but the effects on and interests of the child itself who would be mildly retarded are not relevant. In P2 and P3, on the other hand, the fundamental reason the woman's action would be wrong is the easily preventable harm that she causes her child, or allows it to suffer.

I share with Parfit the no difference view that the woman's action would be equally wrong in P1, P2, and P3. As Parfit notes, the difficulty is identifying and formulating the moral principle on the basis of which the woman's actions in all three cases are equally wrong, and which therefore remedies the limits of traditional ethical theories and their principles of beneficence—doing good—and non-maleficence—not causing or preventing harm. Perhaps the most natural way of trying to account for the moral wrong in wrongful handicap cases is to abandon the feature of the moral principles we appealed to above that generates the difficulty when we move from standard cases of prevention of harm to already existing persons, as in P3 above, to harm prevention in what David Heyd has called genesis cases like P1. That feature is what philosophers have called the person-affecting property of principles of beneficence and non-maleficence, such as principle M:

- M: Those individuals responsible for a child's, or other dependent person's, welfare are morally

required not to let it suffer a serious harm or handicap that they could have prevented without imposing substantial burdens or costs on themselves or others.

Since harms to persons must always be harms to some person, it may seem that there is no alternative to principles that are person-affecting, but that is not so. The alternative is clearest if we follow Derek Parfit by distinguishing "same person" from "same number" choices. In same person choices, the same persons exist in each of the different alternative courses of action from which an agent chooses. Cases P2 and P3 above were same person choices; the harm of mild retardation prevented is to the woman's fetus or born child. In same number choices, the same number of persons exists in each of the alternative courses of action from which an agent chooses, but the identities of some of the persons who exist in those alternatives are affected by the choice. P1 is a same number, but not same person choice—the choice affects *who*, which child, will exist. If the woman does not take the medication nor wait to conceive, her child is born mildly retarded, whereas if she takes the medication and waits to conceive she gives birth to a different child who is not mildly retarded. Arguably, the concept of "harm" is necessarily comparative, and so the concept of "harm prevention" may seem necessarily person-affecting, which is why harm prevention principles seem not to apply to different person choices like P1. But it is a mistake to believe that non person-affecting principles, even harm prevention principles, are not possible. Suppose for simplicity that the harm in question in P1 from the mild retardation is suffering and limited opportunity. Then there would be suffering and limited opportunity in P1 if the woman were to choose to have the mildly retarded child which will not exist and so would be prevented if she made the other choice and took the medication while waiting to conceive a different normal child. An example of a non person-affecting principle that applies to P1 is:

- N: Individuals are morally required not to let any possible child or other dependent person for whose welfare they are responsible experience serious suffering or limited opportunity if they

can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child or other dependent person for whose welfare they would be responsible will not experience serious suffering or limited opportunity.

Although, of course, suffering and limited opportunity must be experienced by some person—they cannot exist in disembodied form so in that sense N remains person-affecting, N does not require that the individuals who experience suffering and limited opportunity in one alternative exist without those effects in the other alternative; it is a same number, not same person principle. The non person-affecting nature of a moral principle concerning the evils of suffering and limited opportunity is clearer still in the following principle:

N': It is morally good to act in a way that results in less suffering and less limited opportunity in the world.

On N', the woman in P<sub>1</sub> acts in a morally good way by taking the medication and waiting to conceive a normal child. In the genetic screening analog, a couple acts in a morally good way by taking steps not to have a child whom they learn from genetic screening will experience suffering and limited opportunity that another child they could have instead would not experience. On N', it is morally good to act in a way that makes the suffering and limited opportunity “avoidable by substitution,” as Philip G. Peters, Jr. has put it.<sup>3</sup>

There is time to mention only one apparent difficulty with this way of avoiding the non-identity problem. It is that it does not account for the apparent aspect of the common sense moral judgment about P<sub>1</sub> that the woman specifically wrongs her child by not preventing its handicap, that is, that her child is the victim of her wrong and so has a moral grievance against her. Her child is the person with the handicap which should have been prevented, but applying N or N' the handicap should not have been prevented for the sake of that child since doing so would have made that child worse off (it would never have had its worthwhile life). Rather, applying N or N', it should have been done only for the sake of less overall suffering and loss of opportunity.

This apparent difficulty with N and N' is that they fail to identify a victim of the harm done who as victim has a special moral complaint against its mother. But when we appeal to non person-affecting principles to criticize the failure of the mother to prevent harm in P<sub>1</sub>, her child who suffers the harm is not a victim who is worse-off and so does not have a special moral complaint against her for her failure which must be accounted for. Unlike the typical cases of harm and rights violations, her child *cannot* claim that *he* has a special complaint against her because he is better, not worse, off as a result of her not meeting her obligation. It is therefore unclear that our moral principles must account for any special wrong done the woman's child, as opposed to a non person-affecting wrong done. This suggests that non person-affecting principles like N or N' may not only be adequate for cases like P<sub>1</sub>, but that they are indeed preferable to person-affecting principles like M precisely because they do not direct us to the special standpoint and complaint of a victim who has been made worse-off; principles for P<sub>1</sub> and other wrongful handicap cases should not direct us to a victim in that way because there is no victim who has been made worse-off and so has a special complaint.

Abandoning person-affecting principles of beneficence and non-maleficence to account for wrongful handicap cases may thus be a promising approach to those cases, especially if reflection on them leaves us confident of our judgment that the woman in P<sub>1</sub> acts wrongly, but weakens our earlier confidence that she wrongs her child in letting it be born handicapped. The latter confidence that she wrongs her child may be further weakened by reflection on wrongful life, not wrongful handicap, cases. Wrongful life cases arise only when the child has a life that is overall not worth living, a life that is worse than no life at all. That is the correct threshold for the claim that the mother acted wrongly in conceiving and/or carrying the child to term knowing how bad its quality of life would be. But since her child's handicap in P<sub>1</sub> could also be prevented only by not conceiving it, or by terminating her pregnancy after it had been conceived, she would not wrong it by allowing it to be born unless its life is not worth living, which by definition in wrongful

handicap cases like P<sub>1</sub> it is not. If she does act wrongly, then perhaps it is correct to insist that she nevertheless wrongs no one, as N and N' imply, and that there is no wrong to her handicapped child for which our principles must account.

What principally explains resistance to this view, I believe, is the handicap that her child suffers, but if her child suffered a similar handicap as a result of an accident for which no one was at fault and which no one could have prevented, there would be no temptation to insist that it had been wronged. The difference, of course, is that she could, and I believe should, have prevented the handicap, but she could not have prevented this child from having the handicap except by never having conceived it, and so we should resist saying that she wrongs this child. In same number, but not same person, cases such as this, if anyone is wronged it is the class—her children—whom she permits without adequate reason or justification to be worse off than her children could have been.<sup>4</sup> But if this class—her children—has been wronged, it is in a sense from which it does not follow that any member of that class—that is, any one child—has been wronged. This is exactly the implication that N and N' have. I conclude that the apparent difficulty with abandoning person-affecting principles—that they fail to identify a victim of the wrong who has a special moral complaint in favor of impersonal principles like N and N' in wrongful handicap cases—is no difficulty after all.

It is worth pointing out one implication of my argument that any moral principle which best fits the features of wrongful handicap cases will be a non person-affecting principle. Others have attempted to solve Parfit's non-identity problem by

seeking to show that person-affecting principles, such as appeal to moral rights, can be successfully applied to it.<sup>5</sup> But my argument has been that appeal to any person-affecting moral principles in cases of wrongful handicap like P<sub>1</sub> will mischaracterize the wrong done. The very features of any appeal to person-affecting principles that are typically their advantage—that they make the wrong a wrong done *to the child* and the loss from the wrong a loss suffered *by the child*—mischaracterize wrongful handicap cases. Non person-affecting principles are correct for wrongful handicap cases because the non-identity problem at the heart of those cases makes the wrong that is done *not done* to the child and the handicap *not a loss* that is suffered by anyone. No person-affecting account of wrongful handicap cases will be correct. The general philosophical non-identity problem is not an obstacle to the position that a woman in cases like P<sub>1</sub> is guilty of causing a wrongful handicap.

#### NOTES

1. Derek Parfit, *Reasons and Persons*, Oxford University Press, 1984, ch. 16.
2. David Heyd, *Genethics: Moral Issues in the Creation of People*, Berkeley, CA: University of California Press, 1992.
3. Philip G. Peters, "Protecting the Unconceived: Nonexistence, Avoidability, and Reproductive Technology," *Arizona Law Review* 31, 1989, 487–548.
4. Peters, *op cit.*; Michael D. Bayles, "Harm to the Unconceived," *Philosophy & Public Affairs* 5, 1976, 292–304.
5. James Woodward, "The Non-Identity Problem," *Ethics* 96, July 1986, 804–31; see also, Derek Parfit, "Comments," *Ethics* 96, July 1986, 854–62.

## Is Gene Therapy a Form of Eugenics?

JOHN HARRIS

Harris addresses a common claim in debates about genetic therapy—that while we have a duty to cure disease (to restore normal functioning), we do not have a duty to enhance or improve upon a normal healthy life. He rejects this distinction, arguing that “[t]here is in short no moral difference between attempts to cure dysfunction and attempts to enhance function where the enhancement protects life or health.”

Eugenic *A. adj.* Pertaining or adapted to the production of fine offspring. *B. sb. in pl.* The science which treats of this. (*The Shorter Oxford English Dictionary*, 3rd edn., 1965.)

It has now become a serious necessity to better the breed of the human race. The average citizen is too base for the everyday work of modern civilization.

Civilized man has become possessed of vaster powers than in old times for good or ill but has made no corresponding advance in wits and goodness to enable him to conduct his conduct rightly.  
(Sir Francis Galton)

If, as I believe, gene therapy is in principle ethically sound except for its possible connection with eugenics, then there are two obvious ways of giving a simple and straightforward answer to a question such as this. The first is to say “yes it is, and so what?” The second is to say “no it isn’t, so we shouldn’t worry.” If we accept the first of the above definitions we might well be inclined to give the first of our two answers. If, on the other hand, we accept the sort of gloss that Ruth Chadwick gives on Galton’s account, “those who are genetically weak should simply be discouraged from reproducing,” either by incentives or compulsory measures, we get a somewhat different flavour, and one which might incline a decent person who favours gene therapy towards the second answer.

The nub of the problem turns on how we are to understand the objective of producing “fine

children.” Does “fine” mean “as fine as children normally are,” or does it mean “as fine as a child can be”? Sorting out the ethics of the connection between gene therapy and eugenics seems to involve the resolution of two morally significant issues. The first is whether or not there is a relevant moral distinction between attempts to remove or repair dysfunction on the one hand and measures designed to enhance function on the other, such that it would be coherent to be in favour of curing dysfunction but against enhancing function? The second involves the question of whether gene therapy as a technique involves something specially morally problematic.

### The Moral Continuum

Is it morally wrong to wish and hope for a fine baby girl or boy? Is it wrong to wish and hope that one’s child will not be born disabled? I assume that my feeling that such hopes and wishes are not wrong is shared by every sane decent person. Now consider whether it would be wrong to wish and hope for the reverse? What would we think of someone who hoped and wished that their child would be born with disability? Again I need not spell out the answer to these questions.

But now let’s bridge the gap between thought and action, between hopes and wishes and their fulfilment. What would we think of someone who, hoping and wishing for a fine healthy child, declined to take the steps necessary to secure this outcome when such steps were open to them?

Again I assume that unless those steps could be shown to be morally unacceptable our conclusions would be the same.

Consider the normal practice at IVF clinics where a woman who has had say, five eggs fertilized *in vitro*, wishes to use some of these embryos to become pregnant. Normal practice would be to insert two embryos or at most three. If pre-implantation screening had revealed two of the embryos to possess disabilities of one sort or another, would it be right to implant the two embryos with disability rather than the others? Would it be right to choose the implantation embryos randomly? Could it be defensible for a doctor to override the wishes of the mother and implant the disabled embryos rather than the healthy ones—would we applaud her for so doing?

The answer that I expect to all these rhetorical questions will be obvious. It depends, however, on accepting that disability is somehow disabling and therefore undesirable. If it were not, there would be no motive to try to cure or obviate disability in health care more generally. If we believe that medical science should try to cure disability where possible, and that parents would be wrong to withhold from their disabled children cures as they become available, then we will be likely to agree on our answers to the rhetorical questions posed.

### **What Is Disability?**

It is notoriously hard to give a satisfactory definition of disability although I believe we all know pretty clearly what we mean by it. A disability is surely a physical or mental condition we have a strong rational preference not to be in; it is, more importantly, a condition which is in some sense a “harmed condition.” I have in mind the sort of condition in which if a patient presented with it unconscious in the casualty department of a hospital and the condition could be easily and immediately reversed, but not reversed unless the doctor acts without delay, a doctor would be negligent were she not to attempt reversal. Or, one which, if a pregnant mother knew that it affected her fetus and knew also she could remove the condition by simple dietary adjustment, then to fail to do so would be to knowingly harm her child.<sup>3</sup>

To make clearer what’s at issue here let’s imagine that as a result of industrial effluent someone had contracted a condition that she felt had disabled or

harmed her in some sense. How might she convince a court say, that she had suffered disability or injury?

The answer is obvious but necessarily vague. Whatever it would be plausible to say in answer to such a question is what I mean (and what is clearly meant) by disability and injury. It is not possible to stipulate exhaustively what would strike us as plausible here, but we know what injury is and we know what disability or incapacity is. If the condition in question was one which set premature limits on their lifespan—made their life shorter than it would be with treatment—or was one which rendered her specially vulnerable to infection, more vulnerable than others, we would surely recognize that she had been harmed and perhaps to some extent disabled. At the very least such events would be plausible candidates for the description “injuries” or “disabilities.”

Against a background in which many people are standardly protected from birth or before against pollution hazards and infections and have their healthy life expectancy extended, it would surely be plausible to claim that failure to protect in this way constituted an injury and left them disabled. Because of their vulnerability to infection and to environmental pollutants, there would be places it was unsafe for them to go and people with whom they could not freely consort. These restrictions on liberty are surely at least *prima facie* disabling as is the increased relative vulnerability.

These points are crucial because it is sometimes said that while we have an obligation to cure disease—to restore normal functioning—we do not have an obligation to enhance or improve upon a normal healthy life, that enhancing function is permissive but could not be regarded as obligatory. But, what constitutes a normal healthy life is determined in part by technological and medical and other advances (hygiene, sanitation, etc.). It is normal now, for example, to be protected against tetanus; the continued provision of such protection is not merely permissive. If the AIDS pandemic continues unabated and the only prospect, or the best prospect, for stemming its advance is the use of gene therapy to insert genes coding for antibodies to AIDS, I cannot think that it would be coherent to regard making available such therapy as permissive rather than mandatory.<sup>4</sup>

If this seems still too like normal therapy to be convincing, suppose genes coding for repair enzymes which would not only repair radiation damage or damage by other environmental pollutants but would also prolong healthy life expectancy could be inserted into humans. Again, would it be permissible to let people continue suffering such damage when they could be protected against it? Would it in short be OK to let them suffer?

It is not normal for the human organism to be self-repairing in this way, this must be eugenic if anything is. But if available, its use would surely, like penicillin before it, be more than merely permissive.

Of course, there will be unclarity at the margins, but at least this conception of disability captures and emphasizes the central notion that a disability is disabling in some sense, that it is a harm to those who suffer it, and that to knowingly disable another individual or leave them disabled when we could remove the disability is to harm that individual.<sup>5</sup>

This is not an exhaustive definition of disability but it is a way of thinking about it which avoids certain obvious pitfalls. First it does not define disability in terms of any conception of normalcy. Secondly it does not depend on *post hoc* ratification by the subject of the condition—it is not a prediction about how the subject of the condition will feel. This is important because we need an account of disability we can use for the potentially self-conscious gametes, embryos, fetuses and neonates, and for the temporarily unconscious, which does not wait upon subsequent ratification by the person concerned.

With this account in mind we can extract the sting from at least one dimension of the charge that attempts to produce fine healthy children might be wrongful. Two related sorts of wrongfulness are often alleged here. One comes from some people and groups of people with disability or from their advocates. The second comes from those who are inclined to label such measures as attempts at eugenic control.

It is often said by those with disability or by their supporters<sup>6</sup> that abortion for disability, or failure to keep disabled infants alive as long as possible, or even positive infanticide for disabled neonates, constitutes discrimination against the disabled as a

group, that it is tantamount to devaluing them as persons, to devaluing them in some existential sense. Alison Davis identifies this view with utilitarianism and comments further that “(i)t would also justify using me as a donor bank for someone more physically perfect (I am confined to a wheelchair due to spina bifida) and, depending on our view of relative worth, it would justify using any of us as a donor if someone of the status of Einstein or Beethoven, or even Bob Geldof, needed one of our organs to survive.”<sup>7</sup> This is a possible version of utilitarianism, of course, but not I believe one espoused by anyone today. On the view assumed here and which I have defended in detail elsewhere,<sup>8</sup> all persons share the same moral status whether disabled or not. To decide not to keep a disabled neonate alive no more constitutes an attack on the disabled than does curing disability. To set the badly broken legs of an unconscious casualty who cannot consent does not constitute an attack on those confined to wheelchairs. To prefer to remove disability where we can is not to prefer non-disabled individuals as persons. To reiterate, if a pregnant mother can take steps to cure a disability affecting her fetus she should certainly do so, for to fail to do so is to deliberately handicap her child. She is not saying that she prefers those without disability as persons when she says she would prefer not to have a disabled child.

The same is analogously true of charges of eugenics in related circumstances. The wrong of practising eugenics is that it involves the assumption that “those who are genetically weak should be discouraged from reproducing” or are less morally important than other persons and that compulsory measures to prevent them reproducing might be defensible.

*It is not that the genetically weak should be discouraged from reproducing but that everyone should be discouraged from reproducing children who will be significantly harmed by their genetic constitution.*<sup>9</sup>

Indeed, gene therapy offers the prospect of enabling the genetically weak to reproduce and give birth to the genetically strong. It is to this prospect and to possible objections to it that we must now turn.

In so far as gene therapy might be used to delete specific genetic disorders in individuals or repair

damage that had occurred genetically or in any other way, it seems straightforwardly analogous to any other sort of therapy and to fail to use it would be deliberately to harm those individuals whom its use would protect.

It might thus, as we have just noted, enable individuals with genetic defects to be sure of having healthy rather than harmed children and thus liberate them from the terrible dilemma of whether or not to risk having children with genetic defects.

Suppose now that it becomes possible to use gene therapy to introduce into the human genome genes coding for antibodies to major infections like AIDS, hepatitis B, malaria and others, or coding for repair enzymes which could correct the most frequently occurring defects caused by radiation damage, or which could retard the ageing process and so lead to greater health longevity, or which might remove predispositions to heart disease, or which would destroy carcinogens or maybe permit human beings to tolerate other environmental pollutants?<sup>10</sup>

I have called individuals who might have these protections built into their germ line a “new breed.”<sup>11</sup> It might be possible to use somatic cell therapy to make the same changes. I am not here interested in the alleged moral differences between germ line and somatic line therapy, though elsewhere I have argued strongly that there is no morally relevant difference.<sup>12</sup> The question we must address is whether it would be wrong to fail to protect individuals in ways like these which would effectively enhance their function rather than cure dysfunction, which would constitute improvements in human individuals or indeed to the human genome, rather than simple (though complex in another sense and sophisticated) repairs? I am assuming of course that the technique is tried, tested and safe.

To answer this question we need to know whether to fail to protect individuals whom we could protect in this way would constitute a harm to them.<sup>13</sup> The answer seems to be clearly that it would. If the gene therapy could enhance prospects for healthy longevity then just as today, someone who had a life expectancy of fifty years rather than one of seventy would be regarded as at a substantial disadvantage, so having one of only seventy when others were able to enjoy ninety or so would be

analogously disadvantageous. However, even if we concentrate on increased resistance, or reduced susceptibility to disease, there would still be palpable harm involved. True, to be vulnerable is not necessarily to suffer the harm to which one is vulnerable, although even this may constitute some degree of psychological damage. However, the right analogy here seems to be drawn from aviation.

Suppose aircraft manufacturers could easily build in safety features which would render an aircraft immune to, or at least much less susceptible to, a wide range of aviation hazards. If they failed to do so we would regard them as culpable whether or not a particular aircraft did in fact succumb to any of these hazards in the course of its life. They would in short be like a parent who failed to protect her children from dangerous diseases via immunization or our imagined parent who fails to protect through gene therapy.

I hope enough has been said to make clear that where gene therapy will effect improvements to human beings or to human nature that provide protections from harm or the protection of life itself in the form of increases in life expectancy (“death postponing” is after all just “life saving” re-described) then call it what you will, eugenics or not, we ought to be in favour of it. There is in short no moral difference between attempts to cure dysfunction and attempts to enhance function where the enhancement protects life or health.

### **What Sorts of Enhancement Protect Health?**

I have drawn a distinction between attempts to protect life and health and other uses of gene therapy. I have done so mostly for the sake of brevity and to avoid the more contentious area of so-called cosmetic or frivolous uses of gene therapy. Equally and for analogous reasons I have here failed to distinguish between gene therapy on the germ line and gene therapy on the somatic line. I avoid contention here not out of distaste for combat but simply because to deploy the arguments necessary to defend cosmetic uses of gene therapy would take up more space than I have available now. Elsewhere I have deployed these arguments.<sup>14</sup> However, the distinction between preservation of life and health or normal medical uses

and other uses of gene therapy is difficult to draw and it is worth here just illustrating this difficulty.

The British Government's "Committee on the Ethics of Gene Therapy" in its report to Parliament attempted to draw this distinction. The report, known by the surname of its chairman as *The Clothier Report*, suggested "in the current state of knowledge it would not be acceptable to attempt to change traits not associated with disease."<sup>15</sup> This was an attempt to rule out so called cosmetic uses of gene therapy which would include attempts to manipulate intelligence.<sup>16</sup>

Imagine two groups of mentally handicapped or educationally impaired children. In one the disability is traceable to a specific disease state or injury, in the other it has no obvious cause. Suppose now that gene therapy offered the chance of improving the intelligence of children generally and those in both these groups in particular. Those who think that using gene therapy to improve intelligence is wrong because it is not a dimension of health care would have to think that neither group of children should be helped, and those, like Clothier, who are marginally more enlightened would have to think that it might be ethical to help children in the first group but not those in the second.<sup>17</sup>

I must now turn to the question of whether or not gene therapy as a technique is specially morally problematic.

### **What's Wrong with Gene Therapy?**

Gene therapy may of course be scientifically problematic in a number of ways and in so far as these might make the procedure unsafe we would have some reason to be suspicious of it. However, these problems are ethically uninteresting and I shall continue to assume that gene therapy is tried and tested from a scientific perspective. What else might be wrong with it?

One other ethical problem for gene therapy has been suggested and it deserves the small space left. Ruth Chadwick has given massive importance to the avoidance of doubt over one's genetic origins. Chadwick suggests that someone

who discovers that her parents had an extra gene or genes added . . . may suffer from what today in the "problem pages" is called an "identity crisis." . . . Part

of this may be an uncertainty about her genetic history. We have stressed the importance of this knowledge, and pointed out that when one does not know where 50 per cent of one's genes come from, it can cause unhappiness.<sup>18</sup>

Chadwick then asks whether this problem can be avoided if only a small amount of genetic makeup is involved. Her answer is equivocal but on balance she seems to feel that "we must be cautious about producing a situation where children feel they do not really belong anywhere, because their genetic history is confused."<sup>19</sup> This sounds mild enough until we examine the cash value of phrases like "can cause unhappiness" or "be cautious" as Chadwick uses them.

In discussing the alleged unhappiness caused by ignorance of 50 per cent of one's genetic origin, Chadwick argued strongly that such unhappiness was so serious that "it seems wise to restrict artificial reproduction to methods that do not involve donation of genetic material. This rules out AID, egg donation, embryo donation and partial surrogacy."<sup>20</sup>

In elevating doubt about one's genetic origin to a cause of unhappiness so poignant that it would be better that a child who might experience it had never been born, Chadwick ignores entirely the (in fact false) truism that, while motherhood is a fact, paternity is always merely a hypothesis. It is a wise child indeed that knows her father and since such doubt might reasonably cloud the lives of a high proportion of the population of the world, we have reason to be sceptical that its effects are so terrible that people should be prevented from reproducing except where such doubt can be ruled out.

The effect of Chadwick's conclusion is to deny gay couples and single people the possibility of reproducing. Chadwick denies this, suggesting "they are not being denied the opportunity to have children. If they are prepared to take the necessary steps ('the primitive sign of wanting is trying to get') their desire to beget can be satisfied." What are we to make of this? It seems almost self-consciously mischievous. In the first place, gay couples and single women resorting to what must, *ex hypothesi*, be distasteful sex with third parties merely for procreative purposes, are unlikely to preserve the

identity of their sexual partners for the benefit of their offspring's alleged future peace of mind. If this is right then doubt over genetic origin will not be removed. Since Chadwick is explicitly addressing public policy issues she should in consistency advocate legislation against such a course of action rather than recommend it.

But surely, if we are to contemplate legislating against practices which give rise to doubt about genetic origins, we would need hard evidence not only that such practices harm the resulting children but that the harm is of such a high order that not only would it have been better that such children had never been born but also better that those who want such children should suffer the unhappiness consequent on a denial of their chance to have children using donated genetic material.

Where such harm is not only unavoidable but is an inherent part of sexual reproduction and must affect to some degree or other a high percentage of all births, it is surely at best unkind to use the fear of it as an excuse for discriminating against already persecuted minorities in the provision of reproductive services.

Where, as in the case of gene therapy, such donated<sup>21</sup> material also protects life and health or improves the human condition, we have an added reason to welcome it.

#### NOTES

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1. The argument here follows that of my paper "Should We Attempt to Eradicate Disability," published in the Proceedings of the Fifteenth International Wittgenstein Symposium.
2. See my discussion of the difference between harming and wronging in my *Wonderwoman & Superman: The Ethics of Human Biotechnology* (Oxford, 1992), ch. 4.
3. This goes for relatively minor conditions like the loss of a finger or deafness and also for disfiguring

conditions right through to major disability like paraplegia.

4. In this sense the definition of disability is like that of "poverty."
5. See my more detailed account of the relationship between harming and wronging in my *Wonderwoman & Superman* (Oxford: Oxford University Press, 1992), ch. 4.
6. Who should of course include us all.
7. Davis, "The Status of Anencephalic Babies: Should Their Bodies Be Used as Donor Banks?" *Journal of Medical Ethics*, 14 (1988), p. 150.
8. See my *The Value of Life* (London: Routledge, 1985 and 1990), ch. 1 and my "Not all babies should be kept alive as long as possible" in Raanan Gillon and Anne Lloyd (eds.), *Principles of Health Care Ethics* (Chichester: John Wiley, 1993).
9. I use the term "weak" here to echo Chadwick's use of the term. I take "genetically weak" to refer to those possessing a debilitating genetic condition or those who will inevitably pass on such a condition. All of us almost certainly carry some genetic abnormalities and are not thereby rendered "weak."
10. Here I borrow freely from my *Wonderwoman & Superman: The Ethics of Human Biotechnology* (Oxford University Press, 1992), ch. 9, where I discuss all these issues in greater depth than is possible here.
11. *Ibid.*
12. *Ibid.*, ch. 8.
13. For an elaboration on the importance of this distinction see my discussion of "the wrong of wrongful life" in *Wonderwoman & Superman*, ch. 4.
14. *Ibid.*, ch. 7.
15. *Report of the Committee on the Ethics of Gene Therapy*, presented to Parliament by Command of Her Majesty, January 1992. London HMSO para. 4.22.
16. In fact intelligence is unlikely to prove responsive to such manipulation because of its multifactorial nature.
17. There would be analogous problems about attempts to block the use of gene therapy to change things like physical stature and height since it might be used in the treatment of achondroplasia or other forms of dwarfism.
18. Ruth Chadwick, *Ethics, Reproduction and Genetic Control* (London: Routledge, 1987), p. 126.
19. *Ibid.*, p. 127.
20. *Ibid.*, p. 39.
21. I use the term "donated" here, but I do not mean to rule out commerce in such genetic material. See my *Wonderwoman & Superman*, ch. 6.

## Genetic Enhancement

WALTER GLANNON

On the question of genetic enhancement, Glannon argues that a line of demarcation can be drawn between treatment and enhancement. Gene therapy is permissible if it is intended to ensure or restore normal functions, but it is morally illegitimate if it is aimed at enhancing functions beyond normal. He thinks there are several moral problems with enhancement, but his main moral concern is “that it would give some people an unfair advantage over others with respect to competitive goods like beauty, sociability, and intelligence.”

Gene therapy must be distinguished from genetic enhancement. The first is an intervention aimed at treating disease and restoring physical and mental functions and capacities to an adequate baseline. The second is an intervention aimed at improving functions and capacities that already are adequate. Genetic enhancement augments functions and capacities “that without intervention would be considered entirely normal.”<sup>1</sup> Its goal is to “amplify ‘normal’ genes in order to make them better.” In chapter 1 [of *Genes and Future People*], I cited Norman Daniels’s definitions of health and disease as well as what the notion of just health care entailed. This involved maintaining or restoring mental and physical functions at or to normal levels, which was necessary to ensure fair equality of opportunity for all citizens. Insofar as this aim defines the goal of medicine, genetic enhancement falls outside this goal. Furthermore, insofar as this type of intervention is not part of the goal of medicine and has no place in a just health care system, there are no medical or moral reasons for genetically enhancing normal human functions and capacities.

Some have argued that it is mistaken to think that a clear line of demarcation can be drawn between treatment and enhancement, since certain forms of enhancement are employed to prevent

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disease. LeRoy Walters and Julie Gage Palmer refer to the immune system as an example to make this point:

In current medical practice, the best example of a widely accepted health-related physical enhancement is immunization against infectious disease.

With immunization against diseases like polio and hepatitis B, what we are saying is in effect, “The immune system that we inherited from our parents may not be adequate to ward off certain viruses if we are exposed to them.” Therefore, we will enhance the capabilities of our immune system by priming it to fight against these viruses.

From the current practice of immunizations against particular diseases, it would seem to be only a small step to try to enhance the general function of the immune system by genetic means. . . . In our view, the genetic enhancement of the immune system would be morally justifiable if this kind of enhancement assisted in preventing disease and did not cause offsetting harms to the people treated by the technique.<sup>3</sup>

Nevertheless, because the goal of the technique would be to prevent disease, it would not, strictly speaking, be enhancement, at least not in terms of the definitions given at the outset of this section. Genetically intervening in the immune system as described by Walters and Palmer is a means of maintaining it in proper working order so that it will be better able to ward off pathogens posing a threat to the organism as a whole. Thus, it is misleading to call this intervention “enhancement.” When we consider what is normal human functioning, we refer to the whole human organism

consisting of immune, endocrine, nervous, cardiovascular, and other systems, not to these systems understood as isolated parts. The normal functioning in question here pertains to the ability of the immune system to protect the organism from infectious agents and thus ensure its survival. Any preventive genetic intervention in this system would be designed to maintain the normal functions of the organism, not to restore them or raise them above the norm. It would be neither therapy nor enhancement but instead a form of maintenance. Therefore, the alleged ambiguity surrounding what Walters and Palmer call “enhancing” the immune system does not impugn the distinction between treatment and enhancement.

If enhancement could make adequately functioning bodily systems function even better, then presumably there would be no limit to the extent to which bodily functions can be enhanced. Yet, beyond a certain point, heightened immune sensitivity to infectious agents can lead to an overly aggressive response, resulting in autoimmune disease that can damage healthy cells, tissues, and organs. In fact, there would be a limit to the beneficial effects of genetic intervention in the immune system, a limit beyond which the equilibrium between humoral and cellular response mechanisms would be disturbed.<sup>4</sup> If any intervention ensured that the equilibrium of the immune system was maintained in proper working order, then it would be inappropriate to consider it as a form of enhancement.

To further support the treatment-enhancement distinction, consider a nongenetic intervention, the use of a bisphosphonate such as alendronate sodium. Its purpose is to prevent postmenopausal women from developing osteoporosis, or to rebuild bone in women or men who already have osteoporosis. Some might claim that, because it can increase bone density, it is a form of enhancement. But its more general purpose is to prevent bone fractures and thus maintain proper bone function so that one can have normal mobility and avoid the morbidity resulting from fractures. In terms of the functioning of the entire organism, therefore, it would be more accurate to consider the use of bisphosphonates as prevention, treatment, or maintenance rather than enhancement.

Some might raise a different question. Suppose that the parents of a child much shorter than the norm for his age persuaded a physician to give him growth hormone injections in order to increase his height. Suppose further that the child’s shortness was not due to an iatrogenic cause, such as radiation to treat a brain tumor. Would this be treatment or enhancement? The question that should be asked regarding this issue is not whether the child’s height is normal for his age group. Rather, the question should be whether his condition implies something less than normal physical functioning, such that he would have fewer opportunities for achievement and a decent minimum level of well-being over his lifetime. Diminutive stature alone does not necessarily imply that one’s functioning is or will be so limited as to restrict one’s opportunities for achievement. Of course, being short might limit one’s opportunities if one wanted to become a professional basketball player. But most of us are quite flexible when it comes to formulating and carrying out life plans. Robert Reich, the treasury secretary in President Clinton’s first administration, is just one example of how one can achieve very much in life despite diminutive stature. If a child’s stature significantly limited his functioning and opportunities, then growth-hormone injections should be considered therapeutic treatment. If his stature were not so limiting, then the injections should be considered enhancement.

Admittedly, there is gray area near the baseline of adequate functioning where it may be difficult to distinguish between treatment and enhancement. Accordingly, we should construe the baseline loosely or thickly enough to allow for some minor deviation above or below what would be considered normal functioning. An intervention for a condition near the baseline that would raise one’s functioning clearly above the critical level should be considered an enhancement. An intervention for a condition making one’s functioning fall clearly below the baseline, with the aim of raising one’s functioning to the critical level, should be considered a treatment. For example, an athlete with a hemoglobin level slightly below the norm for people his age and mildly anemic may want to raise that level significantly in order to be more competitive

in his sport. To the extent that his actual hemoglobin level does not interfere with his ordinary physical functioning, an intervention to significantly raise that level would be an instance of enhancement. In contrast, for a child who has severe thalassemia and severe anemia, with the risk of bone abnormalities and heart failure, an intervention to correct the disorder would be an instance of treatment.

The main moral concern about genetic enhancement of physical and mental traits is that it would give some people an unfair advantage over others with respect to competitive goods like beauty, sociability, and intelligence. . . . Enhancement would be unfair because only those who could afford the technology would have access to it, and many people are financially worse off than others through no fault of their own. Insofar as the possession of these goods gives some people an advantage over others in careers, income, and social status, the competitive nature of these goods suggests that there would be no limit to the benefits that improvements to physical and mental capacities would yield to those fortunate enough to avail themselves of the technology. This is altogether different from the example of immune system enhancement. There would be no diminishing marginal value in the degree of competitive advantage that one could have over others for the social goods in question and presumably no limit to the value of enhancing the physical and mental capacities that would give one this advantage. Not having access to the technology that could manipulate genetic traits in such a way as to enhance these capacities would put one at a competitive disadvantage relative to others who would have access to it.

Advancing an argument similar to the one used by those who reject the treatment-enhancement distinction, one might hold that competitive goods collapse the categorical distinction between correcting deficient capacities and improving normal ones. This is because competitive goods are continuous, coming in degrees, and therefore the capacities that enable one to achieve these goods cannot be thought of as either normal or deficient.<sup>5</sup> Nevertheless, to the extent that any form of genetic intervention is motivated by the medical and moral aim

to enable people to have adequate mental and physical functioning and fair equality of opportunity for a decent minimum level of well-being, the goods in question are not *competitive* but *basic*. In other words, the aim of any medical intervention by genetic means is to make people better off than they were before by raising or restoring them to an absolute baseline of normal physical and mental functioning, not to make them comparatively better off than others. Competitive goods above the baseline may be continuous; but the basic goods that enable someone to reach or remain at the baseline are not. Given that these two types of goods are distinct, and that they result from the distinct aims and practices of enhancement and treatment, we can affirm that enhancement and treatment can and should be treated separately. We can uphold the claim that the purpose of any genetic intervention should be to treat people's abnormal functions and restore them to a normal level, not to enhance those functions that already are normal.

As I have mentioned, genetic enhancement that gave some people an advantage over others in possessing competitive goods would entail considerable unfairness. A likely scenario would be one in which parents paid to use expensive genetic technology to raise the cognitive ability or improve the physical beauty of their children. This would give them an advantage over other children with whom they would compete for education, careers, and income. Children of parents who could not afford to pay for the technology would be at a comparative disadvantage. Even if the goods in question fell above the normal functional baseline, one still could maintain that such an advantage would be unfair. It would depend on people's ability to pay, and inequalities in income are unfair to the extent that they result from some factors beyond people's control.

We could not appeal to the notion of a genetic lottery to resolve the problem of fairness regarding genetic enhancement. For, as I argued in the last section [of *Genes and Future People*], such a lottery is better suited to meeting people's needs than their preferences, and enhancements correspond to people's preferences. Moreover, a lottery might only exacerbate the problem by reinforcing the perception

of unfairness, depending on how losers in the lottery interpreted the fact that others won merely as a result of a random selection. One suggestion for resolving the fairness problem (short of banning the use of the technology altogether) would be to make genetic enhancement available to all. Of course, how this system could be financed is a question that admits of no easy answer. But the more important substantive point is that universal access to genetic enhancement would not be a solution. Indeed, the upshot of such access would provide a reason for prohibiting it.

Universal availability of genetic enhancement would mean that many competitive goods some people had over others would be canceled out collectively. The idea of a competitive advantage gradually would erode, and there would be more equality among people in their possession of goods. There would not be complete equality, however. Differing parental attitudes toward such goods as education could mean differences in the extent to which cognitive enhancement was utilized. Some parents would be more selective than others in sending their children to better schools or arranging for private tutors. So, there still would be some inequality in the general outcome of the enhancement. But quite apart from this, the process of neutralizing competitive goods could end up being self-defeating on a collective level.<sup>6</sup> More specifically, one probable side-effect of boosting children's mental capacity on a broad scale would be some brain damage resulting in cognitive and affective impairment in some of the children who received the genetic enhancement. The net social cost of using the technology would outweigh any social advantage of everyone using it. If no one is made better off than others in their possession of social goods, but some people are made worse off than they were before in terms of their mental functioning, then the net social disadvantage would provide a reason for prohibiting collective genetic enhancement.

There is another moral aspect of enhancement that should be considered. I have maintained that inequalities above the baseline of normal physical and mental functioning are of no great moral importance and may be neutral on the question of

fairness. Although equality and fairness are closely related, one does not necessarily imply the other. Again, fairness pertains to meeting people's needs. Once these needs have been met, inequalities in the possession of goods relating to preferences are not so morally significant. Thus, if the idea of an absolute baseline implies that people's basic physical and mental needs have been met, and if people who are comparatively better or worse off than others all have functioning at or above the baseline, then any inequalities in functioning above this level should not matter very much morally. If this is plausible, then it seems to follow that there would be nothing unfair and hence nothing morally objectionable about enhancements that made some people better off than others above the baseline. Nevertheless, this could undermine our belief in the importance of the fundamental equality of all people, regardless of how well off they are in absolute terms. Equality is one of the social bases of self-respect, which is essential for social harmony and stability.<sup>7</sup> Allowing inequalities in access to and possession of competitive goods at any level of functioning or welfare might erode this basis and the ideas of harmony and stability that rest on it. Although it would be difficult to measure, this type of social cost resulting from genetic enhancement could constitute another reason for prohibiting it.

Yet, suppose that we could manipulate certain genes to enhance our noncompetitive virtuous traits, such as altruism, generosity, and compassion.<sup>8</sup> Surely, these would contribute to a stable, well ordered society and preserve the principle of fair equality of opportunity. Nothing in this program would be incompatible with the goal of medicine as the prevention and treatment of disease. But it would threaten the individual autonomy essential to us as moral agents who can be candidates for praise and blame, punishment and reward. What confers moral worth on our actions, and indeed on ourselves as agents, is our capacity to cultivate certain dispositions leading to actions. This cultivation involves the exercise of practical reason and a process of critical self-reflection, whereby we modify, eliminate, or reinforce dispositions and thereby come to identify with them as our own. Autonomy consists precisely

in this process of reflection and identification. It is the capacity for reflective self-control that enables us to take responsibility for our mental states and the actions that issue from them. Given the importance of autonomy, it would be preferable to have fewer virtuous dispositions that we can identify with as our own than to have more virtuous dispositions implanted in us through genetic enhancement. These would threaten to undermine our moral agency because they would derive from an external source.<sup>9</sup> Even if our genes could be manipulated in such a way that our behavior always conformed to an algorithm for the morally correct course of action in every situation, it is unlikely that we would want it. Most of us would rather make autonomous choices that turned out not to lead to the best courses of action. This is because of the intrinsic importance of autonomy and the moral growth and maturity that come with making our own choices under uncertainty. The dispositions with which we come to identify, imperfect as they may be, are what make us autonomous and responsible moral agents. Enhancing these mental states through artificial means external to our own exercise of practical reason and our own process of identification would undermine our autonomy by making them alien to us.

In sum, there are four reasons why genetic enhancement would be morally objectionable. First, it would give an unfair advantage to some people over others because some would be able to pay for expensive enhancement procedures while others would not. Second, if we tried to remedy the first problem by making genetic enhancement universally accessible, then it would be collectively self-defeating. Although much competitive unfairness at the individual level would be canceled out at the collective level, there would be the unacceptable social cost of some people suffering from adverse cognitive or emotional effects of the enhancement. Third, inequalities resulting from enhancements above the baseline of normal physical and mental functioning could threaten to undermine the conviction in the fundamental importance of equality as one of the bases of self-respect, and in turn social solidarity and stability. Fourth, enhancement of noncompetitive dispositions would threaten to undermine the autonomy and moral agency essential to us as persons.

#### NOTES

1. Jon Gordon, "Genetic Enhancement in Humans," *Science* 283 (March 26, 1999): 2023–2024.
2. Eric Juengst, "Can Enhancement Be Distinguished from Prevention in Genetic Medicine?" *Journal of Medicine and Philosophy* 22 (1997): 125–142, and "What Does Enhancement Mean?", in Erik Parens, ed., *Enhancing Human Traits: Ethical and Social Implications* (Washington, DC: Georgetown University Press, 1998): 27–47, at 27. Also, Dan Brock, "Enhancements of Human Function: Some Distinctions for Policymakers," *Ibid.*, 48–69.
3. *The Ethics of Human Gene Therapy* (New York: Oxford University Press, 1997), 110. Instead of distinguishing between treatments and enhancements, Walters and Palmer distinguish between health-related and non-health-related enhancements. But I do not find this distinction to be very helpful.
4. Brock points this out in "Enhancements of Human Function," 59. Marc Lappe makes a more compelling case for the same point in *The Tao of Immunology* (New York: Plenum Press, 1997).
5. Kavka develops and defends the idea that competitive goods are continuous in "Upside Risks: Social Consequences of Beneficial Biotechnology," in Carl Cranor, ed., *Are Genes Us? The Social Consequences of the New Genetics* (New Brunswick, NJ: Rutgers University Press, 1994): 155–179, at 164–165.
6. Kavka, "Upside Risks," 167. Also, Brock, "Enhancements of Human Function," 60; and Buchanan et al., *From Chance to Choice* (New York: Cambridge University Press, 2000), chap. 8.
7. Rawls makes this point in *A Theory of Justice* (Cambridge, MA: Harvard Belknap Press, 1971), 7–11, and in "Social Unity and Primary Goods," in A. Sen and B. Williams, eds., *Utilitarianism and Beyond* (Cambridge: Cambridge University Press, 1982), 162. See also Daniels, *Just Health Care* (New York: Cambridge University Press, 1985).
8. Walters and Palmer present this thought-experiment in *The Ethics of Human Gene Therapy*, 123–128. As they note, Jonathan Glover introduced this idea in *What Sort of People Should There Be?* (Harmondsworth: Penguin, 1984).
9. Drawing on the work of Lionel Trilling and Charles Taylor, Carl Elliott discusses cognitive and affective enhancements that undermine what he calls the "ethics of authenticity" in "The Tyranny of Happiness: Ethics and Cosmetic Psychopharmacology," in Parens, *Enhancing Human Traits*, 177–188. Also relevant to this issue is Harry Frankfurt, "Identification and Externality," in Frankfurt, *The Importance of What We Care About* (New York: Cambridge University Press, 1989): 58–68.

## Genetic Interventions and the Ethics of Enhancement of Human Beings

JULIAN SAVULESCU

Julian Savulescu is an Australian philosopher and bioethicist and the Uehiro Professor of Practical Ethics at the University of Oxford. Savulescu explores the morality of genetic enhancement, presenting three arguments in favor of the ethical use of enhancement while critiquing the main objections to it. He asserts that not only is enhancement permissible, it is a moral obligation.

Should we use science and medical technology not just to prevent or treat disease, but to intervene at the most basic biological levels to improve biology and enhance people's lives? By enhance, I mean help them to live a longer and/or better life than normal. There are various ways in which we can enhance people but I want to focus on biological enhancement, especially genetic enhancement.

There has been considerable recent debate on the ethics of human enhancement. A number of prominent authors have been concerned about or critical of the use of technology to alter or enhance human beings, citing threats to human nature and dignity as one basis for these concerns. The President's Council Report entitled *Beyond Therapy* was strongly critical of human enhancement. Michael Sandel, in a widely discussed article, has suggested that the problem with genetic enhancement "is in the hubris of the designing parents, in their drive to master the mystery of birth. . . . [I]t would disfigure the relation between parent and child, and deprive the parent of the humility and enlarged human sympathies that an openness to the unbidden can cultivate. . . . [T]he promise of mastery is flawed. It threatens to banish our appreciation of life as a gift, and to leave us with nothing to affirm or behold outside our own will."

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From Julian Savulescu, "Genetic Interventions and the Ethics of Enhancement of Human Beings," in *The Oxford Handbook of Bioethics*, ed. Bonnie Steinbock (Oxford: Oxford University Press, 2007), 516–35 (<http://www.practicaledemics.ox.ac.uk/>).

Frances Kamm has given a detailed rebuttal of Sandel's arguments, arguing that human enhancement is permissible. Nicholas Agar, in his book, *Liberal Eugenics*, argues that enhancement should be permissible but not obligatory. He argues that what distinguishes liberal eugenics from the objectionable eugenic practices of the Nazis is that it is not based on a single conception of a desirable genome and that it is voluntary and not obligatory.

. . . I want to argue that far from being merely permissible, we have a moral obligation or moral reason to enhance ourselves and our children. Indeed, we have the same kind of obligation as we have to treat and prevent disease. Not only *can* we enhance, we *should* enhance. . . .

### The Ethics of Enhancement

I will now give three arguments in favor of enhancement and then consider several objections.

#### First Argument for Enhancement: Choosing Not to Enhance Is Wrong

Consider the case of the Neglectful Parents. The Neglectful Parents give birth to a child with a special condition. The child has a stunning intellect but requires a simple, readily available, cheap dietary supplement to sustain his intellect. But they neglect the diet of this child and this results in a child with a stunning intellect becoming normal. This is clearly wrong.

But now consider the case of the Lazy Parents. They have a child who has a normal intellect but if they introduced the same dietary supplement, the child's intellect would rise to the same level as the

child of the Neglectful Parents. They can't be bothered with improving the child's diet so the child remains with a normal intellect. Failure to institute dietary supplementation means a normal child fails to achieve a stunning intellect. The inaction of the Lazy Parents is as wrong as the inaction of the Neglectful Parents. It has exactly the same consequence: a child exists who could have had a stunning intellect but is instead normal.

Some argue that it is not wrong to fail to bring about the best state of affairs. This may or may not be the case. But in these kinds of case, when there are no other relevant moral considerations, the failure to introduce a diet which sustains a more desirable state is as wrong as the failure to introduce a diet which brings about a more desirable state. The costs of inaction are the same, as are the parental obligations.

If we substitute "biological intervention" for "diet," we see that in order not to wrong our children, we should enhance them. Unless there is something special and optimal about our children's physical, psychological or cognitive abilities, or something different about other biological interventions, it would be wrong not to enhance them.

### Second Argument: Consistency

Some will object that, while we do have an obligation to institute better diets, biological interventions like genetic interventions are different [from] dietary supplementation. I will argue that there is no difference between these interventions.

In general, we accept environmental interventions to improve our children. Education, diet and training are all used to make our children better people and increase their opportunities in life. We train children to be well behaved, co-operative and intelligent. Indeed, researchers are looking at ways to make the environment more stimulating for young children to maximize their intellectual development. But in the study of the rat model of Huntington's Disease, the stimulating environment acted to change the brain structure of the rats. The drug Prozac acted in just the same way. These environmental manipulations do not act mysteriously. They alter our biology.

The most striking example of this is a study of rats which were extensively mothered and rats who

were not mothered. The mothered rats showed genetic changes (changes in the methylation of the DNA) which were passed on to the next generation. As Michael Meaney has observed, "Early experience can actually modify protein-DNA interactions that regulate gene expression." More generally, environmental manipulations can profoundly affect biology. Maternal care and stress have been associated with abnormal brain (hippocampal) development, involving altered nerve growth factors and cognitive, psychological and immune deficits later in life.

Some argue that genetic manipulations are different because they are irreversible. But environmental interventions can equally be irreversible. Child neglect or abuse can scar a person for life. It may be impossible to unlearn the skill of playing the piano or riding a bike, once learned. One may be wobbly, but one is a novice only once. Just as the example of mothering of rats shows that environmental interventions can cause biological changes which are passed onto the next generation, so too can environmental interventions be irreversible, or very difficult to reverse, within one generation.

Why should we allow environmental manipulations which alter our biology but not direct biological manipulations? What is the moral difference between producing a smarter child by immersing that child in a stimulating environment, giving the child a drug or directly altering the child's brain or genes?

One example of a drug which alters brain chemistry is Prozac. It is a serotonin reuptake inhibitor. Early in life it acts as a nerve growth factor. But it may alter the brain early in life to make it more prone to stress and anxiety later in life, by altering receptor development (*Science*, 29 October 2004). People with a polymorphism that reduced their serotonin activity were more likely than others to become depressed in response to stressful experiences (*Science*, 18 July 2003). Both drugs like Prozac and maternal deprivation may have the same biological effects.

If the outcome is the same, why treat biological manipulation differently from environmental manipulation? Not only may a favorable environment improve a child's biology and increase a child's

opportunities, so too may direct biological interventions. Couples should maximize the genetic opportunity of their children to lead a good life and a productive, cooperative social existence. There is no relevant moral difference between environmental and genetic intervention.

### Third Argument: No Difference to Treating Disease

If we accept the treatment and prevention of disease, we should accept enhancement. The goodness of health is what drives a moral obligation to treat or prevent disease. But health is not what ultimately matters—health enables us to live well; disease prevents us from doing what we want and what is good. Health is instrumentally valuable—valuable as a resource that allows us to do what really matters, that is, lead a good life.

What constitutes a good life is a deep philosophical question. According to hedonistic theories, what is good is having pleasant experiences and being happy. According to desire fulfillment theories, and economics, what matters is having our preferences satisfied. According to objective theories, certain activities are good for people—developing deep personal relationships, developing talents, understanding oneself and the world, gaining knowledge, being a part of a family, and so on. We need not decide on which of these theories is correct to understand what is bad about ill health. Disease is important because it causes pain, is not what we want and stops us engaging in those activities that give meaning to life. Sometimes people trade health for well-being—mountain climbers take on risk to achieve, smokers sometimes believe that the pleasures outweigh the risks of smoking, and so on. Life is about managing risk to health and life to promote well-being.

Beneficence—the moral obligation to benefit people—provides a strong reason to enhance people insofar as the biological enhancement increases their chance of having a better life. But can biological enhancements increase people's opportunities for well-being? There are reasons to believe they might.

Many of our biological and psychological characteristics profoundly affect how well our lives go. In the 1960s Walter Mischel conducted impulse

control experiments where 4-year-old children were left in a room with one marshmallow, after being told that if they did not eat the marshmallow, they could later have two. Some children would eat it as soon as the researcher left, others would use a variety of strategies to help control their behavior and ignore the temptation of the single marshmallow. A decade later, they reinterviewed the children and found that those who were better at delaying gratification had more friends, better academic performance and more motivation to succeed. Whether the child had grabbed for the marshmallow had a much stronger bearing on their SAT scores than did their IQ.

Impulse control has also been linked to socio-economic control and avoiding conflict with the law. The problems of a hot and uncontrollable temper can be profound.

Shyness too can greatly restrict a life. I remember one newspaper story about a woman who blushed violet every time she went into a social situation. This led her to a hermitic, miserable existence. She eventually had the autonomic nerves to her face surgically cut. This revolutionized her life and had a greater effect on her well-being than the treatment of many diseases.

Buchanan and colleagues have discussed the value of “all purpose goods.” These are traits which are valuable regardless of which kind of life a person chooses to live. They give us greater all-around capacities to live a vast array of lives. Examples include intelligence, memory, self-discipline, patience, empathy, a sense of humor, optimism and just having a sunny temperament. All of these characteristics—sometimes may include virtues—may have some biological and psychological basis capable of manipulation with technology.

Technology might even be used to improve our *moral character*. We certainly seek through good instruction and example, discipline and other methods to make better children. It may be possible to alter biology to make people predisposed to be more moral by promoting empathy, imagination, sympathy, fairness, honesty, etc.

Insofar as these characteristics have some genetic basis, genetic manipulation could benefit us. There is reason to believe that complex virtues like

fairmindedness may have a biological basis. In one famous experiment, a monkey was trained to perform a task and rewarded either a grape or piece of cucumber. He preferred the grape. On one occasion, he performed the task successfully and was given a piece of cucumber. He watched as another monkey who had not performed the task was given a grape. He became very angry. This shows that even monkeys have a sense of fairness and desert—or at least self-interest!

At the other end, there are characteristics which we believe do not make for a good and happy life. One Dutch family illustrates the extreme end of the spectrum. For over 30 years this family recognized that there were a disproportionate number of male family members who exhibited aggressive and criminal behavior. This was characterized by aggressive outbursts resulting in arson, attempted rape and exhibitionism. The behavior has been documented for almost forty years ago by an unaffected maternal grandfather who could not understand why some of the men in his family appeared to be prone to this type of behavior. Male relatives who did not display this aggressive behavior did not express *any* type of abnormal behavior. Unaffected males reported difficulty in understanding the behavior of their brothers and cousins. Sisters of the males who demonstrated these extremely aggressive outbursts reported intense fear of their brothers. The behavior did not appear to be related to environment and appeared consistently in different parts of the family, regardless of social context and degree of social contact. All affected males were also found to be mildly mentally retarded with a typical IQ of about 85 (females had normal intelligence). When a family tree was constructed, the pattern of inheritance was clearly X-linked recessive. This means, roughly, that women can carry the gene without being affected; 50 percent of men at risk of inheriting the gene get the gene and are affected by the disease.

Genetic analysis suggested that the likely defective gene was a part of the X chromosome known as the Monoamine Oxidase (MAO) region. The MAO region codes for two enzymes which assist in the breakdown of neurotransmitters. Neurotransmitters are substances that play a key role in the conduction

of nerve impulses in our brain. Enzymes like the monoamine oxidases are required to degrade the neurotransmitters after they have performed their desired task. It was suggested that the monoamine oxidase activity might be disturbed in the affected individuals. Urine analysis showed a higher than normal amount of neurotransmitters being excreted in the urine of affected males. These results found were consistent with a reduction in the functioning of one of the enzymes (monoamine oxidase A).

How could such a mutation result in violent and antisocial behavior? A deficiency of the enzyme results in a buildup of neurotransmitters. These abnormal levels of neurotransmitters result in excessive, and even violent, reactions to stress. This hypothesis was further supported by the finding that genetically modified mice which lack this enzyme are more aggressive.

This family is an extreme example of how genes can influence behavior. This mutation has only been isolated in this family. Most genetic contributions to behavior will be weaker predispositions. Yet there may be some association between genes and behavior which results in criminal prosecution and other antisocial behavior.

How could such information be used? Some criminals have attempted a “genetic defense” in the U.S. which stated that their genes caused them to commit the crime. This has never succeeded. However, it is clear that a couple should be allowed to use this test to select offspring who do not have the mutation which predisposes them to act in this way. And if interventions were available, it might be rational to correct it. Children without this mutation have a better chance of a better life.

“Genes, Not Men, May Hold the Key to Female Pleasure” ran the title of one recent newspaper article. It reported the results of a large study of female identical twins in Britain and Australia. It found that “genes accounted for 31 percent of the chance of having an orgasm during intercourse and 51 percent during masturbation.” It concluded that the “ability to gain sexual satisfaction is largely inherited” and went on to speculate that “[t]he genes involved could be linked to physical differences in sex organs and hormone levels or factors such as mood and anxiety.”

Our biology profoundly affects how our lives go. If we can increase sexual satisfaction by modifying biology, we should. Indeed, vast numbers of men attempt to do this already through the use of Viagra.

**Summary: The Case in Favor of Enhancement**  
 What matters is human well-being, not only treatment and prevention of disease. Our biology affects our opportunities to live well. The biological route to improvement is no different [from] the environmental. Biological manipulation to increase opportunity is ethical. If we have an obligation to treat and prevent disease, we have an obligation to try to manipulate these characteristics to give an individual the best opportunity [for] the best life.

### How Do We Decide?

If we are to enhance certain qualities, how should we decide which to choose? Eugenics was the movement early last century which aimed to use selective breeding to prevent degeneration of the gene pool by weeding out criminals, those with mental illness and the poor, on the false belief that these conditions were simple genetic disorders. The eugenics movement had its inglorious peak when the Nazis moved beyond sterilization to extermination of the genetically unfit.

What was objectionable about the eugenics movement, besides its shoddy scientific basis, was that it involved the imposition of a State vision for a healthy population and aimed to achieve this through coercion. The eugenics movement was not aimed at what was good for individuals, but rather what benefited society. Modern eugenics in the form of testing for disorders, such as Down syndrome, occurs very commonly but is acceptable because it is voluntary, gives couples a choice over what kind of child to have and enables them to have a child with the greatest opportunity for a good life.

There are four possible ways in which our genes and biology will be decided.

1. Nature or God
2. “Experts”—philosophers, bioethicists, psychologists, scientists
3. “Authorities”—government, doctors
4. By people themselves—liberty and autonomy

It is a basic principle of liberal states like the UK that the State be “neutral” to different conceptions of the good life. This means that we allow individuals to lead the life that they believe is best for themselves—respect for their personal autonomy or capacity for self-rule. The sole ground for interference is when that individual choice may harm others. Advice, persuasion, information, dialogue are permissible. But coercion and infringement of liberty are impermissible.

There are limits to what a liberal state should provide:

1. Safety—the intervention should be reasonably safe.
2. Harm to others—the intervention (like some manipulation that increases uncontrollable aggressiveness) should not result in harm. Such harm should not be direct or indirect, for example, by causing some unfair competitive advantage.
3. Distributive justice—the interventions should be distributed according to principles of justice.

The situation is more complex with young children, embryos and fetuses who are incompetent. These human beings are not autonomous and cannot make choices themselves about whether a putative enhancement is a benefit or harm. If a proposed intervention can be delayed until that human reaches maturity and can decide for himself or herself, then the intervention should be delayed. However, many genetic interventions will have to be performed very early in life if they are to have an effect. Decisions about such interventions should be left to parents, according to a principle of procreative liberty and autonomy. This states that parents have the freedom to choose when to have children, how many children to have, and arguably what kind of children to have.

Just as parents have wide scope to decide on the conditions of the upbringing of their child, including schooling and religious education, they should have similar freedom over their children’s genes. Procreative autonomy or liberty should be extended to enhancement for two reasons. Firstly, reproduction, bearing and raising children is a very private matter.

Parents must bear much of the burden of having children and they have a legitimate stake in the nature of the child they must invest so much of their lives raising.

But there is a second reason. John Stuart Mill argued that when our actions only affect ourselves, we should be free to construct and act on our own conception of what is the best life for us. Mill was not a libertarian. He did not believe that such freedom was solely valuable for its own sake. He believed freedom was important for people to discover for themselves what kind of life is best for themselves. It is only through “experiments in living” that people discover what works for them. And do others see the richness and variety of lives that can be good. Mill strongly praised “originality” and variety in choice as being essential to discovering which lives are best for human beings.

Importantly, Mill believed that some lives are worse than others. Famously, he said it is better to be Socrates dissatisfied than a fool satisfied. He distinguished between “higher pleasures” of “feelings and imagination” and “lower pleasures” of “mere sensation.” Mill criticized “ape-like imitation,” subjugation of oneself to custom and fashion, indifference to individuality and lack of originality. Nonetheless, he was the champion of people’s right to live their lives as they choose.

I have said that it is important to give the freest scope possible to uncustomary things, in order that it may appear in time which of these are fit to be converted into customs. But independence of action, and disregard of custom, are not solely deserving of encouragement for the chance they afford that better modes of action, and customs more worthy of general adoption, may be struck out; nor is it only persons of decided mental superiority who have a just claim to carry on their lives in their own way. There is no reason that all human existence should be constructed on some one or small number of patterns. If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode.

I believe that reproduction should be about having children with the best prospects. But to

discover what are the best prospects, we must give individual couples the freedom to act on their own value judgement of what constitutes a life of good prospect. “Experiments in reproduction” are as important as “experiments in living” (as long as they don’t harm the children who are produced.) For this reason, procreative freedom is important.

There is one important limit to procreative autonomy that is different [from] the limits to personal autonomy. The limits to procreative autonomy should be:

1. Safety
2. Harm to others
3. Distributive justice
4. *The parent's choices are based on a plausible conception of well-being and a better life for the child*
5. *Consistent with development of autonomy in child and a reasonable range of future life plans*

These last two limits are important. It makes for a higher standard of “proof” that an intervention will be an enhancement because the parents are making choices for their child, not themselves. The critical question to ask in considering whether to alter some gene related to complex behavior is: would the change be better for the individual? Is it better for the individual to have a tendency to be lazy or hardworking; monogamous or polygamous? These questions are difficult to answer. While we might let adults choose to be monogamous or polygamous, we would not let parents decide on their child’s predispositions unless we were reasonably clear that some trait was better for the child.

There will be cases where some intervention is plausibly in a child’s interests: increased empathy with other people, better capacity to understand oneself and the world around, or improved memory. One quality is especially associated with socioeconomic success and staying out of prison: impulse control. If it were possible to correct poor impulse control, we should correct it. Whether we should remove impulsiveness altogether is another question.

Joel Feinberg has described a child’s right to an open future. An open future is one in which a

child has a reasonable range of possible lives to choose from and an opportunity to choose what kind of person to be. That is, to develop autonomy. Some critics of enhancement have argued that genetic interventions are inconsistent with a child's right to an open future. Far from restricting a child's future, however, some biological interventions may increase the possible futures or at least their quality. It is hard to see how improved memory or empathy would restrict a child's future. Many worthwhile possibilities would be open. But it is true that parental choices should not restrict the development of autonomy or [the] reasonable range of possible futures open to a child. In general, fewer enhancements will be permitted in children than in adult[s]. Some interventions, however, may still be clearly enhancements for our children and so just like vaccinations or other preventative health care.

## Objections

### I. Playing God or Against Nature

This objection has various forms. Some people in society believe that children are a gift, of God or of Nature, and that we should not interfere in human nature. Most people implicitly reject this view—we screen embryos and fetuses for diseases, even mild correctible diseases. We interfere in Nature or God's will when we vaccinate, provide pain relief to women in labor (despite objections of some earlier Christians that these practices thwarted God's will) and treat cancer. No one would object to the treatment of disability in a child, if it were possible. Why then, not treat the embryo with genetic therapy if that intervention is safe? This is no more thwarting God's will than giving antibiotics.

Another variant of this objection is that we are arrogant to assume we can have sufficient knowledge to meddle with human nature. Some people object that we cannot know the complexity of the human system, which is like an unknowable magnificent symphony. To attempt to enhance one characteristic may have other unknown, unforeseen effects elsewhere in the system. We should not play God—we should be humble and recognize the limitations of our knowledge. Unlike God, we are not omnipotent or omniscient.

A related objection is that genes are pleiotropic—which means they have different effects in different environments. The gene or genes which predispose to manic depression may also be responsible for heightened creativity and productivity.

One response to both of these objections is to limit our interventions, until our knowledge grows, to selections between different embryos and not intervene to enhance particular embryos or people. Since we would be choosing between complete systems on the basis of their type, we would not be interfering with the internal machinery. In this way, selection is less risky than enhancement.

But such precaution can be also misplaced when considering biological interventions. When benefits are on offer, such objections remind us to refrain from hubris and overconfidence. We must do adequate research before intervening. And because the benefits may be less than when we treat or prevent disease, we may require the standards of safety to be higher than for medical interventions. But we must weigh the risks against the benefit. If confidence is justifiably high, and benefits outweigh harms, we should enhance.

Once technology affords us with the power to enhance our and our children's lives, to fail to do so will be to be responsible for the consequences. To fail to treat our children's disease, is to wrong them. To fail to prevent them getting depression, is to wrong them. To fail to improve their physical, musical, psychological and other capacities, is to wrong them, just as it would be to harm them if we gave them a toxic substance that stunted or reduced these capacities.

Another variant of the "Playing God" objection is that there is a special value in the balance and diversity that natural variation affords, and enhancement will reduce this. But insofar as we are products of evolution, we are merely random chance variations of genetic traits selected for our capacity to survive long enough to reproduce. There is no design to evolution. Evolution selects genes according to environment which confer the greatest chance of survival and reproduction. Evolution would select a tribe which was highly fertile but suffered great pain the whole of their lives over another tribe which was less fertile but suffered less pain. Medicine has

changed evolution—we can now select individuals who experience less pain and disease. The next stage of human evolution will be rational evolution, where we select children who not only have the greatest chance of surviving, reproducing and being free of disease, but who have the greatest opportunities to have the best lives in their likely environment. Evolution was indifferent to how well our lives went. We are not. We want to retire, play golf, read and watch our grandchildren have children.

Enhancement is a misnomer. It suggests luxury. But enhancement is no luxury. Insofar as it promotes well-being, it is the very essence of what is necessary for a good human life.

There is no moral reason to preserve some traits—such as uncontrollable aggressiveness, a sociopathic personality or extreme deviousness. Tell the victim of rape and murder that we must preserve the natural balance and diversity.

## 2. Genetic Discrimination

Some people fear the creation of a two-class society of the enhanced and the unenhanced, where the inferior unenhanced are discriminated against and disadvantaged all through life.

We must remember that nature allots advantage and disadvantage with no gesture to fairness. Some are born horribly disadvantaged, destined to die after short and miserable lives. Some suffer great genetic disadvantage while others are born gifted, physically, musically or intellectually. There is no secret that there are “gifted” children naturally. Allowing choice to change our biology will, if anything, be more egalitarian—allowing the ungifted to approach the gifted. There is nothing fair about the natural lottery—allowing enhancement may be more fair.

But more importantly, how well the lives of those who are disadvantaged go depends not on whether enhancement is permitted, but on the social institutions we have in place to protect the least well off and provide everyone with a fair go. People have disease and disability—egalitarian social institutions and laws against discrimination are designed to make sure everyone, regardless of natural inequality, has a decent chance of a decent life. This would be no different if enhancement were permitted. There is no necessary connection between

enhancement and discrimination, just as there is no necessary connection between curing disability and discrimination against people with disability.

## 3. The Perfect Child, Sterility and Loss of the Mystery of Life

If we engineered perfect children, this objection goes, the world would be a sterile, monotonous place where everyone is the same, and the mystery and surprise of life is gone.

It is impossible to create perfect children. We can only attempt to create children with better opportunities [for] a better life. There will necessarily be difference. Even in the case of screening for disability, like Down syndrome, 10 percent of people choose not to abort a pregnancy known to have Down syndrome. People value different things. There will never be complete convergence. Moreover, there will remain massive challenges for individuals to meet in their personal relationships and in the hurdles our unpredictable environment presents. There will remain much mystery and challenge—we will just be better able to deal with these. We will still have to work to achieve, but our achievements may have greater value.

## 4. Against Human Nature

One of the major objections to enhancement is that it is against human nature. Common alternative phrasings are that enhancement is tampering with our nature or an affront to human dignity. I believe that what separates us from other animals is our rationality, our capacity to make normative judgements and act on the basis of reasons. When we make decisions to improve our lives by biological and other manipulations, we express our rationality and express what is fundamentally important about our nature. And if those manipulations improve our capacity to make rational and normative judgements, they further improve what is fundamentally human. Far from being against the human spirit, such improvements express the human spirit. To be human is to be better.

## 5. Enhancements Are Self-Defeating

Another familiar objection to enhancement is that enhancements will have self-defeating or other

adverse social effects. A typical example is increase in height. If height is socially desired, then everyone will try to enhance the height of their children at great cost to themselves and the environment (as taller people consume more resources), with no advantage in the end since there will be no relative gain.

If a purported manipulation does not improve well-being or opportunity, there is no argument in favor of it. In this case, the manipulation is not an enhancement. In other cases, such as enhancement of intelligence, the enhancement of one individual may increase that individual's opportunities only at the expense of another. So-called positional goods are goods only in relative sense.

But many enhancements will have both positional and non-positional qualities. Intelligence is good not just because it allows an individual to be more competitive for complex jobs, but because it allows an individual to more rapidly process information in her own life, and to develop greater understanding of herself and others. These non-positional effects should not be ignored. Moreover, even in the case of so-called purely positional goods, such as height, there may be important non-positional values. It is better to be taller to be a basketball player, but being tall is a disadvantage in balance sports such as gymnastics, skiing and surfing.

Nonetheless, if there are significant social consequences of enhancement, this is of course a valid objection. But it is not particular to enhancement—there is an old question about how far individuals in society can pursue their own self-interest at cost to others. It applies to education, health care, and virtually all areas of life.

Not all enhancements will be ethical. The critical issue is that the intervention is expected to bring about more benefits than harms to the individual. It must be safe and there must be a reasonable expectation of improvement. Some of the other features of ethical enhancements are summarized next.

#### What is an ethical enhancement?

1. It is in the person's interests
2. Reasonably safe
3. Increases the opportunity to have the best life
4. Promotes or does not unreasonably restrict the range of possible lives open to that person

5. Does not harm others directly through excessive costs by making it freely available (but balance against the costs of prohibition)
6. Does not place that individual at an unfair competitive advantage with respect to others, e.g., mind reading
7. The person retains significant control or responsibility for her achievements and self which cannot be wholly or directly attributed to the enhancement
8. Does not reinforce or increase unjust inequality and discrimination—economic inequality, racism (but balance the costs of social/environmental manipulations against biological manipulations)

#### What is an ethical enhancement for a child or incompetent human being?

All of the above plus:

1. The intervention cannot be delayed until the child can make its own decision
2. The intervention is plausibly in [the] child's interests
3. The intervention is compatible with the development of autonomy.

#### Conclusion

Enhancement is already occurring. In sport, human erythropoietin boosts red blood cells. Steroids and growth hormone improve muscle strength. Many people seek cognitive enhancement—nicotine, ritalin, modavigil, caffeine. Prozac, recreational drugs and alcohol all enhance mood. Viagra is used to improve sexual performance.

And of course mobile phones and airplanes are examples of external enhancing technologies. In the future, genetic technology, nanotechnology, and artificial intelligence may profoundly affect our capacities.

Will the future be better or just disease-free? We need to shift our frame of reference from health to life enhancement. What matters is how we live. Technology can now improve that. We have two options:

1. Intervention
  - Treating disease
  - Preventing disease

- Supraprevention of disease—preventing disease in a radically unprecedented way
  - Protection of well-being
  - Enhancement of well-being
2. No intervention, and to remain in a state of nature—no treatment or prevention of disease, no technological enhancement.

I believe to be human is to be better. Or, at least, to strive to be better. We should be here for a *good* time, not just a *long* time. Enhancement, far from being merely permissible, is something we should aspire to achieve.

## Germ-Line Gene Therapy

LEROY WALTERS AND JULIE GAGE PALMER

In this essay Walters and Palmer examine arguments for and against germ-line gene therapy. Major moral arguments in its favor include that it may be the only way to prevent damage to some people, that it may enable parents to avoid passing on a genetic disorder to children or grandchildren, and that this kind of therapy “best accords with the health professions’ healing role and with the concern to protect rather than penalize individuals who have disabilities.” Among the arguments against germ-line therapy are that any unanticipated negative effects will hurt not only the patient but also his descendants and that the intervention fails to show proper respect for preimplantation embryos and implanted fetuses. Walters and Palmer conclude that some of the pro arguments are strong and all of the con arguments are weak.

. . . Standard medical therapies, like somatic cell gene therapy, are somatic treatments and do not correct genetic defects in a patient’s germ line. They may allow patients to live and to reproduce, passing on genetic mistakes which, without treatment, would not be perpetuated. Preimplantation and prenatal selection, like somatic medicine, may also result in a higher incidence of germ-line genetic defects because, unless they employ selective discard and selective abortion of unaffected carriers, both strategies increase the number of carriers of genetic defects that are born.

Successful germ-line gene replacement, on the other hand, will not perpetuate genetic mistakes. It will not only cure the patient at hand; it will also prevent the disease in question from arising in that

patient’s descendants. Applied to heterozygous carriers on a large scale, it could theoretically eliminate chosen disease-causing genes from the human gene pool.

As long as germ-line gene therapy must be performed on human zygotes or embryos one at a time after in vitro fertilization, it is likely to remain an expensive technology with limited use. Only if a technique is developed for performing gene replacement or gene repair within the reproductive cells of human adults—perhaps through the injection of highly refined vectors that “home in” only on those cells (or their precursors in males)—are we likely to see the widespread diffusion of germ-line genetic intervention for disease prevention. . . .

### For What Clinical Situations Will Germ-Line Gene Therapy Be Proposed?

It is difficult to predict the precise context in which germ-line gene therapy will first be considered.

Tables 1 through 4 show four scenarios where the issue of germ-line intervention may at least be discussed at some point in the future.

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**TABLE 1 MODE OF INHERITANCE I**


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Both the wife and the husband are afflicted with a recessive genetic disorder. That is, both have two copies of the same malfunctioning gene at a particular site in their chromosomes. Therefore, all of their offspring are likely to be affected with the same genetic disorder.

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**TABLE 2 MODE OF INHERITANCE 2**


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Both the wife and the husband are carriers of a recessive genetic disorder. That is, each has one copy of a properly functioning and one copy of a malfunctioning gene at a particular site in their chromosomes. Following Mendel's laws, 25% of the couple's offspring are likely to be "normal," 50% are likely to be carriers like their parents, and 25% are likely to be afflicted with the genetic disorder.

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**TABLE 3 DISEASE CONDITION I**


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A diagnosable genetic disorder results in major irreversible damage to the brains of affected fetuses during the first trimester of pregnancy. There is no known method for making genetic repairs in the uterus during pregnancy. If any genetic repair is to be made, it must be completed before the embryo begins its intrauterine development.

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**TABLE 4 DISEASE CONDITION 2**


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A diagnosable genetic disorder affects many different cell types in many different parts of the bodies of patients affected by the disorder. Somatic cell gene therapy that targets a particular cell type is therefore unlikely to be successful in combating the disorder. Therefore, germ-line gene therapy delivered early enough to affect *all* cell types may be the only feasible way to prevent disease in a particular future person.

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The kind of situation described in Table 1 is likely to arise as medical care succeeds in prolonging the lives of people with genetic disorders such as sickle cell disease or cystic fibrosis. If somatic cell gene therapy is employed in significant numbers of people afflicted with recessive genetic diseases, some of those people's somatic cells will be able to function normally, but their reproductive cells will remain unchanged, thus assuring that they will be carriers of genetic disease to the next generation. If two such phenotypically cured people marry and have children, all or almost all of their children will be afflicted with the disease which their parents had. Each succeeding generation of these children will need somatic cell gene therapy for the treatment of their disease.

Table 2 sketches a scenario frequently encountered by genetic counselors. In this case, germ-line genetic intervention could be viewed as an alternative to prenatal diagnosis and selective abortion of affected fetuses or to preimplantation diagnosis and the selective discard of affected early embryos. A couple might also elect germ-line genetic intervention in order to avoid producing children who are *carriers* of genetic defects, even if the children are not themselves afflicted with genetic disease. The parents would know that children who are carriers may one day face precisely the kind of difficult reproductive decisions that they as parents are facing.

In the type of case outlined in Table 3, somatic cell gene therapy might be effective if one could deliver it to the developing embryo and fetus during the earliest stages of pregnancy, that is, shortly after the embryo has implanted in the uterus. However, there is no known method of administering intrauterine therapy to an early first-trimester embryo, and a deferral of treatment until the second or third trimester would probably allow irreversible damage to occur. Preimplantation treatment, which would almost certainly affect the future germ-line cells as well as the future somatic cells, could be the only feasible approach to producing children who are not brain damaged, especially for couples who reject the alternative of selectively discarding early embryos.<sup>1</sup>

The scenario presented in Table 4 may be especially relevant to the development of particular

kinds of cancers as a result of inborn genetic factors and subsequent mutations. For example, about 40% of people with a cancer of the retina called *retinoblastoma* transmit a dominant gene for this disorder to their children. In patients with this germ-line type of retinoblastoma, somatic mutational events that occur after birth seem to activate the cancer-causing gene and can result in multiple types of cancer developing in different cell types within the patient's body. For example, a kind of cancer called *osteogenic sarcoma* frequently develops later in life in patients who have been successfully treated for retinoblastoma.<sup>2</sup> With germ-line retinoblastoma, the only effective antidote to the development of multiple types of cancers may be early germ-line gene therapy that effectively repairs *all* of the cells in a developing embryo.<sup>3</sup>

### **The Needed Technological Breakthrough: Gene Replacement or Gene Repair**

As we noted earlier in this chapter [of *The Ethics of Human Gene Therapy*], the current technique for somatic-cell gene therapy relies on rather imprecise methods of gene addition. For safe and effective germ-line gene therapy, it seems likely that a more precisely targeted method of gene replacement or gene repair will be necessary. The most obvious reason for preferring gene replacement is that gene addition in embryos would result in their (later-developing) sperm or egg cells containing *both* the malfunctioning and the properly functioning genes. Thus, one undesirable effect of researchers' treating present or future reproductive cells by gene addition is that the researchers would be directly contributing to an increase in the number of malfunctioning genes in future generations. In addition, if any of the germ-line disorders are dominant, as retinoblastoma seems to be, then only gene replacement is likely to eradicate the deleterious effects of the malfunctioning gene.

### **Major Ethical Arguments in Favor of Germ-Line Gene Therapy**

In this and the following section we will analyze the major ethical arguments<sup>4</sup> for and against germ-line gene therapy.<sup>5</sup> For this analysis we will make the optimistic assumption that germ-line intervention

methods will gradually be refined until they reach the point where gene replacement or gene repair is technically feasible and able to be accomplished in more than 95% of attempted gene transfer procedures. Thus, the following analysis presents the arguments for and against germ-line intervention under the most favorable conditions for such intervention.

A first argument in favor of germ-line intervention is that it may be the only way to prevent damage to particular biological individuals when that damage is caused by certain kinds of genetic defects. This argument is most closely related to the last two scenarios presented above. That is, only genetic modifications introduced into preimplantation embryos are likely to be early enough to affect all of the important cell types (as in retinoblastoma), or to reach a large enough fraction of brain cells, or to be in time to prevent irreversible damage to the developing embryo. In these circumstances the primary intent of gene therapy would, or at least could, be to provide gene therapy for the early embryo. A side effect of the intervention would be that all of the embryonic cells, including the reproductive cells that would later develop, would be genetically modified.<sup>6</sup>

A second moral argument for germ-line genetic intervention might be advanced by parents. It is that they wish to spare their children and grandchildren from either (1) having to undergo somatic cell gene therapy if they are born affected with a genetic defect or (2) having to face difficult decisions regarding possibly transmitting a disease-related gene to their own children and grandchildren. In our first scenario, admittedly a rare case, two homozygous parents who have a genetic disease know in advance that all of their offspring are likely to be affected with the same genetic disease. In the second scenario, there is a certain probability that the parents' offspring will be affected or carriers. An assumption lying behind this second argument is that parents should enjoy a realm of moral and legal protection when they are making good-faith decisions about the health of their children. Only if their decisions are clearly adverse to the health interests of the children should moral criticism or legal intervention be considered.

A third moral argument for germ-line intervention is more likely to be made by health professionals, public-health officials, and legislators casting a wary eye toward the expenditures for health care. This argument is that, from a social and economic point of view, germ-line intervention is more efficient than repeating somatic cell gene therapy generation after generation. From a medical and public health point of view, germ-line intervention fits better with the increasingly preferred model of disease prevention and health promotion. In the very long run, germ-line intervention, if applied to both affected individuals and asymptomatic carriers of serious genetic defects, could have a beneficial effect on the human gene pool and the frequency of genetic disease.<sup>7</sup>

A fourth argument refers to the roles of researchers and health professionals. As a general rule, researchers deserve to have the freedom to explore new modes of treating and/or preventing human disease.<sup>8</sup> To be sure, moral rules set limits on how this research is conducted. For example, animals involved in the preclinical stages of the research should be treated humanely. In addition, the human subjects involved in the clinical trials should be treated with respect. When and if germ-line gene therapy is some day validated as a safe and effective intervention, health care providers should be free to, and may have a moral obligation to, offer it to their patients as a possible treatment. This freedom is based on the professional's general obligation to seek out and offer the best possible therapeutic alternatives to patients and society's recognition of a sphere in which health professionals are at liberty to exercise their best judgment on behalf of their patients.

A fifth and final argument in favor of germ-line gene therapy is that this kind of intervention best accords with the health professions' healing role and with the concern to protect rather than penalize individuals who have disabilities. This argument is not simply a plea for protecting all embryos and fetuses from the time of fertilization forward. Both authors of this book [*The Ethics of Human Gene Therapy*] think that abortion is morally justifiable in certain circumstances. However, prenatal diagnosis followed by selective abortion and

preimplantation diagnosis followed by selective discard seem to us to be uncomfortable and probably discriminatory halfway technologies that should eventually be replaced by effective modes of treatment. The options of selective abortion and selective discard essentially say to prospective parents, "There is nothing effective that the health care system has to offer. You may want to give up on this fetus or embryo and try again." To people with disabilities that are diagnosable at the prenatal or preimplantation stages of development the message of selective abortion and selective discard may seem more threatening. That message may be read as, "If we health professionals and prospective parents had known you were coming, we would have terminated your development and attempted to find or create a nondisabled replacement."

This argument is not intended to limit the legal access of couples to selective abortion in the case of serious health problems for the fetus. We support such access. Rather, it is an argument about what the long-term goal of medicine and society should be. In our view, that long-term goal should be to prevent disability and disease wherever possible. Where prevention is not possible, the second-best alternative is a cure or other definitive remedy. In cases where neither prevention nor cure is possible, our goal should be to help people cope with disability and disease while simultaneously seeking to find a cure.

### **Major Arguments Against Germ-Line Gene Therapy**

First, if the technique has unanticipated negative effects, those effects will be visited not only on the recipient of the intervention himself or herself but also on all of the descendants of that recipient. This argument seems to assume that a mistake, once made, could not be corrected, or at least that the mistake might not become apparent until the recipient became the biological parent of at least one child. For that first child, at least, the negative effects could be serious, as well as uncorrectable.

Second, some critics of germ-line genetic intervention argue that this technique will never be necessary because of available alternative strategies for preventing the transmission of diagnosable genetic

diseases. Specifically, critics of germ-line gene therapy have sometimes suggested that preimplantation diagnosis and the selective discard of affected embryos might be a reasonable alternative to the high technology, potentially risky attempt to repair genetic defects in early human embryos. Even without in vitro fertilization and preimplantation diagnosis, the option of prenatal diagnosis and selective abortion is available for many disorders. According to this view, these two types of selection, before embryos or fetuses have reached the stage of viability, are effective means for achieving the same goal.

The third argument is closely related to the second: this technique will always be an expensive option that cannot be made available to most couples, certainly not by any publicly funded health care system. Therefore, like in vitro fertilization for couples attempting to overcome the problem of infertility, germ-line gene therapy will be available only to wealthy people who can afford to pay its considerable expense on their own.

The fourth argument builds on the preceding two: precisely because germ-line intervention will be of such limited utility in preventing disease, there will be strong pressures to use this technique for genetic enhancement at the embryonic stage, when it could reasonably be expected to make a difference in the future life prospects of the embryo. Again in this case, only the affluent would be able to afford the intervention. However, if enhancement interventions were safe and efficacious, the long-term effect of such germ-line intervention would probably be to exacerbate existing differences between the most-well-off and the least-well-off segments of society.

Fifth, even though germ-line genetic intervention aims in the long run to treat rather than to abort or discard, the issue of appropriate respect for preimplantation embryos and implanted fetuses will nonetheless arise in several ways. After thoroughgoing studies of germ-line intervention have been conducted in nonhuman embryos, there will undoubtedly be a stage at which parallel studies in human embryos will be proposed. The question of human embryo research was recently studied by a committee appointed by the director of the National Institutes of Health.<sup>9</sup> Although the

committee specifically avoided commenting on germ-line intervention, its recommendation that certain kinds of human embryo research should be continued and that such research should be funded by NIH provoked considerable controversy. Critics of the committee's position would presumably also oppose the embryo research that would be proposed to prepare the way for germ-line gene therapy in humans.<sup>10</sup> Their principal argument would be that the destruction or other harming of preimplantation embryos in research is incompatible with the kind of respect that should be shown to human embryos.

Even after the research phase of germ-line genetic intervention is concluded, difficult questions about the treatment of embryos will remain. For example, preimplantation diagnosis may continue to involve the removal of one or two totipotential cells from a four- to eight-cell embryo. While the moral status of totipotential human embryonic cells has received scant attention in bioethical debates, there is at least a plausible argument that a totipotential cell, once separated from the remainder of a preimplantation embryo, is virtually equivalent to a zygote; that is, under favorable conditions it could develop into an embryo, a fetus, a newborn, and an adult. This objection to the destruction of totipotential embryonic cells will only be overcome if a noninvasive genetic diagnostic test for early embryos (like an x-ray or a CT scan) can be developed. Further, even if a noninvasive diagnostic test is available, as we have noted above, a postintervention diagnostic test will probably be undertaken with each embryo to verify that the intervention has been successful. Health professionals and prospective parents will probably be at least open to the possibility of selective discard or selective abortion if something has gone radically wrong in the intervention procedure. Thus, germ-line genetic intervention may remain foreclosed as a moral option to those who are conscientiously opposed to any action that would directly terminate the life of a preimplantation embryo or a fetus.

The sixth argument points to potential perils of concentrating great power in the hands of human beings. According to this view, the technique of germ-line intervention would give human beings,

or a small group of human beings, too much control over the future evolution of the human race. This argument does not necessarily attribute malevolent intentions to those who have the training that would allow them to employ the technique. It implies that there are built-in limits that humans ought not to exceed, perhaps for theological or metaphysical reasons, and at least hints that corruptibility is an ever-present possibility for the very powerful.

The seventh argument explicitly raises the issue of malevolent use. If one extrapolates from Nazi racial hygiene programs, this argument asserts, it is likely the germ-line intervention will be used by unscrupulous dictators to produce a class of superior human beings. The same techniques could be also used in precisely the opposite way, to produce humanlike creatures who would willingly perform the least-attractive and the most-dangerous work for a society. According to this view, Aldous Huxley's *Brave New World* should be updated, for modern molecular biology provides tyrants with tools for modifying human beings that Huxley could not have imagined in 1932.

The eighth and final argument against germline genetic intervention is raised chiefly by several European authors who place this argument in the context of human rights.<sup>11</sup> According to these commentators, human beings have a moral right to receive from their parents a genetic patrimony that has not been subjected to artificial tampering. Although the term "tampering" is not usually defined, it seems to mean any intentional effort to introduce genetic changes into the germ line, even if the goal is to reduce the likelihood that a genetic disease will be passed on to the children and grandchildren of a particular couple. The asserted right to be protected against such tampering may be a slightly different formulation of the sixth argument noted above—namely, that there are built-in limits, embedded in the nature of things, beyond which not even the most benevolent human beings should attempt to go.

### A Brief Evaluation of the Arguments

In our view, the effort to cure and prevent serious disease and premature death is one of the noblest of all human undertakings. For this reason the first

pro argument—that germ-line intervention may be the only way to treat or prevent certain diseases—seems to us to be of overriding importance. We also find the third pro argument to be quite strong, that a germ-line correction, if demonstrated to be safe and effective, would be more efficient than repeated applications of somatic cell gene therapy. In addition, the final pro argument about the overall mission of the health professions and about society's approach to disabilities seems to us to provide a convincing justification for the germ-line approach, when gene replacement is available.

Our replies to the objections raised by critics of germ-line intervention are as follows:

1. *Irreversible mistakes.* While we acknowledge that mistakes may be made in germ-line gene therapy, we think that the same sophisticated techniques that were employed to introduce the new genes will be able to be used to remove those genes or to compensate for their presence in some other way. Further, in any sphere of innovative therapy, a first step into human beings must be taken at some point.
2. *Alternative strategies.* Some couples, perhaps even most couples, will choose the alternative strategies of selective abortion or selective discard. In our view, a strategy of attempting to prevent or treat potential disease or disability in the particular biological individual accords more closely with the mission of the health sciences and shows greater respect for children and adults who are afflicted with disease or disability.
3. *High cost, limited availability.* It is too early to know what the relative cost of germ-line intervention will be when the technique is fully developed. In addition, the financial costs and other personal and social harms of preventable diseases will need to be compared with the financial costs of germ-line gene therapy. It is at least possible that this new technology could become widely diffused and available to many members of society.
4. *Use for enhancement.* Prudent social policy should be able to set limits on the use of

germ-line genetic intervention. Further, some enhancements of human capabilities may be morally justifiable, especially when those enhancements are health related. We acknowledge that the distribution of genetic enhancement is an important question for policy makers.

5. *Human embryos.* In our view, research with early human embryos that is directed toward the development of germ-line gene therapy is morally justifiable in principle. Further, we acknowledge the potential of a totipotential cell but think that the value of a genetic diagnosis outweighs the value of such a cell. We also accept that, if a serious error is made in germ-line gene therapy, terminating the life of the resulting embryo or fetus may be morally justifiable. In short, there is a presumption in favor of fostering the continued development of human embryos and fetuses, but that presumption can in our view be overridden by other considerations like serious harm to the developing individual or others and the needs of preclinical research.
6. *Concentration of power.* We acknowledge that those who are able to use germ-line intervention will have unprecedented ability to introduce precise changes into the germ lines of particular individuals and families. However, in our view, it is better for human beings to possess this ability and to use it for constructive purposes like preventing disease in families than not to possess the ability. The central ethical question is public accountability by the scientists, health providers, and companies that will be involved with germ-line intervention. Such accountability presupposes transparency about the use of the technology and an ongoing monitoring process aimed at preventing its misuse.
7. *Misuse by dictators.* This objection focuses too much attention on technology and too little on politics. There is no doubt that bona fide tyrants have existed in the 20th century and that they have made use of all manner of technologies—whether the low-tech methods of surgical sterilization or the annihilation of

concentration camp inmates with poison gas or high-tech weapons like nuclear warheads and long-range missiles—to terrify and to dominate. However, the best approach to preventing the misuse of genetic technologies may not be to discourage the development of the technologies but rather to preserve and encourage democratic institutions that can serve as an antidote to tyranny. A second possible reply to the tyrannical misuse objection is that germ-line intervention requires a long lead time, in order to allow the offspring produced to grow to adulthood. Tyrants are often impatient people and are likely to prefer the more instantaneous methods of propaganda, intimidation, and annihilation of enemies to the relatively slow pace of germ-line modification.

8. *Human rights and tampering.* It is a daunting task to imagine what the unborn and as-yet-unconceived generations of people coming after us will want.<sup>12</sup> Even more difficult is the effort to ascribe rights to [future] human beings. Insofar as we can anticipate the needs and wants of future generations, we think that any reasonable future person would prefer health to serious disease and would therefore welcome a germ-line intervention in his or her family line that effectively prevented cystic fibrosis from being transmitted to him or her. In our view, such a person would not regard this intervention as tampering and would regard as odd the claim that his or her genetic patrimony has been artificially tampered with. Cystic fibrosis was not a part of his or her family's heritage that the future person was eager to receive or to claim. . . .

#### NOTES

1. It is perhaps worth noting that researchers performing somatic-cell gene therapy have carefully avoided diseases and subtypes of diseases that affect mental functioning. One thinks, for example, of Lesch-Nyhan syndrome, of certain subtypes of Gaucher disease and Hunter syndrome, of Tay-Sachs disease, and of metachromatic leukodystrophy.

2. We owe the suggestion of retinoblastoma as a candidate disorder to Kevin FitzGerald, S. J. We are also indebted to Nelson A. Wivel for information on the genetics of retinoblastoma. See Nelson A. Wivel and LeRoy Walters, "Germ-Line Gene Modification and Disease Prevention: Some Medical and Ethical Perspectives," *Science* 262(5133): 533–538; 22 October 1993. See also Stephen H. Friend et al., "A Human DNA Segment with Properties of the Gene That Predisposes to Retinoblastoma and Osteosarcoma," *Nature* 323(6089): 643–646; 16 October 1986; and Ei Matsunaga, "Hereditary Retinoblastoma: Host Resistance and Second Primary Tumors," *Journal of the National Cancer Institute* 65(1): 47–51; July 1980.
3. Although the genetics of the germ-line p53 gene mutation are more complex than the genetics of the germ-line mutation that causes retinoblastoma, p53 may turn out to be another important tumor suppressor gene to which the same comments apply. On the germ-line p53 mutation, see Frederick P. Li et al., "Recommendations on Predictive Testing for Germ Line p53 Mutations Among Cancer-Prone Individuals," *Journal of the National Cancer Institute* 84(15): 1156–1160; 5 August 1992; and Curtis C. Harris and Monica Hollstein, "Clinical Implications of the p53 Tumor-Suppressor Gene," *New England Journal of Medicine* 329(18): 1318–1327; 28 October 1993.
4. Eric T. Juengst, "Germ-Line Gene Therapy: Back to Basics," *Journal of Medicine and Philosophy* 16(6): 589–590; December 1991.
5. Burke K. Zimmerman, "Human Germ-Line Therapy: The Case for Its Development and Use," *Journal of Medicine and Philosophy* 16(6): 596–598; December 1991.
6. For a detailed discussion of and justification for germ-line intervention in this setting, see Marc Lappé, "Ethical Issues in Manipulating the Human Germ Line," *Journal of Medicine and Philosophy* 16(6): 621–639; December 1991.
7. As noted above, already in 1962 Joshua Lederberg was arguing against H. J. Muller's proposals for improving the human gene pool through programs of "voluntary germinal choice" by appealing to the prospect of rapid, global genetic intervention by means of germ-line gene therapy. See Joshua Lederberg, "Biological Future of Man," in Gordon Wolstenholme, ed., *Man and His Future* (London: J. & A. Churchill, 1963), pp. 265 and 269.
8. On the general issue of the freedom of scientific inquiry, see Loren R. Graham, "Concerns About Science and Attempts to Regulate Inquiry," *Daedalus* 107(2): 1–21; Spring 1978.
9. National Institutes of Health, Human Embryo Research Panel, *Report* (Bethesda, MD: NIH, 27 September 1994).
10. See, for example, the following critiques of human embryo research: "The Inhuman Use of Human Beings," *First Things* 49: 17–21; January 1995; Dianne N. Irving, "Testimony Before the NIH Human Embryo Research Panel," *Linacre Quarterly* 61(4): 82–89; November 1994; and Kevin O'Rourke, "Embryo Research: Ethical Issues," *Health Care Ethics USA* 2(4): 2–3; Fall 1994.
11. Alex Mauron and Jean-Marie Thévoz, "Germ-Line Engineering: A Few European Voices," *Journal of Medicine and Philosophy* 16(6): 654–655; December 1991.
12. There is a rather substantial literature on this topic. See, for example, Ruth Faden, Gail Geller, and Madison Powers, eds., *AIDS, Women and the Next Generation* (New York: Oxford University Press, 1991); LeRoy Walters, "Ethical Issues in Maternal Serum Alpha-Fetoprotein Testing and Screening: A Reappraisal," in Mark I. Evans et al., eds., *Fetal Diagnosis and Therapy: Science, Ethics and the Law* (Philadelphia: J.B. Lippincott, 1989), pp. 54–60; and Lori B. Andrews et al., eds., *Assessing Genetic Risks: Implications for Health and Social Policy: Report* (Washington, DC: National Academy Press, 1994).

## What Does “Respect for Embryos” Mean in the Context of Stem Cell Research?

BONNIE STEINBOCK

Steinbock examines the question of whether embryonic stem-cell research is consistent with proper respect for embryos. She argues that early embryos have less than full moral status—they are not due the same respect that we give persons—but they still have a “significance and moral value that other bodily tissues do not have.” We must not use embryos in frivolous ways, she says, but “respect for embryos does not require refraining from research likely to have significant benefits, such as treating disease and prolonging life.”

Like abortion, embryo research polarizes those who believe that embryos have as much of a right to life as any born human being, and those who maintain that embryos are not the kinds of entities that can have rights, because rights are restricted either to persons or to sentient beings.<sup>1</sup> However, those who deny that embryos can be possessors of rights need not strip them of moral significance altogether. There is a “third alternative,” which is that although human embryos do not have full moral status, or human moral status, they are a form of human life and, as such, deserving of respect. This is the view that virtually every commission considering the issue has taken, including the Human Embryo Research Panel of the National Institutes of Health (NIH)<sup>2</sup> and the Warnock Committee<sup>3</sup> in Great Britain. But what does “respect for embryos” mean? Is this simply an empty phrase, solemnly invoked by national commissions to soften or conceal the fact that they are endorsing killing embryos?

This was charged by Daniel Callahan,<sup>4</sup> who took the NIH Human Embryo Research Panel to task for failing to demonstrate (as opposed to merely asserting) that progress in scientific research depends on using human embryos. Callahan’s point is not that respect for embryos entails that they never be destroyed or used in research. Rather, it is that the interests or goals to be accomplished by using human

embryos in research must be shown to be compelling, and unreachable by other means. If less than compelling purposes can justify the destruction of embryos, or if compelling goals could be reached without destroying embryos, the idea that embryos are due profound respect rings hollow.

A similar view regarding embryonic stem (ES) cell research was expressed by Richard M. Doerflinger.<sup>5</sup> He cited advances in isolating and culturing adult stem (AS) cells and suggested that AS cells might be more clinically useful than embryonic cells because treatments based on a patient’s own cells would avoid problems of tissue rejection<sup>5</sup>:

No one can say with certainty at this time whether embryonic stem cells will have any clinical use that cannot equally well be addressed by other means. . . . At a minimum, an ethic that demands serious respect for human embryonic life will also demand that other, morally accepted alternatives be explored first. (p. 144)

The suggestion that other alternatives should be explored first makes sense only if there is some reason to believe that these alternatives are likely to yield comparable results. As a nonscientist, I cannot evaluate the research cited by Doerflinger. A recent article in *Science*<sup>6</sup> says, “Scientists are now speeding ahead with work on adult stem cells, hoping to discover whether their promise will rival that of embryonic stem (ES) cells.” If that is so, it is possible that it will not be necessary to use ES cells for therapeutic purposes. At the same time, no one can accuse the National Bioethics Advisory Commission of simply

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assuming that there will be scientific benefits from embryonic stem cell research, or ignoring the possibility that AS could be used instead of ES cells. Its report, *Ethical Issues in Human Stem Cell Research*,<sup>7</sup> examines at great length the scientific evidence, and the possibility that AS cells can replace embryonic cells. It concludes that this is unlikely because ES cells have a property that AS cells do not: the ability to differentiate into all cell types. The report states<sup>7</sup>:

... although much promising research currently is being conducted with stem cells obtained from adult organisms, studies in animals suggest that this approach will be scientifically and technically limited. . . . Moreover, because important biological differences exist between embryonic and adult stem cells, this source of stem cells should not be considered an alternative to ES and EG [embryonic germ] cell research. (p. ii)

This raises the intriguing question of how promising evidence for the utility of AS cells must be to pursue that line of research while delaying research using ES cells, out of respect for embryos. Certainly, if current research indicated that significant medical benefit was just as likely from research using AS, as opposed to ES, cells, respect for embryos would require us to use AS cells. However, no one is making this claim. Although no one can say for sure, the likelihood is that stopping research using ES cells and exploring instead the therapeutic possibilities of AS cells will result in the loss of significant medical benefits for people. A better alternative would be to conduct both kinds of research simultaneously. In any event, Doerflinger's reference to doing research with AS cells appears to be a red herring because it is clear from what he says in his Abstract that he rejects absolutely stem cell research that involves the destruction of human embryos. If such research is never morally acceptable, why go on about doing other research "first"? Doerflinger's views about embryo research derive from the right-to-life position on the moral status of the human embryo. They are unrelated to the "third alternative" which accords respect, but not full moral status, to the human embryo.

What, then, does respect for embryos require? It is important, first, to differentiate respect for

embryos from respect for persons. Respect for persons means, as Kant instructs us, never treating persons as mere means to our ends, but always treating them as ends in themselves. This obscure phrase means that we must take seriously the ends—the projects, the goals—that other people have (at least if they are morally permissible ends). We cannot do this with embryos as they do not have ends of their own. Lacking the kinds of ends that persons have, embryos cannot be given the respect that is due to persons. Nevertheless, they have a significance and moral value that other bodily tissues do not have because they are "potent symbols of human life."<sup>8</sup> In this respect, embryos are like dead bodies, which also do not have interests.<sup>9</sup> Unlike dead bodies, embryos are potential human beings in the sense that, under certain conditions, embryos can develop into human persons. This potential gives them a significance and importance that does not belong to other cells of the body, and imposes restrictions on what it is permissible to do to embryos. We show respect for human embryos by not using them in unimportant or frivolous ways, say, to teach high school biology or to make cosmetics or jewelry. However, respect for embryos does not require refraining from research likely to have significant benefits, such as treating disease and prolonging life.

Embryonic stem cells can be derived from embryos remaining after infertility treatment (sometimes called "spare" embryos), or they can be derived from embryos made solely for research purposes using in vitro fertilization (IVF). Both involve the destruction of embryos. However, the NBAC report distinguished morally between the two. It recommended that an exception should be made to the present ban on federal funding of embryo research to permit funding of research using spare embryos, but it recommended that federal agencies should not fund research involving the derivation of human ES cells from embryos made solely for research purposes<sup>7</sup>:

The primary objection to creating embryos specifically for research is that there is a morally relevant difference between generating an embryo for the sole purpose of creating a child and producing an embryo with no such goal. Those who object to

creating embryos for research often appeal to arguments about respecting human dignity by avoiding instrumental use of human embryos (i.e., using embryos merely as a means to some other goal does not treat them with appropriate respect or concern as a form of human life). (p. v)

Certainly, if one takes the right-to-life view of human embryos, it is morally wrong to create embryos and then destroy them, regardless of the purpose. However, according to the right-to-life view, it is also wrong to create more embryos than will be transferred for implantation; that is, it is wrong to create spare embryos and also wrong to use them in research. Because NBAC does not reject using spare embryos in research, but only creating embryos for the purpose of research, the question is, what justifies this distinction? Here is NBAC's argument<sup>7</sup>:

Embryos that are discarded following the completion of IVF treatment were presumably created by individuals who had the primary intention of implanting them for reproductive purposes. . . . By contrast, research embryos are created for use in research and, in the case of stem cell research, their destruction in the process of research. Hence, one motivation that encourages serious consideration of the "discarded-created" distinction is a concern about instrumentalization—treating the embryo as a mere object—a practice that may increasingly lead us to think of embryos generally as means to our ends rather than as ends in themselves. (p. 56)

The first part of this paragraph simply reiterates the difference between spare and created embryos; it does not explain why there is a moral difference between the two. The last part attempts to provide a justification for a moral difference, but it relies on the view I have argued is conceptually confused: namely, that embryos should be treated as ends in themselves.

If we reject the view that embryos are ends in themselves, what follows? In my view, it makes no moral difference whether one creates an embryo for reproductive purposes but ends up using it in

research, or whether one creates an embryo for the explicit purpose of research. Respect for embryos is demonstrated by restricting their use to important ends. Research that promises to cure disease and save lives clearly qualifies.

The acceptability of this view depends, of course, on one's view of the moral status of the embryo. If embryos are people, there is a moral difference between creating embryos for reproductive purposes and creating them for research purposes. Creating embryos for birth benefits the embryo, whereas creating them for research purposes harms (kills) the embryos to benefit others. But if you reject the idea that preimplantation embryos are the kinds of beings who can be benefited or harmed,<sup>1</sup> creating embryos for research purposes is just as acceptable as creating them for reproductive purposes. Both are valid; neither is frivolous. Therefore, neither contravenes the principle of respect for embryos as a form of human life.

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## **Declaration on the Production and the Scientific and Therapeutic Use of Human Embryonic Stem Cells**

PONTIFICAL ACADEMY FOR LIFE

In this official position statement on embryonic stem cells, the Roman Catholic Church declares that it is morally impermissible to produce or use living human embryos to obtain embryonic stem (ES) cells, to produce and then destroy cloned human embryos to acquire ES cells, or to use ES cells that others have already derived.

### **Ethical Problems**

... Given the nature of this article, the key ethical problems implied by these new technologies are presented briefly, with an indication of the responses which emerge from a careful consideration of the human subject from the moment of conception. It is this consideration which underlies the position affirmed and put forth by the Magisterium of the Church.

The *first ethical problem*, which is fundamental, can be formulated thus: *Is it morally licit to produce and/or use living human embryos for the preparation of ES cells?*

*The answer is negative*, for the following reasons:

1. On the basis of a complete biological analysis, the living human embryo is—from the moment of the union of the gametes—a *human subject* with a well defined identity, which from that point begins its own *coordinated, continuous and gradual development*, such that at no later stage can it be considered as a simple mass of cells.
2. From this it follows that as a “*human individual*” it has the *right* to its own life; and therefore every intervention which is not in favour of the embryo is an act which violates that right. Moral theology has always taught that in the case of “*jus certum tertii*” the system of probabilism does not apply.
3. Therefore, the ablation of the inner cell mass (ICM) of the blastocyst, which critically and irremediably damages the human embryo, curtailing its development, is a *gravely immoral* act and consequently is *gravely illicit*.
4. *No end believed to be good*, such as the use of stem cells for the preparation of other differentiated cells to be used in what look to be promising therapeutic procedures, *can justify an intervention of this kind*. A good end does not make right an action which in itself is wrong.
5. For Catholics, this position is explicitly confirmed by the Magisterium of the Church which, in the Encyclical *Evangelium Vitae*, with reference to the Instruction *Donum Vitae* of the Congregation for the Doctrine of the Faith, affirms: “The Church has always taught and continues to teach that the result of human procreation, from the first moment of its existence, must be guaranteed that unconditional respect which is morally due to the human being in his or her totality and unity in body and spirit: The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his right as a person must be recognized, among which in the first place is the inviolable right of every innocent human being to life.”

The *second ethical problem* can be formulated thus: *Is it morally licit to engage in so-called “therapeutic cloning” by producing cloned human*

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From Pontifical Academy for Life, Vatican City, August 25, 2000.

embryos and then destroying them in order to produce ES cells?

*The answer is negative*, for the following reason: Every type of therapeutic cloning, which implies producing human embryos and then destroying them in order to obtain stem cells, is illicit; for there is present the ethical problem examined above, which can only be answered in the negative.

The *third ethical problem* can be formulated thus: *Is it morally licit to use ES cells, and the differentiated cells obtained from them, which are supplied by other researchers or are commercially obtainable?*

*The answer is negative*, since: prescinding from the participation—formal or otherwise—in the morally illicit intention of the principal agent, the case in question entails a proximate material cooperation in the production and manipulation of

human embryos on the part of those producing or supplying them.

In conclusion, it is not hard to see the seriousness and gravity of the ethical problem posed by the desire to extend to the field of human research the production and/or use of human embryos, even from an humanitarian perspective.

The possibility, now confirmed, of using *adult stem cells* to attain the same goals as would be sought with embryonic stem cells—even if many further steps in both areas are necessary before clear and conclusive results are obtained—indicates that adult stem cells represent a more reasonable and human method for making correct and sound progress in this new field of research and in the therapeutic applications which it promises. These applications are undoubtedly a source of great hope for a significant number of suffering people.

## Euthanasia and Physician-Assisted Suicide

No one escapes death—or the ethical issues that come with it. Advances in medicine now raise the old life-and-death questions anew, force new ones more unsettling, and provoke answers that are disturbing even when plausible. In euthanasia and physician-assisted suicide, the bioethical heart of the matter is the moral rightness of killing or letting die for the good of the patient. The countless disputes on this terrain are often fierce and elemental, for they are the visible signs of deep conflicts among fundamental moral principles and perspectives. Doctors and nurses have sworn to preserve life and relieve suffering—but how to do this when the only way to end suffering is to end life? They understand the need to respect patient autonomy, the right of self-determination—but what should they do when the patient freely chooses to forgo all their best efforts and to embrace extinction? Or if the terminal patient, inching in agony toward destruction, asks them to cut short her torment by killing her with a lethal injection? Or if she begs only for some help in dying by her own hand? Or if she has never expressed a choice about such matters and has slipped into permanent unconsciousness, withering in pain to the inevitable? In such cases, what does beneficence or mercy or respect for autonomy or regard for the sanctity of life demand?

More so than most other issues in bioethics, the morality of euthanasia and physician-assisted suicide is tangled with legal and policy debates. The ethical questions are, of course, logically distinct from these concerns. You are not necessarily guilty of inconsistency if you think some instances of physician-assisted suicide are morally permissible but believe the

practice should never be legalized because legalization might lead to abuses. Or you may, without contradicting yourself, favor legalization to protect patient autonomy but argue that suicide in any form is almost never morally acceptable. In the heat of controversy, these distinctions often get blurred, and a major task of good moral reasoning is to keep the focus sharp.

Nowhere was moral reasoning and conceptual clarity needed more and used less than in the case of Terri Schiavo. In 1990, when she was 26, Schiavo's heart stopped suddenly for reasons that are still unclear; by the time she was resuscitated, she had suffered catastrophic and irreversible brain damage. She was left in what doctors call a persistent vegetative state—wakeful but without consciousness or intentional behavior and almost no chance of significant improvement. In this condition she was sustained for years by food and water injected into her body through tubes. The question arose: Would Terri have wanted to be kept alive like this? Would she have chosen death over this perpetual darkness? She could not answer and had left no written record of her preferences. Her husband, Michael Schiavo, became her legal guardian and claimed that Terri had once told him that she would rather die than be artificially sustained as she eventually was. He said he wanted to have Terri's feeding tube removed so she could die with dignity. Terri's parents would have none of this and insisted that efforts to keep her alive should continue because she could eventually regain consciousness. Across the country people debated the moral questions. Would removing Terri's feeding tube be murder? Would allowing her to die be a permissible act of mercy? All the while,

the legal war between Michael Schiavo and Terri's parents dragged on, with the former seeking permission to disconnect the feeding tube and the latter trying to thwart him. The essential legal issue was who had the legal right to decide Terri Schiavo's fate. The list of people who weighed in on both the legal and moral questions is long and diverse—President George W. Bush, state legislators, members of the U.S. Congress, bioethicists, religious leaders, prolife groups, the governor of Florida, disability rights organizations, and a vast assortment of media commentators. Time after time, state and federal courts sided with Michael Schiavo, and in the end a judge gave permission to remove Terri's feeding tube. Thirteen days after its removal, on March 31, 2005, Terri Schiavo was dead.

In some ways the Schiavo case is unique, but several of its more disturbing features are not. Many compelling end-of-life dramas are being played out right now behind closed hospital doors, away from news cameras, the posturing of politicians, and the gaze of unaffected people. The need for informed moral reasoning to come to terms with the heartbreaking realities is acute—and likely to grow.

### **DECIDING LIFE AND DEATH**

Almost all of the terms used to discuss the morality of killing and letting die are controversial to some degree. Even the meaning of *death*—a seemingly straightforward concept to most people—has been a point of dispute. Nevertheless, some helpful distinctions are possible. For the sake of clarity (and neutrality), **euthanasia** can be characterized as directly or indirectly bringing about the death of another person for that person's sake.<sup>1</sup> The term derives from the Greek words meaning “good death” and evokes the idea that causing or contributing to someone's end may bestow on that person a good. Death is usually considered an evil, perhaps the greatest evil, but many think it can be a blessing if it spares someone from a slow, horrific dying or a hopeless, vegetative sleep.

Many philosophers maintain that there are two forms of euthanasia. **Active euthanasia** is said to involve performing an action that directly causes someone to die—what most people think of as “mercy killing.” Giving a patient a lethal injection to end his suffering, then, is a case of active euthanasia. **Passive euthanasia** is allowing someone to die by *not* doing something that would prolong life. It includes removing a patient's feeding tube or ventilator, failing to perform necessary surgery, and refraining from giving life-saving antibiotics. The distinction between the two is thought to be essentially this: Active euthanasia is *killing*, but passive euthanasia is *letting die*.

To some people, this conceptual border between active and passive euthanasia is crucial for assessing the morality of euthanasia. They point out that whereas letting a patient die is sometimes morally permissible, deliberately and directly killing a patient is always wrong. The former practice is legal and officially endorsed by the medical profession; the latter is illegal and officially condemned. The American Medical Association sanctioned this dichotomy in a 1973 policy statement:

The intentional termination of the life of one human being by another—mercy killing—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association. . . . The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or immediate family.<sup>2</sup>

For many (including most physicians), passive euthanasia may be moral, but active euthanasia is not.

But not everyone thinks this active-passive distinction makes sense. Some argue that there is no morally significant difference between mercifully killing a patient and mercifully letting the patient die. In both situations the doctor causes the patient's death—by either intentionally doing something in the one instance or

intentionally refraining from doing something in the other. Thus an act of euthanasia may be morally right or wrong, but the rightness or wrongness does not depend purely on this active-passive divide. Moreover, in practice, distinguishing examples of active and passive euthanasia may not be as easy as some think. The usual view is that passive euthanasia can sometimes be performed by disconnecting a dying patient's feeding tube and ventilator. But this event can also be seen as an instance of performing an action that directly causes someone to die—that is, active euthanasia.

The moral permissibility of euthanasia is linked to the concept of patient consent. Thus, bioethicists talk about euthanasia that is voluntary, nonvoluntary, or involuntary. **Voluntary euthanasia** refers to situations in which competent patients voluntarily request or agree to euthanasia, communicating their wishes either while competent or through instructions to be followed if they become incompetent (if they fall into a persistent vegetative state, for example). Patients can indicate what is to be done in incompetence by formulating an advance directive—usually a living will or a document designating a surrogate, or proxy, to act on their behalf. **Nonvoluntary euthanasia** is performed when patients are not competent to choose death for themselves and have not previously disclosed their preferences. (Incompetent patients include not only incapacitated adults but infants and small children as well.) In these circumstances, the patient's family, physician, or other officially designated persons decide for the patient. **Involuntary euthanasia** is bringing about someone's death against her will or without asking for her consent while she is competent to decide. It is illegal and considered morally impermissible by both those who approve and disapprove of euthanasia. It is therefore generally left out of moral debates, except perhaps in slippery-slope arguments warning that voluntary or nonvoluntary euthanasia will inevitably become involuntary.

Combining the terms *active*, *passive*, *voluntary*, and *nonvoluntary*, we can identify four

kinds of euthanasia that have been the main focus in bioethics:

- 1. Active voluntary**—Directly causing death (mercy killing) with the consent of the patient
- 2. Active nonvoluntary**—Directly causing death (mercy killing) without the consent of the patient
- 3. Passive voluntary**—Withholding or withdrawing life-sustaining measures with the consent of the patient
- 4. Passive nonvoluntary**—Withholding or withdrawing life-sustaining measures without the consent of the patient

The starker contrast among these is generally thought to be between active and passive euthanasia. Active euthanasia (whether voluntary or nonvoluntary) is unlawful, while passive euthanasia (both voluntary and nonvoluntary) is legal provided certain conditions are met. Judicial rulings have firmly established a right of patients to refuse treatment—and thus to have life-sustaining treatment withheld or withdrawn—even though the patient dies as a result. Withdrawing or withholding treatment from an incompetent patient is generally legal if the patient has left instructions or if an appropriate person can be chosen to make the necessary decisions. Contemporary moral debate centers more on active than on passive euthanasia. There is considerable agreement about the moral rightness of allowing a patient to die but intense controversy about the permissibility of deliberately causing a patient's death (by administering a lethal injection, for example), whether the act is considered voluntary or nonvoluntary.

Recently, disputes over euthanasia have raged alongside arguments about **physician-assisted suicide**, in which a patient takes his own life with the aid of a physician. In a typical scenario, a patient asks the physician for help in committing suicide, the physician assists the patient by prescribing lethal doses of drugs or explaining a method of suicide, and the patient—not the physician—performs the final

**LEGAL BRIEF****Euthanasia and Assisted Suicide:  
Major Developments**

**1990** In *Cruzan v. Director, Missouri Department of Health*, the U.S. Supreme Court recognizes the right of patients to refuse treatment (essentially a “right to die”) and finds constitutional justification for living wills and surrogates who make medical decisions for incompetent patients.

**1994** Oregon passes the Death With Dignity Act, legalizing the use of physician-assisted suicide under specific conditions. It permits doctors to prescribe drugs that terminally ill patients can use to commit suicide.

**1997** In separate cases—*Washington v. Glucksberg* and *Vacco v. Quill*—the Supreme Court rules that there is no constitutional right to physician-assisted suicide but notes that each state may establish its own policy on the issue. It explicitly acknowledges a distinction between assisted suicide and the withdrawal of life-sustaining treatment.

**2001** U.S. Attorney General John Ashcroft tries to thwart the Oregon right-to-die law by authorizing the Drug Enforcement Agency to act against physicians prescribing drugs for assisted suicide.

**2006** The Supreme Court rules that the Justice Department (headed by Ashcroft and later Alberto Gonzales) had no authority to interfere with physicians acting under the Oregon law.

**2008** Through a referendum vote, Washington becomes the second state to legalize physician-assisted suicide.

**2008** A district court ruling in the case of *Baxter v. State of Montana* asserts that Montana residents have a right to physician-assisted suicide, thereby legalizing the practice in a third state. In 2009 the Montana Supreme Court affirmed the earlier court ruling.

**2013** Vermont becomes the fourth state to legalize physician-assisted suicide. The Vermont legislature passed the “End of Life Choices” bill, and the governor signed it into law.

**2015** The New Mexico Court of Appeals invalidates a lower-court ruling that had legalized physician-assisted suicide. The Court asserted that “aid in dying is not a fundamental liberty interest under the New Mexico Constitution.”

**2015** California becomes the fifth state to legalize physician-assisted suicide. Governor Jerry Brown signed into law a bill permitting physicians to prescribe fatal doses of drugs to help terminally ill patients end their lives.

**2016** Colorado passes the “End of Life Options Act,” and the “Death with Dignity Act of 2016” becomes law in Washington, DC. Both laws legalize physician-assisted suicide.

**2018** Hawaii becomes the seventh state to enact an assisted dying law.

**2019** New Jersey becomes the eighth state to enact an assisted dying law, and Maine becomes the ninth.

**2021** New Mexico becomes the tenth state to enact an assisted dying law.

act that causes death. In contrast, in active euthanasia the physician performs the final act. Many argue that this difference in the ultimate cause of death implies a difference in moral responsibility. In physician-assisted suicide, the patient is thought to bear ultimate moral responsibility for the taking of life. Others doubt

that any distinction in ultimate causes can amount to a moral difference. Thus, they contend that physician-assisted suicide and active voluntary euthanasia are morally equivalent. What is the moral difference, they ask, between a physician helping a patient die by (1) administering a lethal injection upon request or

**IN DEPTH****ASSISTED SUICIDE: WHAT DO DOCTORS THINK?**

Results from a 2014 survey of 21,000 physicians (17,000 U.S. and 4,000 European):

Should physician-assisted suicide be allowed (U.S. physicians)?

<b>Yes</b>	<b>No</b>	<b>It depends</b>
54%	31%	15%

Should physician-assisted suicide be allowed (European physicians)?

<b>Yes</b>	<b>No</b>	<b>It depends</b>
41%	41%	18%

Would you give life-sustaining therapy if you considered it futile (U.S. and European)?

<b>Yes</b>	<b>No</b>	<b>It depends</b>
19%	35%	46%

Would you go against a family's wishes and continue treating a patient whom you felt had a chance to recover (U.S. and European)?

<b>Yes</b>	<b>No</b>	<b>It depends</b>
22%	28%	50%

Leslie Kane, *Medscape Ethics Report 2014*, December 16, 2014, <https://www.medscape.com/features/slideshow/public/ethics2014-part1#21>. Sample size: 21,531 physicians across 25+ specialties, September 18 through November 12, 2014; margin of error: +0.72 (U.S. sample), +1.55 (European sample); 95% confidence level.

(2) prescribing a lethal dose of medications upon request?

The American Medical Association has denounced physician-assisted suicide as unethical and inconsistent with physicians' duty to promote healing and preserve life. Surveys suggest, however, that many doctors support the use of physician-assisted suicide, and over 70 percent of adults believe it should be legal in cases of terminal illness or incurable disease with severe pain. To date, it is legal in Washington, DC, and ten states: California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington. The U.S. Supreme Court has ruled that states may legalize or prohibit it as they see fit.

Part of the difficulty of making everyday moral decisions about end-of-life situations is that death itself is not so easy to define. Traditionally death was understood to occur when breathing and heartbeat ceased. A person who wasn't breathing and had no heartbeat was dead. But thanks to modern medicine, machines can maintain someone's breathing and heartbeat

indefinitely—even though there is permanent loss of all brain function. Heart and lungs keep going, but the individual is irreversibly brain-dead and can remain that way for decades. By the traditional standard, the individual is alive, but this seems counterintuitive.

We seem to need a new concept of death—an important consideration since any notion we adopt would dramatically influence our judgments about morally permissible behavior toward the living and the dead. If we judge an individual to be dead, then we would presumably think her no longer a person. If she is no longer a person, then it would seem to be permissible to disconnect all life support, harvest organs from the body for transplant, or prepare the body for burial. But if, despite appearances, she is still a person, wouldn't doing any of these things be murder? If so, those who perform these acts would be morally and legally culpable.

In 1968 a committee at Harvard Medical School formulated a new way of conceiving death, a perspective that has since become the

standard in legal and medical matters. According to this *whole brain* view of death, an individual should be judged dead when all brain functions permanently cease. Brain death means genuine death. But several experts take issue with this view. They point out that some physiological processes such as respiration are partly independent of brain functions, and individuals that many would regard as dead (those in persistent vegetative states, for example) may have some residual brain activity. By the whole brain standard, Terri Schiavo, being wakeful but lacking consciousness, was alive until all brain activity stopped. To some, this consequence makes sense; to others, it seems odd. A better notion of death, some argue, is the *higher brain* view, which says that an individual should be considered dead when the higher brain operations responsible for consciousness permanently shut down. The thought behind this standard is that individuals are dead when they are no longer persons, regardless of what physiological activity persists, and individuals are no longer persons when consciousness permanently terminates. By the higher brain criterion, Terri Schiavo died when her higher brain functions permanently stopped, even though other brain activity continued for years. Again, some would find this judgment plausible; others, bizarre.

### AUTONOMY, MERCY, AND HARM

Let us examine the two main flashpoints in end-of-life bioethics: active voluntary euthanasia and physician-assisted suicide. We can focus mostly on the former since arguments for and against it are largely relevant to the latter.

What arguments might be offered to support active voluntary euthanasia? The strongest one derives from the principle of autonomy—a person's inherent right of self-determination. Proponents say that respecting autonomous persons means respecting their autonomous choices, including the choice to end their lives in their own way. Their right is preeminent, its only limit

marking the point where their choices bring harm to others. As one philosopher explains it,

People have an interest in making important decisions about their lives in accordance with their own conception of how they want their lives to go. In exercising autonomy or self-determination, people take responsibility for their lives; since dying is a part of life, choices about the manner of their dying and the timing of their death are, for many people, part of what is involved in taking responsibility for their lives. Many people are concerned about what the last phase of their lives will be like, not merely because of fears that their dying might involve them in great suffering, but also because of the desire to retain dignity and as much control over their lives as possible during this phase. . . . There is no single, objectively correct answer as to when, if at all, life becomes a burden and unwanted. But that simply points up the importance of individuals being able to decide autonomously for themselves whether their own lives retain sufficient quality and dignity to make life worth living.<sup>3</sup>

Proponents believe that this right to die, though strong, does not necessarily compel others. Almost no one who seriously urges the autonomy argument thinks that having a right to die forces a duty on others (physicians, for example) to help in the dying.

Another major argument for active euthanasia appeals to the principle of beneficence, or mercy: If we are in a position to relieve the severe suffering of another without excessive cost to ourselves, we have a duty to do so. To refuse would be cruel, inhumane, and wrong. The argument would run something like this: If a competent, hopelessly ill patient in unrelieved agony requests help to be put out of his misery, we may have a duty to bring about his death. As bioethicist Dan W. Brock says,

When there is a life-sustaining treatment that, if forgone, will lead relatively quickly to death [passive euthanasia], then doing so can bring an end to these patients' suffering without recourse to [active] euthanasia. For patients receiving no such

treatment, however, [active] euthanasia may be the only release from their otherwise prolonged suffering and agony. This argument from mercy has always been the strongest argument for euthanasia in those cases to which it applies.<sup>4</sup>

By these lights, active euthanasia is sometimes better than passive, for withholding or withdrawing treatment from a dying patient in unspeakable pain may only draw out his agony.

The argument from beneficence taps into very deep intuitions about the point of mercy killing. Consider this variation of a twice-told tale in bioethics: A truck overturns on the highway, pinning the screaming driver under the cabin as the wreckage bursts into flames. He is burning alive, and there is no hope of pulling him out of the fire. To avoid slow incineration, he begs the lone onlooker to smash him in the head with a rock to kill him immediately. Should the onlooker oblige him?

A common response to such horrific suffering, at least in cases of medical euthanasia, is to insist that the torment can almost always be relieved without resort to lethal means. It is likely that most patients who request euthanasia because of unrelenting pain and deep depression can get relief through improved pain treatment and enlightened psychiatric care. Therefore, euthanasia or physician-assisted suicide is unnecessary. But many bioethicists are not convinced. They argue that there will always be some patients whose pain cannot be eased by any means short of death, or who have no access to adequate palliative care, or whose suffering is neither physical nor psychiatric but social, philosophical, or spiritual. The main cause of the suffering may be loss of dignity or independence or concern for loved ones who will be left behind.

Those who oppose active voluntary euthanasia give moral weight to autonomy and beneficence but argue that other considerations undermine the pro-euthanasia arguments. One such matter is the supposed moral difference between killing and letting die, or between active and passive euthanasia. The thought is that

killing a person is morally worse than letting that person die. Killing is wrong; letting die is permissible. Thus, giving a patient a lethal injection is wrong, but unplugging his feeding tube or ventilator may be morally acceptable. Some think that killing is morally worse because it involves a person causing the death of another person (murder), while letting die is a matter of allowing nature to do its work. In the first, a person kills; in the second, a disease kills.

But critics deny that there is a morally significant difference between killing and letting die. If there is no difference, they can argue that since passive euthanasia is permissible, and it is morally equivalent to active euthanasia, active euthanasia must be permissible as well. James Rachels tries to demonstrate this no-difference thesis in a famous thought experiment about parallel cases:

In the first case, Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening while the child is taking his bath, Smith sneaks into the bathroom, drowns the child, and arranges things so that it will look like an accident.

In the second, Jones also stands to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in, planning to drown the child in his bath. However, as he enters the bathroom Jones sees the child slip, hit his head and fall face down in the water. Jones is delighted; he stands by, ready to push the child's head back under if it is necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally," as Jones watches and does nothing.

Now Smith killed the child, while Jones merely let the child die. That is the only difference between them. Did either man behave better, from a moral point of view?<sup>5</sup>

Rachels concludes that any dissimilarity between killing and letting die does not make a moral difference.

Winston Nesbitt rejects Rachels's no-difference view, arguing that the real reason Smith

and Jones seem equally reprehensible is that they are both *prepared to kill*. If we assumed that Jones is ready to let his cousin die but is not prepared to kill him, we would judge Jones less harshly than Smith. If this is correct, Nesbitt says, then Rachels fails to make his case.<sup>6</sup>

Some argue against active voluntary euthanasia by advancing another kind of distinction—between *intending* someone's death and *not intending but foreseeing* it. This difference is emphasized in the doctrine of double effect, an essential feature of Roman Catholic ethics (see Chapter 2). Applying the distinction to euthanasia, we get this principle: It is wrong to intentionally harm someone (cause her death) to produce a good result (release from suffering, for example), but it is permissible to do something intended to produce a good result (release from suffering), even if the action

leads to unintended but foreseen harm (her death). The difference is that in the former, a bad thing is directly intended; in the latter, a bad thing is not intended, only foreseen. By this formula, it would be wrong for a physician to try to relieve the chronic misery of a terminally ill patient by deliberately giving her high doses of morphine to hasten her death. But it would be morally acceptable for that physician to give the patient the same amount of morphine with the sole intention of easing her pain, even though the physician foresees that she will die as a result. (Giving a dying, suffering patient extremely high doses of analgesics to the point of unconsciousness and accelerated death is known as terminal sedation; provided the patient consents, it is legal and generally considered morally permissible in medical practice.)

### IN DEPTH

#### OREGON'S DEATH WITH DIGNITY ACT

On March 6, 2020, the Oregon Health Authority released the annual report for the 22nd year of implementation of the Oregon Death with Dignity Act, the world's first assisted dying statute.

In 2019, 112 Oregon physicians wrote 290 prescriptions to dying Oregonians who qualified for the Act; 188 people died using the medications obtained under the law.

Similar to previous years, most patients

- were 65 years or over (75 percent), with the median age of 74;
- had cancer (68 percent);
- were on hospice at the time of death (90 percent);
- died at home (90 percent);
- had some form of health insurance (99 percent).

Consistent with past reports, the most frequently reported end-of-life concerns were loss of autonomy (87%), decreasing ability to participate in activities that made life enjoyable (90%), and loss of dignity (72%).

During 2019, the estimated rate of deaths under the law was 51.9 per 10,000 total deaths in the state.

Since the first Oregonian took medication under the law in 1998, a total of 2,518 people have received prescriptions under the Act, of whom 1,657, or 66 percent, have died from ingesting the medications.

These figures continue to underscore not only that only a small number of people use the law but also that more than one-third of those who received the medication took it, finding great comfort in merely knowing it was available to them.

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From Death with Dignity, "Latest Report on Oregon Death with Dignity Act Shows Law Continues to Work as Intended," March 11, 2020, <https://deathwithdignity.org/news/2020/03/2019-report-on-oregon-death-with-dignity-act/>.

Many question whether in practice this intended/unintended distinction can always be drawn as clearly as proponents assume. For example:

In the case of euthanasia, just as in pain and symptom control, critics maintain, the physician's end may be the good one of relieving the patient's suffering. In neither case would death be wanted by the patient or the physician if the suffering could be avoided without it, but both patient and physician may be prepared to accept the patient's earlier death in order to relieve his or her suffering. Although the patient's death in the case of euthanasia may be the necessary means taken in the causal path to relief of suffering, it is the unavoidable side-effect following upon the relief of the patient's suffering in the causal path taken to achieve pain and symptom control.<sup>7</sup>

Others are skeptical of the intended/unintended principle itself. Their view is that even if it is wrong to intentionally do harm to bring about good, directly intending a patient's death may still be permissible because to her, *death may not be a harm*. If her pain is unbearable and untreatable, and she makes an autonomous request to die, then active euthanasia may be a blessing—and therefore within ethical bounds.

Probably the most straightforward arguments against active euthanasia and physician-assisted suicide are appeals to bad consequences. They make their case at the policy level, asking us to consider the ramifications of legalizing or widely accepting these practices. Often their logical shape is the slippery slope: Allowing active euthanasia or physician-assisted suicide will inevitably lead to heinous extensions or perversions of the original practices. The usual worries are that legalization will lead quickly from active voluntary euthanasia to active non-voluntary euthanasia to outright involuntary forms of killing. Or that physicians or families will start pushing unwilling or unsure patients toward assisted suicide or voluntary euthanasia. Or that physicians and nurses will become increasingly willing to give lethal injections to

people who are elderly, mentally ill, chronically ill, uninsured, and disabled. As one philosopher explains it,

[E]uthanasia as a policy is a slippery slope. A person apparently hopelessly ill may be allowed to take his own life. Then he may be permitted to deputize others to do it for him should he no longer be able to act. The judgment of others then becomes the ruling factor. Already at this point euthanasia is not personal and voluntary, for others are acting "on behalf of" the patient as they see fit. This may well incline them to act on behalf of other patients who have not authorized them to exercise their judgment. It is only a short step, then, from voluntary euthanasia (self-inflicted or authorized), to directed euthanasia administered to a patient who has given no authorization, to involuntary euthanasia conducted as part of a social policy.<sup>8</sup>

The key premise in most slippery-slope arguments, then, is an empirical claim that a policy permitting active voluntary euthanasia or assisted-suicide will lead to unjustified killing (involuntary euthanasia, for example). Much of the debate therefore has centered on whether any good empirical evidence supports such a premise. Unfortunately, scientific research on the issue has been limited, with most of it focused on the Netherlands (where physician-assisted suicide and active voluntary euthanasia have been legal since 2002) and on Oregon (where a law permitting physician-assisted suicide was passed by Oregon voters in 1994 but was not green-lighted until the Supreme Court decision of 2006). One question of particular interest has been whether vulnerable groups—the elderly, the poor, uninsured people, racial and ethnic minorities, people with psychiatric illness, women, people with little education, and others—have been at greater risk of physician-assisted death. Research in both Oregon and the Netherlands has found little or no evidence that this is the case. Opponents of legalization point to all the instances of Dutch physicians performing active euthanasia without the patient's consent (approximately 1,000 per year, or about

## IN DEPTH

### END-OF-LIFE DECISIONS IN THE NETHERLANDS

In the Netherlands, physician-assisted suicide and euthanasia (where a physician administers lethal medication explicitly requested by the patient) has been legal since 2002. This help in dying is permitted only for patients who are “suffering unbearably” without hope of relief. Physicians who investigated end-of-life decision-making from 1990 to 2015 reported the following:

- The number of patients involved rose from 5,197 in 1990 to 7,761 in 2015.
- In 1990, 1.7 percent of all deaths were the result of euthanasia; in 2015, 4.5 percent.
- In 2015, physician help in dying was requested by 8.3 percent of all deceased persons.

- The ending of life without an explicit request from patients in this 25-year-period decreased from 0.8 percent to 0.3 percent.
- The use of morphine as “terminal sedation” increased from 19 percent to 36 percent.
- A 2015 survey of physicians showed that “92% of the patients who received physician assistance in dying had a serious somatic disease; 14% had an accumulation of health problems related to old age, and a small minority had early-stage dementia (3%) or psychiatric problems (3%).”
- “About half of all requests for physician assistance in dying were granted in 2015. Such assistance is provided predominantly to patients with severe disease but increasingly involves older patients and those with a life expectancy of more than a month.”

From Agnes van der Heide, Johannes J. M. van Delden, and Bregje D. Onwuteaka-Philipsen, “End-of-Life Decisions in the Netherlands over 25 Years,” *New England Journal of Medicine* 377 (August 3, 2017): 492–94.

0.8 percent of all deaths nationwide). Proponents reply that most of those patients were already near death or had become incompetent after initially asking for euthanasia or that the euthanasia was passive, consisting of withholding or withdrawing treatment. Most of all, they emphasize that the few studies done so far do not demonstrate that legalization has significantly multiplied the cases of nonvoluntary euthanasia. Dutch authorities have reported that data gathered so far indicate that physician misconduct in euthanasia cases is extremely rare, despite rumors in the United States about rampant involuntary euthanasia committed by Dutch doctors.

The best minds on all sides of these debates recognize the need for better evidence to assess the slipperiness of the slippery slope. But they also know that the *mere possibility* of abuses arising from allowing euthanasia or assisted suicide is not in itself a good reason to ban the

practices. If merely possible dangers or abuses justified prohibiting a practice, then we would have good reason to disallow advance directives, surrogate decision-making, and any kind of voluntary passive euthanasia. For a slippery-slope argument to work, there must be good evidence that the bad consequences of taking the first step are probable and serious.

## APPLYING MAJOR THEORIES

Utilitarians can consistently adopt different views on active euthanasia and assisted suicide depending on how they define the good to be maximized, whether their moral focus is acts or rules, and how much importance they give to self-determination. Classic utilitarianism defines the good as happiness and would therefore judge the issues by how much happiness various actions might produce for everyone involved. From this perspective, euthanasia or assisted

**IN DEPTH**

## PHYSICIAN-ASSISTED SUICIDE AND PUBLIC OPINION

When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient's life by some painless means if the patient and his or her family request it?

	<b>Yes, should</b>	<b>No, should not</b>
<b>All Adults</b>	72%	27%
<b>Gender</b>		
Men	79%	20%
Women	65%	34%
<b>Age</b>		
18–29	85%	15%
30–49	72%	28%
65 and older	65%	34%

suicide for someone suffering horrible, inescapable pain might be permissible because ending life would bring about the most net happiness. Of course, the calculations would have to include other factors such as the psychological, social, and financial impact on the patient's family, friends, and caregivers. With everything factored in, the utilitarian answer could easily come out against euthanasia.

However, many utilitarians (following John Stuart Mill) think that there's more to consider in making moral judgments than just net happiness. As utilitarian philosopher Peter Singer says,

Many people prefer to live a life with less happiness or pleasure in it, and perhaps even more pain and suffering, if they can thereby fulfill other important preferences. For example, they may choose to strive for excellence in art, or literature, or sport, even though they know that they are unlikely to achieve it, and may experience pain and suffering in the attempt.<sup>9</sup>

Those in utilitarianism's camp who take this view are known as *preference utilitarians*,

### Church Attendance

Attend church weekly	37%	60%
Attend church seldom/never	86%	14%

Regardless of whether or not you think it should be legal, please tell me whether you personally believe that in general it is morally acceptable or morally wrong. How about doctor-assisted suicide?

<b>Morally acceptable</b>	<b>Morally wrong</b>
54%	42%

Gallup Poll, "America's Strong Support for Euthanasia Persists," Megan Brenan. Results are based on telephone interviews conducted May 1–10, 2018, with a random sample of 1,024 adults aged 18 and older, living in all 50 U.S. states and the District of Columbia.

holding that right actions are those that satisfy more of a person's preferences overall. To them, killing is bad when it prevents someone from satisfying his own preferences; it can be good (as in euthanasia) when more of the person's future preferences will be frustrated than satisfied. According to Singer,

[I]f the goods that life holds are, in general, reasons against killing, those reasons lose all their force when it is clear that those killed will not have such goods, or that the goods they have will be outweighed by bad things that will happen to them. When we apply this reasoning to the case of someone who is capable of judging the matter, and we add Mill's view that individuals are the best judges of their own interests, we can conclude that this reason against killing does not apply to a person who, with unimpaired capacities for judgment, comes to the conclusion that his or her future is so clouded that it would be better to die than to continue to live. Indeed, the reason against killing is turned into its opposite, a reason for acceding to that person's request.<sup>10</sup>

## CLASSIC CASE FILE

**Nancy Cruzan**

In the 1990 case of *Cruzan v. Director, Missouri Department of Health*, the U.S. Supreme Court issued its first momentous ruling involving an individual's "right to die." The question was whether a feeding tube could be removed from a young woman named Nancy Cruzan, who had been left in a persistent vegetative state after a terrible car crash.

On January 11, 1983, Nancy Cruzan's car overturned on an icy road in Missouri, flinging her into a ditch and stopping her heart. By the time paramedics restarted it, her brain had been oxygen-deprived for at least 15 minutes. The resulting brain damage was profound and permanent. So at age 25 she fell into a persistent vegetative state, a benighted condition of minimal brain activity without consciousness or purposeful behavior. "The vegetative state," says an expert panel, "is a clinical condition of complete unawareness of the self and the environment. . . . Recovery from a nontraumatic persistent vegetative state after three months is exceedingly rare."<sup>12</sup> Nancy lingered in that state for years, her body coiled into a rigid fetal position, nourished only by a surgically implanted feeding tube.

After three years of hoping that Nancy would somehow recover, her parents finally asked that the feeding tube be removed so she could die in peace. "You try your damnedest as long as there's hope," said Nancy's father, "and then when there is none anymore, you must let her go."

But authorities in the state of Missouri saw things differently. They sought to block the removal of Nancy's feeding tube. The Missouri Supreme Court said that the state has an extremely strong interest in preserving life and that the Cruzans may not disconnect their daughter's feeding tube without "clear and convincing evidence" of what Nancy would have

wanted. At one time she had mentioned to a friend that she would not want to be kept alive like a "vegetable," but she had left no living will or other explicit instructions.

The Cruzans appealed to the U.S. Supreme Court, and in June 1990 the Court delivered its far-reaching decision in its first right-to-die case. The Court held that Missouri had a legitimate interest in demanding "clear and convincing evidence" of an incompetent individual's preferences. By sanctioning this strict standard of evidence, the Court effectively ruled against the Cruzans. But in making its decision, it also laid out some weighty principles pertaining to a person's end-of-life choices.

The Court found that competent individuals have a constitutionally guaranteed "liberty interest" in refusing medical treatment, even when refusing could bring about their death. And for the first time, it acknowledged that if a person became incompetent, this right could be exercised through a living will or by a designated surrogate. States could still restrict this liberty interest, however, if a person's refusal of treatment was not stated clearly or strongly enough.

As part of its case, the state argued that there was a difference between withdrawing medical treatment and withdrawing food and fluids. But the Supreme Court recognized no such distinction.

A few months after the Court's ruling, Missouri said it would stop opposing the Cruzans' efforts, and a Missouri judge declared that the evidence of Nancy's intent was sufficiently convincing. In December 1990 he ordered her feeding tube removed.

On December 26, 1990, at the age of 33 and nearly eight years after her accident, Nancy Cruzan died peacefully.

Rule-utilitarian approaches can lead to positions both favoring and opposing euthanasia and assisted suicide. Most slippery-slope arguments are essentially rule-utilitarian, asserting that a general policy of authorized killing will, step by step, take society down a path to awful consequences. The outcomes to be avoided are many, including increases in nonvoluntary or involuntary euthanasia, erosion of respect for the medical profession, and a weakening of society's abhorrence of homicide. Some also argue on rule-utilitarian grounds *for* a general policy, citing relief of suffering as the most obvious benefit.

The natural law view in Roman Catholicism condemns active and passive euthanasia, though the condemnation comes with qualifications. Directly intending to bring about a person's death to end suffering is prohibited, but the doctrine of double effect permits actions that have unintended but fatal results. As discussed earlier, the doctrine would not allow doctors to give high-dose analgesics to put patients out of their misery, but it would sanction their doing the same thing with the intention of easing pain though death is foreseen. In addition, under Catholic principles there is no obligation to use every means possible to prolong a person's life in every case. The Vatican declares:

When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.<sup>11</sup>

What is clear in Kant's theory is that suicide is prohibited because it treats persons as mere things and obliterates personhood. Kant asserts that "the rule of morality does not admit of [suicide] under any condition because it degrades human nature below the level of animal nature and so destroys it." It is also apparent on Kant's view that competent persons must not be killed or permitted to die. But it is not obvious what

Kant's opinion would be of individuals no longer regarded as persons because they have lapsed into a persistent vegetative state. Would respect for persons demand that they be kept alive at all costs—or that we perform nonvoluntary euthanasia to allow them to die with dignity?

### KEY TERMS

- active euthanasia
- euthanasia
- involuntary euthanasia
- nonvoluntary euthanasia
- passive euthanasia
- physician-assisted suicide
- voluntary euthanasia

### SUMMARY

Euthanasia is directly or indirectly bringing about the death of another person for that person's sake. A common distinction is that active euthanasia involves performing an action that directly causes someone's death, while passive euthanasia is allowing someone to die by not doing something to prolong life. Voluntary euthanasia is performed when competent patients request or agree to it; nonvoluntary euthanasia, when patients are not competent to choose for themselves and have not previously disclosed their preferences. Involuntary euthanasia, both illegal and morally impermissible, is bringing about someone's death against her will or without asking for her consent. In physician-assisted suicide a patient takes his own life with the help of a physician.

Death traditionally has been understood as the cessation of breathing and heartbeat, but medical advances have rendered this notion problematic. The whole brain view is now the standard in legal and medical matters. It says that an individual should be judged dead when all brain functions permanently stop. Many experts object to this definition because some physiological processes such as respiration are partly independent of brain functions, a fact that would suggest on the whole brain view that individuals in persistent vegetative states with

some brain activity must be considered alive. An alternative notion is the higher brain standard, which asserts that individuals are dead when the higher brain functions responsible for consciousness permanently close down. This view implies that those in persistent vegetative states whose higher brain functions have irreversibly ceased are dead.

The main argument for the moral permissibility of active voluntary euthanasia is an appeal to autonomy. It contends that respecting people's inherent right of self-determination means respecting their autonomous choices about ending their lives. Another major argument appeals to the principle of beneficence, or mercy: If we are in a position to relieve the severe suffering of another without excessive cost to ourselves, we have an obligation to do so.

An important argument against active voluntary euthanasia appeals to the supposed moral difference between killing and letting die. Killing is thought to be worse than letting die, so giving a patient a lethal injection to effect an easy death is wrong, but disconnecting his feeding tube may be permissible. Critics argue that there is no morally significant difference between these two. Those opposed to voluntary euthanasia make a related distinction between intending someone's death and not intending but foreseeing it. The former is said to be wrong; the latter, permissible. Many are skeptical of this distinction as well.

Very often cases against active euthanasia and physician-assisted suicide are built on slippery-slope arguments, which contend that allowing these practices would inevitably lead to abuses, most notably unjustified killing. Typically, both those who make these arguments and those who criticize them appeal to empirical data on the legalized use of euthanasia or physician-assisted suicide in Oregon or the Netherlands. But the data are sparse and subject to much debate, leaving the key premise in most slippery-slope arguments weak.

## Cases for Evaluation

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### CASE I

#### Doctor-Aided Suicide and “Vulnerable Groups”

(*ScienceDaily*)—Contrary to arguments by critics, a University of Utah-led study found that legalizing physician-assisted suicide in Oregon and the Netherlands did not result in a disproportionate number of deaths among the elderly, poor, women, minorities, uninsured, minors, chronically ill, less educated, or psychiatric patients.

Of 10 “vulnerable groups” examined in the study, only AIDS patients used doctor-assisted suicide at elevated rates.

“Fears about the impact on vulnerable people have dominated debate about physician-assisted suicide. We find no evidence to support those fears where this practice already is legal,” says the study’s lead author, bioethicist Margaret Battin, a University of Utah distinguished professor of philosophy and adjunct professor of internal medicine.

The study will be published in the October 2007 issue of the *Journal of Medical Ethics*. Battin conducted the research with public health physician Agnes van der Heide, of Erasmus Medical Center, Rotterdam; psychiatrist Linda Ganzini at Oregon Health & Science University, Portland; and physician Gerrit van der Wal and health scientist Bregje Onwuteaka-Philipsen, of the VU University Medical Center, Amsterdam. Van der Wal currently is inspector general of the Netherlands Health Care Inspectorate, which advises that nation’s health minister.

The research deals with the so-called “slippery-slope” argument that has been made by critics of doctor-assisted suicide and has raised concern even among proponents. The argument is that by making it legal for medical doctors to help certain patients end their lives, vulnerable people will die in disproportionately large numbers.

“Would these patients be pressured, manipulated or forced to request or accept physician-assisted

dying by overburdened family members, callous physicians, or institutions or insurers concerned about their own profits,” the researchers asked.

The American College of Physicians said in 2005 that it was “concerned with the risks that legalization [of physician-assisted suicide] posed to vulnerable populations, including poor persons, patients with dementia, disabled persons, those from minority groups that have experienced discrimination, those confronting costly chronic illnesses, or very young children.” . . .

Battin’s team analyzed data on assisted suicide and voluntary active euthanasia in the Netherlands during 1985–2005—data taken from four government studies and several smaller ones. They analyzed Oregon Department of Human Services annual reports for 1998–2006, and surveys of physicians and hospice professionals.

The findings fell into three categories, based on the strength of the data. The researchers found:

- Direct evidence that elderly people, women, and uninsured people do not die in disproportionate numbers where physician-assisted death is legal, but AIDS patients do. (The insurance data is from Oregon only; everyone is insured in the Netherlands.)
- Evidence that is partly direct and partly inferred showing that physician-assisted death does not kill disproportionate numbers of people who are poor, uneducated, racial and ethnic minorities, minors, or people with chronic physical or mental disabilities or chronic but not terminal illnesses.
- Evidence that is based on inference or that is partly contested showing that people with psychiatric illness—including depression and Alzheimer’s disease—are not likely to die in lopsided numbers.

“Those who received physician-assisted dying . . . appeared to enjoy comparative social, economic, educational, professional and other privileges,” the researchers write.

The researchers noted that in both Oregon and the Netherlands, people who received a doctor’s

help in dying averaged 70 years old, and 80 percent were cancer patients.\*

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*Suppose the data of this study are accurate. Would they show that all slippery-slope arguments against physician-assisted suicide are unsuccessful? Suppose the study proved that legalization did harm vulnerable populations. Would that finding support the conclusion that physician-assisted suicide should not be legalized under any circumstances? What might someone who is opposed to legalization say about this study? Or someone who favors legalization? How does the news of this study affect your own views on legalization? Give reasons for your answer.*

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\*“Doctor-Aided Suicide: No Slippery Slope, Study Finds,” *ScienceDaily*, September 29, 2007, <http://www.sciencedaily.com/releases/2007/09/070926191348.htm>.

## CASE 2

### Suicide Pacts Among Friends

(*London Telegraph*)—Jenni Murray, the presenter of BBC Radio 4’s *Woman’s Hour*, has made plans to end her life if she becomes a burden to her family.

She said: “When my time comes I want to be able to decide about my destiny.”

The last thing she wanted, she said, was for her children to suffer from her being desperately ill.

She is sealing a pact with two friends that they will assist each other to die if any of them is diagnosed with a debilitating and incurable illness. Methods they might use include injections or smothering with a pillow.

This is despite a law outlawing assisted suicide, which Murray says is sustained by a religious minority.

She speaks of the pact tomorrow night on a Channel 5 documentary, *Don’t Get Me Started!*, that produces statistics to back the theory that many people in the country share her views on euthanasia.

Her appearance is part of a “personal rant” series in which noted people are given the chance to sound off about a subject they feel strongly about.

Publicity material for the show says that Murray “does not want to look after her sick and aging mother, and plans to end her own life when she becomes a burden to those around her.”

The network said: “Jenni is angry that, having fought so hard to become liberated and independent, women are now being trapped into caring for dependent parents.”

Murray, 56, from Barnsley, South Yorks, has been presenting *Woman's Hour* since 1987. In 1999 she was awarded an OBE for radio broadcasting.

Her pact is with Sally Feldman, a former editor of *Woman's Hour*, and Jane Wilton, another friend. They plan to sign a written agreement.

Murray is the vice-president of a society that concerns itself with Parkinson's disease, which her mother suffers from. Her father is a carer.

In the programme she emphasises that, while she supports her friends helping her to die, she would find it hard to do the same if her mother told her “Let me go.”\*

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*Do you agree with Murray's decision? Does she have a right to take her life for any reason? Is not wanting to be a burden to one's family a good reason? Should assisted-suicide pacts be legalized? Is it just as moral (or immoral) to assist in a friend's suicide as it is to directly kill her? Explain your answers.*

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\*Hugh Davies, “Jenni Murray Makes a Suicide Pact,” *Telegraph.co.uk*, August 14, 2006, <http://www.telegraph.co.uk/news/main.jhtml?xml;eq/news/2006/08/14/nmurray14.xml>.

### CASE 3

#### “Baby Euthanasia”

(*TimesOnline*)—When Frank and Anita's daughter Chanou was born with an extremely rare, incurable illness in August 2000, they knew that her life would be short and battled against the odds to make it happy.

They struggled around the clock against their baby's pain. “We tried all sorts of things,” said Anita, a 37-year-old local government worker. “She cried all the time. Every time I touched her it hurt.”

Chanou was suffering from a metabolic disorder that had resulted in abnormal bone development. Doctors gave her no more than 30 months to live. “We felt terrible watching her suffer,” said Anita at their home near Amsterdam. “We felt we were letting her down.”

Frank and Anita began to believe that their daughter would be better off dead. “She kept throwing up milk that was fed through a tube in her nose,” said Anita. “She seemed to be saying, ‘Mummy, I don't want to live any more. Let me go.’”

Eventually, doctors agreed to help the baby die at seven months. The feeding was stopped. Chanou was given morphine. “We were with her at that last moment,” said Anita. “She was exhausted. She took a very deep last breath. It was so peaceful. It made me feel at peace inside to know that she wasn't suffering any more.”

Even so, they felt that the suffering had gone on too long. Child euthanasia is illegal in Holland and doctors were afraid of being prosecuted. “It was a long road to find the humane solution that we reluctantly decided we wanted,” said Frank, a bank worker.

Each year in Holland at least 15 seriously ill babies, most of them with severe spina bifida or chromosomal abnormalities, are helped to die by doctors acting with the parents' consent. But only a fraction of those cases are reported to the authorities because of the doctors' fears of being charged with murder.

Things are about to change, however, making it much easier for parents and doctors to end the suffering of an infant.

A committee set up to regulate the practice will begin operating in the next few weeks, effectively making Holland, where adult euthanasia is legal, the first country in the world to allow “baby euthanasia” as well.

The development has angered opponents of euthanasia who warn of a “slippery slope” leading to abuses by doctors and parents, who will be making decisions for individuals incapable of expressing a will.

Others welcome more openness about a practice that, according to doctors, goes on secretly anyway—even in Britain—regardless of the law.

"It is a giant step forward and we are very happy about it," said Eduard Verhagen, clinical director of paediatrics at the University Medical Centre in Groningen, northern Holland.

Anti-euthanasia campaigners have been addressing hate mail to "Dr. Death," as they call him, ever since he admitted having personally overseen four "assisted neo-natal terminations." He then began drawing up guidelines for doctors carrying out euthanasia on babies.

It forced the government to confront the issue and Verhagen's so-called "Groningen protocol" has been adopted as the standard to be upheld by the regulatory committee.

It emphasises that life can be ended only in cases involving "unbearable suffering," with parental consent and after consultation with other physicians.

"If a child is untreatably ill," Verhagen explained, "there can be horrendous suffering that makes the last few days or weeks of this child's life unbearable. Now the question is: Are you going to leave the child like that or are you going to prevent that suffering?" He went on: "Does the child have to sit it out until the end? We think that the answer is no. There can be circumstances where, under very strict conditions, if all the requirements are fulfilled, active ending of life can be an option—but only in cases of untreatable disease and unbearable suffering."\*

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*How would you respond to Verhagen's questions in the last paragraph? Do you believe that neonatal euthanasia performed under the strict conditions described by Verhagen is morally permissible? Why or why not? Should it be legalized?*

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\*"Holland to Allow 'Baby Euthanasia,'" *The Times Online*, March 5, 2006, <http://www.timesonline.co.uk/article/0,2089-2,069,963,00.html>.

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#### READINGS

## Death and Dignity: A Case of Individualized Decision Making

TIMOTHY E. QUILL

Quill recounts the story of Diane, a patient of his with terminal cancer who wanted to face death with dignity and on her own terms. He admits that although he did not directly assist her in committing suicide, he "helped indirectly to make it possible, successful, and relatively painless." Quill says that from this experience he learned about, among other things, "the range of help I can provide if I know people well and if I allow them to say what they really want."

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From Timothy E. Quill, "Death and Dignity: A Case of Individualized Decision Making," *New England Journal of Medicine* 324, no. 10 (March 7, 1991): 691–94.

Diane was feeling tired and had a rash. A common scenario, though there was something subliminally worrisome that prompted me to check her blood count. Her hematocrit was 22, and the white-cell count was 4.3 with some metamyelocytes and unusual white cells. I wanted it to be viral, trying to deny what was staring me in the face. Perhaps in a repeated count it would disappear. I called Diane and told her it might be more serious than I had initially thought—that the test needed to be repeated and that if she felt worse, we might have to move quickly. When she pressed for the possibilities, I reluctantly opened the door to leukemia. Hearing the word seemed to make it exist. “Oh, shit!” she said. “Don’t tell me that.” Oh, shit! I thought, I wish I didn’t have to.

Diane was no ordinary person (although no one I have ever come to know has been really ordinary). She was raised in an alcoholic family and had felt alone for much of her life. She had vaginal cancer as a young woman. Through much of her adult life, she had struggled with depression and her own alcoholism. I had come to know, respect, and admire her over the previous eight years as she confronted these problems and gradually overcame them. She was an incredibly clear, at times brutally honest, thinker and communicator. As she took control of her life, she developed a strong sense of independence and confidence. In the previous 3½ years, her hard work had paid off. She was completely abstinent from alcohol, she had established much deeper connections with her husband, college-age son, and several friends, and her business and her artistic work were blossoming. She felt she was really living fully for the first time.

Not surprisingly, the repeated blood count was abnormal, and detailed examination of the peripheral blood smear showed myelocytes. I advised her to come into the hospital, explaining that we needed to do a bone marrow biopsy and make some decisions relatively rapidly. She came to the hospital knowing what we would find. She was terrified, angry, and sad. Although we knew the odds, we both clung to the thread of possibility that it might be something else.

The bone marrow confirmed the worst: acute myelomonocytic leukemia. In the face of this

tragedy, we looked for signs of hope. This is an area of medicine in which technological intervention has been successful, with cures 25 percent of the time—long-term cures. As I probed the costs of these cures, I heard about induction chemotherapy (three weeks in the hospital, prolonged neutropenia, probable infectious complications, and hair loss; 75 percent of patients respond, 25 percent do not). For the survivors, this is followed by consolidation chemotherapy (with similar side effects; another 25 percent die, for a net survival of 50 percent). Those still alive, to have a reasonable chance of long-term survival, then need bone marrow transplantation (hospitalization for two months and whole-body irradiation, with complete killing of the bone marrow, infectious complications, and the possibility for graft-versus-host disease—with a survival of approximately 50 percent, or 25 percent of the original group). Though hematologists may argue over the exact percentages, they don’t argue about the outcome of no treatment—certain death in days, weeks, or at most a few months.

Believing that delay was dangerous, our oncologist broke the news to Diane and began making plans to insert a Hickman catheter and begin induction chemotherapy that afternoon. When I saw her shortly thereafter, she was enraged at his presumption that she would want treatment, and devastated by the finality of the diagnosis. All she wanted to do was go home and be with her family. She had no further questions about treatment and in fact had decided that she wanted none. Together we lamented her tragedy and the unfairness of life. Before she left, I felt the need to be sure that she and her husband understood that there was some risk in delay, that the problem was not going to go away, and that we needed to keep considering the options over the next several days. We agreed to meet in two days.

She returned in two days with her husband and son. They had talked extensively about the problem and the options. She remained very clear about her wish not to undergo chemotherapy and to live whatever time she had left outside the hospital. As we explored her thinking further, it became clear that she was convinced she would die during the period of treatment and would suffer unspeakably

in the process (from hospitalization, from lack of control over her body, from the side effects of chemotherapy, and from pain and anguish). Although I could offer support and my best effort to minimize her suffering if she chose treatment, there was no way I could say any of this would not occur. In fact, the last four patients with acute leukemia at our hospital had died very painful deaths in the hospital during various stages of treatment (a fact I did not share with her). Her family wished she would choose treatment but sadly accepted her decision. She articulated very clearly that it was she who would be experiencing all the side effects of treatment and that odds of 25 percent were not good enough for her to undergo so toxic a course of therapy, given her expectations of chemotherapy and hospitalization and the absence of a closely matched bone marrow donor. I had her repeat her understanding of the treatment, the odds, and what to expect if there were no treatment. I clarified a few misunderstandings, but she had a remarkable grasp of the options and implications.

I have been a longtime advocate of active, informed patient choice of treatment or nontreatment, and of a patient's right to die with as much control and dignity as possible. Yet there was something about her giving up a 25 percent chance of long-term survival in favor of almost certain death that disturbed me. I had seen Diane fight and use her considerable inner resources to overcome alcoholism and depression, and I half expected her to change her mind over the next week. Since the window of time in which effective treatment can be initiated is rather narrow, we met several times that week. We obtained a second hematology consultation and talked at length about the meaning and implications of treatment and nontreatment. She talked to a psychologist she had seen in the past. I gradually understood the decision from her perspective and became convinced that it was the right decision for her. We arranged for home hospice care (although at that time Diane felt reasonably well, was active, and looked healthy), left the door open for her to change her mind, and tried to anticipate how to keep her comfortable in the time she had left.

Just as I was adjusting to her decision, she opened up another area that would stretch me profoundly.

It was extraordinarily important to Diane to maintain control of herself and her own dignity during the time remaining to her. When this was no longer possible, she clearly wanted to die. As a former director of a hospice program, I know how to use pain medicines to keep patients comfortable and lessen suffering. I explained the philosophy of comfort care, which I strongly believe in. Although Diane understood and appreciated this, she had known of people lingering in what was called relative comfort, and she wanted no part of it. When the time came, she wanted to take her life in the least painful way possible. Knowing of her desire for independence and her decision to stay in control, I thought this request made perfect sense. I acknowledged and explored this wish but also thought that it was out of the realm of currently accepted medical practice and that it was more than I could offer or promise. In our discussion, it became clear that preoccupation with her fear of a lingering death would interfere with Diane's getting the most out of the time she had left until she found a safe way to ensure her death. I feared the effects of a violent death on her family, the consequences of an ineffective suicide that would leave her lingering in precisely the state she dreaded so much, and the possibility that a family member would be forced to assist her, with all the legal and personal repercussions that would follow. She discussed this at length with her family. They believed that they should respect her choice. With this in mind, I told Diane that information was available from the Hemlock Society that might be helpful to her.

A week later she phoned me with a request for barbiturates for sleep. Since I knew that this was an essential ingredient in a Hemlock Society suicide, I asked her to come to the office to talk things over. She was more than willing to protect me by participating in a superficial conversation about her insomnia, but it was important to me to know how she planned to use the drugs and to be sure that she was not in despair or overwhelmed in a way that might color her judgment. In our discussion, it was apparent that she was having trouble sleeping, but it was also evident that the security of having enough barbiturates available to commit suicide when and if the time came would leave her secure enough to

live fully and concentrate on the present. It was clear that she was not despondent and that in fact she was making deep, personal connections with her family and close friends. I made sure that she knew how to use the barbiturates for sleep, and also that she knew the amount needed to commit suicide. We agreed to meet regularly, and she promised to meet with me before taking her life, to ensure that all other avenues had been exhausted. I wrote the prescription with an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional, and personal. Yet I also felt strongly that I was setting her free to get the most out of the time she had left, and to maintain dignity and control on her own terms until her death.

The next several months were very intense and important for Diane. Her son stayed home from college, and they were able to be with one another and say much that had not been said earlier. Her husband did his work at home so that he and Diane could spend more time together. She spent time with her closest friends. I had her come into the hospital for a conference with our residents, at which she illustrated in a most profound and personal way the importance of informed decision making, the right to refuse treatment, and the extraordinarily personal effects of illness and interaction with the medical system. There were emotional and physical hardships as well. She had periods of intense sadness and anger. Several times she became very weak, but she received transfusions as an outpatient and responded with marked improvement of symptoms. She had two serious infections that responded surprisingly well to empirical courses of oral antibiotics. After three tumultuous months, there were two weeks of relative calm and well-being, and fantasies of a miracle began to surface.

Unfortunately, we had no miracle. Bone pain, weakness, fatigue, and fevers began to dominate her life. Although the hospice workers, family members, and I tried our best to minimize the suffering and promote comfort, it was clear that the end was approaching. Diane's immediate future held what she feared the most—increasing discomfort, dependence, and hard choices between pain and sedation. She called up her closest friends and asked them to come over to say goodbye, telling them that she

would be leaving soon. As we had agreed, she let me know as well. When we met, it was clear that she knew what she was doing, that she was sad and frightened to be leaving, but that she would be even more terrified to stay and suffer. In our tearful goodbye, she promised a reunion in the future at her favorite spot on the edge of Lake Geneva, with dragons swimming in the sunset.

Two days later her husband called to say that Diane had died. She had said her final goodbyes to her husband and son that morning, and asked them to leave her alone for an hour. After an hour, which must have seemed an eternity, they found her on the couch, lying very still and covered by her favorite shawl. There was no sign of struggle. She seemed to be at peace. They called me for advice about how to proceed. When I arrived at their house, Diane indeed seemed peaceful. Her husband and son were quiet. We talked about what a remarkable person she had been. They seemed to have no doubts about the course she had chosen or about their cooperation, although the unfairness of her illness and the finality of her death were overwhelming to us all.

I called the medical examiner to inform him that a hospice patient had died. When asked about the cause of death, I said, "acute leukemia." He said that was fine and that we should call a funeral director. Although acute leukemia was the truth, it was not the whole story. Yet any mention of suicide would have given rise to a police investigation and probably brought the arrival of an ambulance crew for resuscitation. Diane would have become a "coroner's case," and the decision to perform an autopsy would have been made at the discretion of the medical examiner. The family or I could have been subject to criminal prosecution, and I to professional review, for our roles in support of Diane's choices. Although I truly believe that the family and I gave her the best care possible, allowing her to define her limits and directions as much as possible, I am not sure the law, society, or the medical profession would agree. So I said "acute leukemia" to protect all of us, to protect Diane from an invasion into her past and her body, and to continue to shield society from the knowledge of the degree of suffering that people often undergo in the process of dying. Suffering can be lessened to some extent, but in no way

eliminated or made benign, by the careful intervention of a competent, caring physician, given current social constraints.

Diane taught me about the range of help I can provide if I know people well and if I allow them to say what they really want. She taught me about life, death, and honesty and about taking charge and facing tragedy squarely when it strikes. She taught me that I can take small risks for people that I really know and care about. Although I did not assist in her suicide directly, I helped indirectly to make it possible, successful, and relatively painless. Although I know we have measures to help control pain and lessen suffering, to think that people do not suffer in the process of dying is an illusion. Prolonged dying can occasionally be peaceful, but more often the role of the physician and family is

limited to lessening but not eliminating severe suffering.

I wonder how many families and physicians secretly help patients over the edge into death in the face of such severe suffering. I wonder how many severely ill or dying patients secretly take their lives, dying alone in despair. I wonder whether the image of Diane's final aloneness will persist in the minds of her family, or if they will remember more the intense, meaningful months they had together before she died. I wonder whether Diane struggled in that last hour, and whether the Hemlock Society's way of death by suicide is the most benign. I wonder why Diane, who gave so much to so many of us, had to be alone for the last hour of her life. I wonder whether I will see Diane again, on the shore of Lake Geneva at sunset, with dragons swimming on the horizon.

## **Voluntary Active Euthanasia**

DAN W. BROCK

Brock argues that the same two basic moral principles that support a patient's right to make choices about life-sustaining treatment also support the permissibility of voluntary active euthanasia. The first principle is individual self-determination; the second is individual well-being. Individual self-determination applies to the manner, circumstances, and timing of one's death and dying. A concern for individual well-being may justify euthanasia when a suffering patient determines that life is no longer a benefit.

... The central ethical argument for euthanasia is familiar. It is that the very same two fundamental ethical values supporting the consensus on patient's rights to decide about life-sustaining treatment also support the ethical permissibility of euthanasia. These values are individual self-determination or autonomy and individual well-being. By self-determination as it bears on euthanasia, I mean people's interest in making important decisions about their

lives for themselves according to their own values or conceptions of a good life, and in being left free to act on those decisions. Self-determination is valuable because it permits people to form and live in accordance with their own conception of a good life, at least within the bounds of justice and consistent with others doing so as well. In exercising self-determination people take responsibility for their lives and for the kinds of persons they become. A central aspect of human dignity lies in people's capacity to direct their lives in this way. The value of exercising self-determination presupposes some minimum of decision making capacities or competence, which thus limits the scope of euthanasia

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supported by self-determination; it cannot justifiably be administered, for example, in cases of serious dementia or treatable clinical depression.

Does the value of individual self-determination extend to the time and manner of one's death? Most people are very concerned about the nature of the last stage of their lives. This reflects not just a fear of experiencing substantial suffering when dying, but also a desire to retain dignity and control during this last period of life. Death is today increasingly preceded by a long period of significant physical and mental decline, due in part to the technological interventions of modern medicine. Many people adjust to these disabilities and find meaning and value in new activities and ways. Others find the impairments and burdens in the last stage of their lives at some point sufficiently great to make life no longer worth living. For many patients near death, maintaining the quality of one's life, avoiding great suffering, maintaining one's dignity, and insuring that others remember us as we wish them to become of paramount importance and outweigh merely extending one's life. But there is no single, objectively correct answer for everyone as to when, if at all, one's life becomes all things considered a burden and unwanted. If self-determination is a fundamental value, then the great variability among people on this question makes it especially important that individuals control the manner, circumstances, and timing of their dying and death.

The other main value that supports euthanasia is individual well-being. It might seem that individual well-being conflicts with a person's self-determination when the person requests euthanasia. Life itself is commonly taken to be a central good for persons, often valued for its own sake, as well as necessary for pursuit of all other goods within a life. But when a competent patient decides to forgo all further life-sustaining treatment then the patient, either explicitly or implicitly, commonly decides that the best life possible for him or her with treatment is of sufficiently poor quality that it is worse than no further life at all. Life is no longer considered a benefit by the patient, but has now become a burden. The same judgment underlies a request for euthanasia: continued life is seen by the patient as no longer a benefit, but now a burden. Especially in the often

severely compromised and debilitated states of many critically ill or dying patients, there is no objective standard, but only the competent patient's judgment of whether continued life is no longer a benefit.

Of course, sometimes there are conditions, such as clinical depression, that call into question whether the patient has made a competent choice, either to forgo life-sustaining treatment or to seek euthanasia, and then the patient's choice need not be evidence that continued life is no longer a benefit for him or her. Just as with decisions about treatment, a determination of incompetence can warrant not honoring the patient's choice; in the case of treatment, we then transfer decisional authority to a surrogate, though in the case of voluntary active euthanasia a determination that the patient is incompetent means that choice is not possible.

The value or right of self-determination does not entitle patients to compel physicians to act contrary to their own moral or professional values. Physicians are moral and professional agents whose own self-determination or integrity should be respected as well. If performing euthanasia became legally permissible, but conflicted with a particular physician's reasonable understanding of his or her moral or professional responsibilities, the care of a patient who requested euthanasia should be transferred to another.

Most opponents do not deny that there are some cases in which the values of patient self-determination and well-being support euthanasia. Instead, they commonly offer two kinds of arguments against it that on their view outweigh or override this support. The first kind of argument is that in any individual case where considerations of the patient's self-determination and well-being do support euthanasia, it is nevertheless always ethically wrong or impermissible. The second kind of argument grants that in some individual cases euthanasia may not be ethically wrong, but maintains nonetheless that public and legal policy should never permit it. The first kind of argument focuses on features of any individual case of euthanasia, while the second kind focuses on social or legal policy. In the next section I consider the first kind of argument.

### Euthanasia Is the Deliberate Killing of an Innocent Person

The claim that any individual instance of euthanasia is a case of deliberate killing of an innocent person is, with only minor qualifications, correct. Unlike forgoing life-sustaining treatment, commonly understood as allowing to die, euthanasia is clearly killing, defined as depriving of life or causing the death of a living being. While providing morphine for pain relief at doses where the risk of respiratory depression and an earlier death may be a foreseen but unintended side effect of treating the patient's pain, in a case of euthanasia the patient's death is deliberate or intended even if in both the physician's ultimate end may be respecting the patient's wishes. If the deliberate killing of an innocent person is wrong, euthanasia would be nearly always impermissible.

In the context of medicine, the ethical prohibition against deliberately killing the innocent derives some of its plausibility from the belief that nothing in the currently accepted practice of medicine is deliberate killing. Thus, in commenting on the "It's Over, Debbie" case, four prominent physicians and bioethicists could entitle their paper "Doctors Must Not Kill."<sup>1</sup> The belief that doctors do not in fact kill requires the corollary belief that forgoing life-sustaining treatment, whether by not starting or by stopping treatment, is allowing to die, not killing. Common though this view is, I shall argue that it is confused and mistaken.

Why is the common view mistaken? Consider the case of a patient terminally ill with ALS disease. She is completely respirator dependent with no hope of ever being weaned. She is unquestionably competent but finds her condition intolerable and persistently requests to be removed from the respirator and allowed to die. Most people and physicians would agree that the patient's physician should respect the patient's wishes and remove her from the respirator, though this will certainly cause the patient's death. The common understanding is that the physician thereby allows the patient to die. But is that correct?

Suppose the patient has a greedy and hostile son who mistakenly believes that his mother will never decide to stop her life-sustaining treatment and that even if she did her physician would not remove her

from the respirator. Afraid that his inheritance will be dissipated by a long and expensive hospitalization, he enters his mother's room while she is sedated, extubates her, and she dies. Shortly thereafter the medical staff discovers what he has done and confronts the son. He replies, "I didn't kill her, I merely allowed her to die. It was her ALS disease that caused her death." I think this would rightly be dismissed as transparent sophistry—the son went into his mother's room and deliberately killed her. But, of course, the son performed just the same physical actions, did just the same thing, that the physician would have done. If that is so, then doesn't the physician also kill the patient when he extubates her?

I underline immediately that there are important ethical differences between what the physician and the greedy son do. First, the physician acts with the patient's consent whereas the son does not. Second, the physician acts with a good motive—to respect the patient's wishes and self-determination—whereas the son acts with a bad motive—to protect his own inheritance. Third, the physician acts in a social role through which he is legally authorized to carry out the patient's wishes regarding treatment whereas the son has no such authorization. These and perhaps other ethically important differences show that what the physician did was morally justified whereas what the son did was morally wrong. What they do not show, however, is that the son killed while the physician allowed to die. One can either kill or allow to die with or without consent, with a good or bad motive, within or outside of a social role that authorizes one to do so.

The difference between killing and allowing to die that I have been implicitly appealing to here is roughly that between acts and omissions resulting in death.<sup>2</sup> Both the physician and the greedy son act in a manner intended to cause death, do cause death, and so both kill. One reason this conclusion is resisted is that on a different understanding of the distinction between killing and allowing to die, what the physician does is allow to die. In this account, the mother's ALS is a lethal disease whose normal progression is being held back or blocked by the life-sustaining respirator treatment. Removing this artificial intervention is then viewed as standing aside and allowing the patient to die of her

underlying disease. I have argued elsewhere that this alternative account is deeply problematic, in part because it commits us to accepting that what the greedy son does is to allow to die, not kill.<sup>3</sup> Here, I want to note two other reasons why the conclusion that stopping life support is killing is resisted.

The first reason is that killing is often understood, especially within medicine, as unjustified causing of death; in medicine it is thought to be done only accidentally or negligently. It is also increasingly widely accepted that a physician is ethically justified in stopping life support in a case like that of the ALS patient. But if these two beliefs are correct, then what the physician does cannot be killing, and so must be allowing to die. Killing patients is not, to put it flippantly, understood to be part of physicians' job description. What is mistaken in this line of reasoning is the assumption that all killings are unjustified causings of death. Instead, some killings are ethically justified, including many instances of stopping life support.

Another reason for resisting the conclusion that stopping life support is often killing is that it is psychologically uncomfortable. Suppose the physician had stopped the ALS patient's respirator and had made the son's claim, "I didn't kill her, I merely allowed her to die. It was her ALS disease that caused her death." The clue to the psychological role here is how naturally the "merely" modifies "allowed her to die." The characterization as allowing to die is meant to shift felt responsibility away from the agent—the physician—and to the lethal disease process. Other language common in death and dying contexts plays a similar role; "letting nature take its course" or "stopping prolonging the dying process" both seem to shift responsibility from the physician who stops life support to the fatal disease process. However psychologically helpful these conceptualizations may be in making the difficult responsibility of a physician's role in the patient's death bearable, they nevertheless are confusions. Both physicians and family members can instead be helped to understand that it is the patient's decision and consent to stopping treatment that limits their responsibility for the patient's death and that shifts that responsibility to the patient.

Many who accept the difference between killing and allowing to die as the distinction between acts

and omissions resulting in death have gone on to argue that killing is not in itself morally different from allowing to die.<sup>4</sup> In this account, very roughly, one kills when one performs an action that causes the death of a person (we are in a boat, you cannot swim, I push you overboard, and you drown), and one allows to die when one has the ability and opportunity to prevent the death of another, knows this, and omits doing so, with the result that the person dies (we are in a boat, you cannot swim, you fall overboard, I don't throw you an available life ring, and you drown). Those who see no moral difference between killing and allowing to die typically employ the strategy of comparing cases that differ in these and no other potentially morally important respects. This will allow people to consider whether the mere difference that one is a case of killing and the other of allowing to die matters morally, or whether instead it is other features that make most cases of killing worse than most instances of allowing to die. Here is such a pair of cases:

#### Case 1

A very gravely ill patient is brought to a hospital emergency room and sent up to the ICU. The patient begins to develop respiratory failure that is likely to require intubation very soon. At that point the patient's family members and long-standing physician arrive at the ICU and inform the ICU staff that there had been extensive discussion about future care with the patient when he was unquestionably competent. Given his grave and terminal illness, as well as his state of debilitation, the patient had firmly rejected being placed on a respirator under any circumstances, and the family and physician produce the patient's advance directive to that effect. The ICU staff do not intubate the patient, who dies of respiratory failure.

#### Case 2

The same as Case 1 except that the family and physician are slightly delayed in traffic and arrive shortly after the patient has been intubated and placed on the respirator. The ICU staff extubate the patient, who dies of respiratory failure.

In Case 1 the patient is allowed to die, in Case 2 he is killed, but it is hard to see why what is done in

Case 2 is significantly different morally than what is done in Case 1. It must be other factors that make most killings worse than most allowings to die, and if so, euthanasia cannot be wrong simply because it is killing instead of allowing to die.

Suppose both my arguments are mistaken. Suppose that killing is worse than allowing to die and that withdrawing life support is not killing, although euthanasia is. Euthanasia still need not for that reason be morally wrong. To see this, we need to determine the basic principle for the moral evaluation of killing persons. What is it that makes paradigm cases of wrongful killing wrongful? One very plausible answer is that killing denies the victim something that he or she values greatly—continued life or a future. Moreover, since continued life is necessary for pursuing any of a person's plans and purposes, killing brings the frustration of all of these plans and desires as well. In a nutshell, wrongful killing deprives a person of a valued future, and of all the person wanted and planned to do in that future.

A natural expression of this account of the wrongness of killing is that people have a moral right not to be killed.<sup>5</sup> But in this account of the wrongness of killing, the right not to be killed, like other rights, should be waivable when the person makes a competent decision that continued life is no longer wanted or a good, but is instead worse than no further life at all. In this view, euthanasia is properly understood as a case of a person having waived his or her right not to be killed.

This rights view of the wrongness of killing is not, of course, universally shared. Many people's moral views about killing have their origins in religious views that human life comes from God and cannot be justifiably destroyed or taken away, either by the person whose life it is or by another. But in a pluralistic society like our own with a strong commitment to freedom of religion, public policy should not be grounded in religious beliefs which many in that society reject. I turn now to the general evaluation of public policy on euthanasia.

### **Would the Bad Consequences of Euthanasia Outweigh the Good?**

The argument against euthanasia at the policy level is stronger than at the level of individual cases,

though even here I believe the case is ultimately unpersuasive, or at best indecisive. The policy level is the place where the main issues lie, however, and where moral considerations that might override arguments in favor of euthanasia will be found, if they are found anywhere. It is important to note two kinds of disagreement about the consequences for public policy of permitting euthanasia. First, there is empirical or factual disagreement about what the consequences would be. This disagreement is greatly exacerbated by the lack of firm data on the issue. Second, since on any reasonable assessment there would be both good and bad consequences, there are moral disagreements about the relative importance of different effects. In addition to these two sources of disagreement, there is also no single, well-specified policy proposal for legalizing euthanasia on which policy assessments can focus. But without such specification, and especially without explicit procedures for protecting against well-intentioned misuse and ill-intentioned abuse, the consequences for policy are largely speculative. Despite these difficulties, a preliminary account of the main likely good and bad consequences is possible. This should help clarify where better data or more moral analysis and argument are needed, as well as where policy safeguards must be developed.

### **Potential Good Consequences of Permitting Euthanasia**

What are the likely good consequences? First, if euthanasia were permitted it would be possible to respect the self-determination of competent patients who want it, but now cannot get it because of its illegality. We simply do not know how many such patients and people there are. In the Netherlands, with a population of about 14.5 million (in 1987), estimates in a recent study were that about 1,900 cases of voluntary active euthanasia or physician-assisted suicide occur annually. No straightforward extrapolation to the United States is possible for many reasons, among them, that we do not know how many people here who want euthanasia now get it, despite its illegality. Even with better data on the number of persons who want euthanasia but cannot get it, significant moral disagreement would remain about

how much weight should be given to any instance of failure to respect a person's self-determination in this way.

One important factor substantially affecting the number of persons who would seek euthanasia is the extent to which an alternative is available. The widespread acceptance in the law, social policy, and medical practice of the right of a competent patient to forgo life-sustaining treatment suggests that the number of competent persons in the United States who would want euthanasia if it were permitted is probably relatively small.

A second good consequence of making euthanasia legally permissible benefits a much larger group. Polls have shown that a majority of the American public believes that people should have a right to obtain euthanasia if they want it.<sup>6</sup> No doubt the vast majority of those who support this right to euthanasia will never in fact come to want euthanasia for themselves. Nevertheless, making it legally permissible would reassure many people that if they ever do want euthanasia they would be able to obtain it. This reassurance would supplement the broader control over the process of dying given by the right to decide about life-sustaining treatment. Having fire insurance on one's house benefits all who have it, not just those whose houses actually burn down, by reassuring them that in the unlikely event of their house burning down, they will receive the money needed to rebuild it. Likewise, the legalization of euthanasia can be thought of as a kind of insurance policy against being forced to endure a protracted dying process that one has come to find burdensome and unwanted, especially when there is no life-sustaining treatment to forgo. The strong concern about losing control of their care expressed by many people who face serious illness likely to end in death suggests that they give substantial importance to the legalization of euthanasia as a means of maintaining this control.

A third good consequence of the legalization of euthanasia concerns patients whose dying is filled with severe and unrelievable pain or suffering. When there is a life-sustaining treatment that, if forgone, will lead relatively quickly to death, then doing so can bring an end to these patients' suffering without recourse to euthanasia. For patients

receiving no such treatment, however, euthanasia may be the only release from their otherwise prolonged suffering and agony. This argument from mercy has always been the strongest argument for euthanasia in those cases to which it applies.<sup>7</sup>

The importance of relieving pain and suffering is less controversial than is the frequency with which patients are forced to undergo untreatable agony that only euthanasia could relieve. If we focus first on suffering caused by physical pain, it is crucial to distinguish pain that could be adequately relieved with modern methods of pain control, though it in fact is not, from pain that is relievable only by death.<sup>8</sup> For a variety of reasons, including some physicians' fear of hastening the patient's death, as well as the lack of a publicly accessible means for assessing the amount of the patient's pain, many patients suffer pain that could be, but is not, relieved.

Specialists in pain control, as for example the pain of terminally ill cancer patients, argue that there are very few patients whose pain could not be adequately controlled, though sometimes at the cost of so sedating them that they are effectively unable to interact with other people or their environment. Thus, the argument from mercy in cases of physical pain can probably be met in a large majority of cases by providing adequate measures of pain relief. This should be a high priority, whatever our legal policy on euthanasia—the relief of pain and suffering has long been, quite properly, one of the central goals of medicine. Those cases in which pain could be effectively relieved, but in fact is not, should only count significantly in favor of legalizing euthanasia if all reasonable efforts to change pain management techniques have been tried and have failed.

Dying patients often undergo substantial psychological suffering that is not fully or even principally the result of physical pain.<sup>9</sup> The knowledge about how to relieve this suffering is much more limited than in the case of relieving pain, and efforts to do so are probably more often unsuccessful. If the argument from mercy is extended to patients experiencing great and unrelievable psychological suffering, the numbers of patients to which it applies are much greater.

One last good consequence of legalizing euthanasia is that once death has been accepted, it is often more humane to end life quickly and peacefully, when that is what the patient wants. Such a death will often be seen as better than a more prolonged one. People who suffer a sudden and unexpected death, for example by dying quickly or in their sleep from a heart attack or stroke, are often considered lucky to have died in this way. We care about how we die in part because we care about how others remember us, and we hope they will remember us as we were in “good times” with them and not as we might be when disease has robbed us of our dignity as human beings. As with much in the treatment and care of the dying, people’s concerns differ in this respect, but for at least some people, euthanasia will be a more humane death than what they have often experienced with other loved ones and might otherwise expect for themselves.

Some opponents of euthanasia challenge how much importance should be given to any of these good consequences of permitting it, or even whether some would be good consequences at all. But more frequently, opponents cite a number of bad consequences that permitting euthanasia would or could produce, and it is to their assessment that I now turn.

### Potential Bad Consequences of Permitting Euthanasia

Some of the arguments against permitting euthanasia are aimed specifically against physicians, while others are aimed against anyone being permitted to perform it. I shall first consider one argument of the former sort. Permitting physicians to perform euthanasia, it is said, would be incompatible with their fundamental moral and professional commitment as healers to care for patients and to protect life. Moreover, if euthanasia by physicians became common, patients would come to fear that a medication was intended not to treat or care, but instead to kill, and would thus lose trust in their physicians. This position was forcefully stated in a paper by Willard Gaylin and his colleagues:

The very soul of medicine is on trial. . . . This issue touches medicine at its moral center; if this moral center collapses, if physicians become killers or are

even licensed to kill, the profession—and, therewith, each physician—will never again be worthy of trust and respect as healer and comforter and protector of life in all its frailty.

These authors go on to make clear that, while they oppose permitting anyone to perform euthanasia, their special concern is with physicians doing so:

We call on fellow physicians to say that they will not deliberately kill. We must also say to each of our fellow physicians that we will not tolerate killing of patients and that we shall take disciplinary action against doctors who kill. And we must say to the broader community that if it insists on tolerating or legalizing active euthanasia, it will have to find nonphysicians to do its killing.<sup>10</sup>

If permitting physicians to kill would undermine the very “moral center” of medicine, then almost certainly physicians should not be permitted to perform euthanasia. But how persuasive is this claim? Patients should not fear, as a consequence of permitting voluntary active euthanasia, that their physicians will substitute a lethal injection for what patients want and believe is part of their care. If active euthanasia is restricted to cases in which it is truly voluntary, then no patient should fear getting it unless she or he has voluntarily requested it. (The fear that we might in time also come to accept non-voluntary, or even involuntary, active euthanasia is a slippery slope worry I address below.) Patients’ trust of their physicians could be increased, not eroded, by knowledge that physicians will provide aid in dying when patients seek it.

Might Gaylin and his colleagues nevertheless be correct in their claim that the moral center of medicine would collapse if physicians were to become killers? This question raises what at the deepest level should be the guiding aims of medicine, a question that obviously cannot be fully explored here. But I do want to say enough to indicate the direction that I believe an appropriate response to this challenge should take. In spelling out above what I called the positive argument for voluntary active euthanasia, I suggested that two principal values—respecting patients’ self-determination and promoting their well-being—underlie the consensus that competent patients, or the surrogates of

incompetent patients, are entitled to refuse any life-sustaining treatment and to choose from among available alternative treatments. It is the commitment to these two values in guiding physicians' actions as healers, comforters, and protectors of their patients' lives that should be at the "moral center" of medicine, and these two values support physicians' administering euthanasia when their patients make competent requests for it. . . .

A second bad consequence that some foresee is that permitting euthanasia would weaken society's commitment to provide optimal care for dying patients. We live at a time in which the control of health care costs has become, and is likely to continue to be, the dominant focus of health care policy. If euthanasia is seen as a cheaper alternative to adequate care and treatment, then we might become less scrupulous about providing sometimes costly support and other services to dying patients. Particularly if our society comes to embrace deeper and more explicit rationing of health care, frail, elderly, and dying patients will need to be strong and effective advocates for their own health care and other needs, although they are hardly in a position to do this. We should do nothing to weaken their ability to obtain adequate care and services.

This second worry is difficult to assess because there is little firm evidence about the likelihood of the feared erosion in the care of dying patients. There are at least two reasons, however, for skepticism about this argument. The first is that the same worry could have been directed at recognizing patients' or surrogates' rights to forgo life-sustaining treatment, yet there is no persuasive evidence that recognizing the right to refuse treatment has caused a serious erosion in the quality of care of dying patients. The second reason for skepticism about this worry is that only a very small proportion of deaths would occur from euthanasia if it were permitted. In the Netherlands, where euthanasia under specified circumstances is permitted by the courts, though not authorized by statute, the best estimate of the proportion of overall deaths that result from it is about 2 percent.<sup>11</sup> Thus, the vast majority of critically ill and dying patients will not request it, and so will still have to be cared for by physicians, families, and others. Permitting euthanasia should not

diminish people's commitment and concern to maintain and improve the care of these patients.

A third possible bad consequence of permitting euthanasia (or even a public discourse in which strong support for euthanasia is evident) is to threaten the progress made in securing the rights of patients or their surrogates to decide about and to refuse life-sustaining treatment.<sup>12</sup> This progress has been made against the backdrop of a clear and firm legal prohibition of euthanasia, which has provided a relatively bright line limiting the dominion of others over patients' lives. It has therefore been an important reassurance to concerns about how the authority to take steps ending life might be misused, abused, or wrongly extended.

Many supporters of the right of patients or their surrogates to refuse treatment strongly oppose euthanasia, and if forced to choose might well withdraw their support of the right to refuse treatment rather than accept euthanasia. Public policy in the last fifteen years has generally let life-sustaining treatment decisions be made in health care settings between physicians and patients or their surrogates, and without the involvement of the courts. However, if euthanasia is made legally permissible greater involvement of the courts is likely, which could in turn extend to a greater court involvement in life-sustaining treatment decisions. Most agree, however, that increased involvement of the courts in these decisions would be undesirable, as it would make sound decisionmaking more cumbersome and difficult without sufficient compensating benefits.

As with the second potential bad consequence of permitting euthanasia, this third consideration too is speculative and difficult to assess. The feared erosion of patients' or surrogates' rights to decide about life-sustaining treatment, together with greater court involvement in those decisions, are both possible. However, I believe there is reason to discount this general worry. The legal rights of competent patients and, to a lesser degree, surrogates of incompetent patients to decide about treatment are very firmly embedded in a long line of informed consent and life-sustaining treatment cases, and are not likely to be eroded by a debate over, or even acceptance of, euthanasia. It will not be accepted

without safeguards that reassure the public about abuse, and if that debate shows the need for similar safeguards for some life-sustaining treatment decisions they should be adopted there as well. In neither case are the only possible safeguards greater court involvement, as the recent growth of institutional ethics committees shows.

The fourth potential bad consequence of permitting euthanasia has been developed by David Velleman and turns on the subtle point that making a new option or choice available to people can sometimes make them worse off, even if once they have the choice they go on to choose what is best for them.<sup>13</sup> Ordinarily, people's continued existence is viewed by them as given, a fixed condition with which they must cope. Making euthanasia available to people as an option denies them the alternative of staying alive by default. If people are offered the option of euthanasia, their continued existence is now a choice for which they can be held responsible and which they can be asked by others to justify. We care, and are right to care, about being able to justify ourselves to others. To the extent that our society is unsympathetic to justifying a severely dependent or impaired existence, a heavy psychological burden of proof may be placed on patients who think their terminal illness or chronic infirmity is not a sufficient reason for dying. Even if they otherwise view their life as worth living, the opinion of others around them that it is not can threaten their reason for living and make euthanasia a rational choice. Thus the existence of the option becomes a subtle pressure to request it.

This argument correctly identifies the reason why offering some patients the option of euthanasia would not benefit them. Velleman takes it not as a reason for opposing all euthanasia, but for restricting it to circumstances where there are "unmistakable and overpowering reasons for persons to want the option of euthanasia," and for denying the option in all other cases. But there are at least three reasons why such restriction may not be warranted. First, polls and other evidence support that most Americans believe euthanasia should be permitted (though the recent defeat of the referendum to permit it in the state of Washington raises some doubt about this support). Thus, many more people

seem to want the choice than would be made worse off by getting it. Second, if giving people the option of ending their life really makes them worse off, then we should not only prohibit euthanasia, but also take back from people the right they now have to decide about life-sustaining treatment. The feared harmful effect should already have occurred from securing people's right to refuse life-sustaining treatment, yet there is no evidence of any such widespread harm or any broad public desire to rescind that right. Third, since there is a wide range of conditions in which reasonable people can and do disagree about whether they would want continued life, it is not possible to restrict the permissibility of euthanasia as narrowly as Velleman suggests without thereby denying it to most persons who would want it; to permit it only in cases in which virtually everyone would want it would be to deny it to most who would want it.

A fifth potential bad consequence of making euthanasia legally permissible is that it might weaken the general legal prohibition of homicide. This prohibition is so fundamental to civilized society, it is argued, that we should do nothing that erodes it. If most cases of stopping life support are killing, as I have already argued, then the court cases permitting such killing have already in effect weakened this prohibition. However, neither the courts nor most people have seen these cases as killing and so as challenging the prohibition of homicide. The courts have usually grounded patients' or their surrogates' rights to refuse life-sustaining treatment in rights to privacy, liberty, self-determination, or bodily integrity, not in exceptions to homicide laws.

Legal permission for physicians or others to perform euthanasia could not be grounded in patients' rights to decide about medical treatment. Permitting euthanasia would require qualifying, at least in effect, the legal prohibition against homicide, a prohibition that in general does not allow the consent of the victim to justify or excuse the act. Nevertheless, the very same fundamental basis of the right to decide about life-sustaining treatment—respecting a person's self-determination—does support euthanasia as well. Individual self-determination has long been a well-entrenched and fundamental value in the law, and so extending it to euthanasia would not

require appeal to novel legal values or principles. That suicide or attempted suicide is no longer a criminal offense in virtually all states indicates an acceptance of individual self-determination in the taking of one's own life analogous to that required for voluntary active euthanasia. The legal prohibition (in most states) of assisting in suicide and the refusal in the law to accept the consent of the victim as a possible justification of homicide are both arguably a result of difficulties in the legal process of establishing the consent of the victim after the fact. If procedures can be designed that clearly establish the voluntariness of the person's request for euthanasia it would under those procedures represent a carefully circumscribed qualification on the legal prohibition of homicide. Nevertheless, some remaining worries about this weakening can be captured in the final potential bad consequence, to which I will now turn.

This final potential bad consequence is the central concern of many opponents of euthanasia and, I believe, is the most serious objection to a legal policy permitting it. According to this "slippery slope" worry, although active euthanasia may be morally permissible in cases in which it is unequivocally voluntary and the patient finds his or her condition unbearable, a legal policy permitting euthanasia would inevitably lead to active euthanasia being performed in many other cases in which it would be morally wrong. To prevent those other wrongful cases of euthanasia we should not permit even morally justified performance of it.

Slippery slope arguments of this form are problematic and difficult to evaluate.<sup>14</sup> From one perspective, they are the last refuge of conservative defenders of the status quo. When all the opponent's objections to the wrongness of euthanasia itself have been met, the opponent then shifts ground and acknowledges both that it is not in itself wrong and that a legal policy which resulted only in its being performed would not be bad. Nevertheless, the opponent maintains, it should still not be permitted because doing so would result in its being performed in other cases in which it is not voluntary and would be wrong. In this argument's most extreme form, permitting euthanasia is the first and fateful step down the slippery slope to Nazism. Once on the slope we will be unable to get off.

Now it cannot be denied that it is possible that permitting euthanasia could have these fateful consequences, but that cannot be enough to warrant prohibiting it if it is otherwise justified. A similar possible slippery slope worry could have been raised to securing competent patients' rights to decide about life support, but recent history shows such a worry would have been unfounded. It must be relevant how likely it is that we will end with horrendous consequences and an unjustified practice of euthanasia. How likely and widespread would the abuses and unwarranted extensions of permitting it be? By abuses, I mean the performance of euthanasia that fails to satisfy the conditions required for voluntary active euthanasia, for example, if the patient has been subtly pressured to accept it. By unwarranted extensions of policy, I mean later changes in legal policy to permit not just voluntary euthanasia, but also euthanasia in cases in which, for example, it need not be fully voluntary. Opponents of voluntary euthanasia on slippery slope grounds have not provided the data or evidence necessary to turn their speculative concerns into well-grounded likelihoods.

It is at least clear, however, that both the character and likelihood of abuses of a legal policy permitting euthanasia depend in significant part on the procedures put in place to protect against them. I will not try to detail fully what such procedures might be, but will just give some examples of what they might include:

1. The patient should be provided with all relevant information about his or her medical condition, current prognosis, available alternative treatments, and the prognosis of each.
2. Procedures should ensure that the patient's request for euthanasia is stable or enduring (a brief waiting period could be required) and fully voluntary (an advocate for the patient might be appointed to ensure this).
3. All reasonable alternatives must have been explored for improving the patient's quality of life and relieving any pain or suffering.
4. A psychiatric evaluation should ensure that the patient's request is not the result of a treatable psychological impairment such as depression.<sup>15</sup>

These examples of procedural safeguards are all designed to ensure that the patient's choice is fully informed, voluntary, and competent, and so a true exercise of self-determination. Other proposals for euthanasia would restrict its permissibility further—for example, to the terminally ill—a restriction that cannot be supported by self-determination. Such additional restrictions might, however, be justified by concern for limiting potential harms from abuse. At the same time, it is important not to impose procedural or substantive safeguards so restrictive as to make euthanasia impermissible or practically infeasible in a wide range of justified cases.

These examples of procedural safeguards make clear that it is possible to substantially reduce, though not to eliminate, the potential for abuse of a policy permitting voluntary active euthanasia. Any legalization of the practice should be accompanied by a well-considered set of procedural safeguards together with an ongoing evaluation of its use. Introducing euthanasia into only a few states could be a form of carefully limited and controlled social experiment that would give us evidence about the benefits and harms of the practice. Even then firm and uncontroversial data may remain elusive, as the continuing controversy over what has taken place in the Netherlands in recent years indicates.<sup>16</sup>

### **The Slip into Nonvoluntary Active Euthanasia**

While I believe slippery slope worries can largely be limited by making necessary distinctions both in principle and in practice, one slippery slope concern is legitimate. There is reason to expect that legalization of voluntary active euthanasia might soon be followed by strong pressure to legalize some nonvoluntary euthanasia of incompetent patients unable to express their own wishes. Respecting a person's self-determination and recognizing that continued life is not always of value to a person can support not only voluntary active euthanasia, but some nonvoluntary euthanasia as well. These are the same values that ground competent patients' right to refuse life-sustaining treatment. Recent history here is instructive. In the medical ethics literature, in the courts since Quinlan, and in norms of medical practice, that right has been extended to

incompetent patients and exercised by a surrogate who is to decide as the patient would have decided in the circumstances if competent.<sup>17</sup> It has been held unreasonable to continue life-sustaining treatment that the patient would not have wanted just because the patient now lacks the capacity to tell us that. Life-sustaining treatment for incompetent patients is today frequently forgone on the basis of a surrogate's decision, or less frequently on the basis of an advance directive executed by the patient while still competent. The very same logic that has extended the right to refuse life-sustaining treatment from a competent patient to the surrogate of an incompetent patient (acting with or without a formal advance directive from the patient) may well extend the scope of active euthanasia. The argument will be, Why continue to force unwanted life on patients just because they have now lost the capacity to request euthanasia from us?

A related phenomenon may reinforce this slippery slope concern. In the Netherlands, what the courts have sanctioned has been clearly restricted to voluntary euthanasia. In itself, this serves as some evidence that permitting it need not lead to permitting the nonvoluntary variety. There is some indication, however, that for many Dutch physicians euthanasia is no longer viewed as a special action, set apart from their usual practice and restricted only to competent persons.<sup>18</sup> Instead, it is seen as one end of a spectrum of caring for dying patients. When viewed in this way it will be difficult to deny euthanasia to a patient for whom it is seen as the best or most appropriate form of care simply because that patient is now incompetent and cannot request it.

Even if voluntary active euthanasia should slip into nonvoluntary active euthanasia, with surrogates acting for incompetent patients, the ethical evaluation is more complex than many opponents of euthanasia allow. Just as in the case of surrogates' decisions to forgo life-sustaining treatment for incompetent patients, so also surrogates' decisions to request euthanasia for incompetent persons would often accurately reflect what the incompetent person would have wanted and would deny the person nothing that he or she would have considered worth having. Making nonvoluntary active

euthanasia legally permissible, however, would greatly enlarge the number of patients on whom it might be performed and substantially enlarge the potential for misuse and abuse. As noted above, frail and debilitated elderly people, often demented or otherwise incompetent and thereby unable to defend and assert their own interests, may be especially vulnerable to unwanted euthanasia.

For some people, this risk is more than sufficient reason to oppose the legalization of voluntary euthanasia. But while we should in general be cautious about inferring much from the experience in the Netherlands to what our own experience in the United States might be, there may be one important lesson that we can learn from them. One commentator has noted that in the Netherlands families of incompetent patients have less authority than do families in the United States to act as surrogates for incompetent patients in making decisions to forgo life-sustaining treatment.<sup>19</sup> From the Dutch perspective, it may be we in the United States who are already on the slippery slope in having given surrogates broad authority to forgo life-sustaining treatment for incompetent persons. In this view, the more important moral divide, and the more important with regard to potential for abuse, is not between forgoing life-sustaining treatment and euthanasia, but instead between voluntary and nonvoluntary performance of either. If this is correct, then the more important issue is ensuring the appropriate principles and procedural safeguards for the exercise of decision-making authority by surrogates for incompetent persons in all decisions at the end of life. This may be the correct response to slippery slope worries about euthanasia.

I have cited both good and bad consequences that have been thought likely from a policy change permitting voluntary active euthanasia, and have tried to evaluate their likelihood and relative importance. Nevertheless, as I noted earlier, reasonable disagreement remains both about the consequences of permitting euthanasia and about which of these consequences are more important. The depth and strength of public and professional debate about whether, all things considered, permitting euthanasia would be desirable or undesirable reflects these disagreements. While my own

view is that the balance of considerations supports permitting the practice, my principal purpose here has been to clarify the main issues.

#### NOTES

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## When Self-Determination Runs Amok

DANIEL CALLAHAN

Callahan is opposed to the use of voluntary euthanasia and assisted suicide. He argues that a person's right of self-determination does not morally justify someone else killing that person, even for mercy's sake. He contends that, contrary to common opinion, there is indeed a moral difference between killing and letting die. A policy that lets physicians practice euthanasia will lead to dire consequences and pervert the profession of medicine.

The euthanasia debate is not just another moral debate, one in a long list of arguments in our pluralistic society. It is profoundly emblematic of three important turning points in Western thought. The first is that of the legitimate conditions under which one person can kill another. The acceptance of voluntary active euthanasia would morally sanction what can only be called "consenting adult killing." By the term I mean the killing of one person by another in the name of their mutual right to be killer and killed if they freely agree to play those roles. This turn flies in the face of a long-standing effort to limit the circumstances under which one person can take the life of another, from efforts to control the free flow of guns and arms, to abolish capital punishment, and to more tightly control warfare.

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Euthanasia would add a whole new category of killing to a society that already has too many excuses to indulge itself in that way.

The second turning point lies in the meaning and limits of self-determination. The acceptance of euthanasia would sanction a view of autonomy holding that individuals may, in the name of their own private, idiosyncratic view of the good life, call upon others, including such institutions as medicine, to help them pursue that life, even at the risk of harm to the common good. This works against the idea that the meaning and scope of our own right to lead our own lives must be conditioned by, and be compatible with, the good of the community, which is more than an aggregate of self-directing individuals.

The third turning point is to be found in the claim being made upon medicine: it should be prepared to make its skills available to individuals to help them achieve their private vision of the good life. This puts medicine in the business of

promoting the individualistic pursuit of general human happiness and well-being. It would overturn the traditional belief that medicine should limit its domain to promoting and preserving human health, redirecting it instead to the relief of that suffering which stems from life itself, not merely from a sick body.

I believe that, at each of these three turning points, proponents of euthanasia push us in the wrong direction. Arguments in favor of euthanasia fall into four general categories, which I will take up in turn: (1) the moral claim of individual self-determination and well-being; (2) the moral irrelevance of the difference between killing and allowing to die; (3) the supposed paucity of evidence to show likely harmful consequences of legalized euthanasia; and (4) the compatibility of euthanasia and medical practice.

### **Self-Determination**

Central to most arguments for euthanasia is the principle of self-determination. People are presumed to have an interest in deciding for themselves, according to their own beliefs about what makes life good, how they will conduct their lives. That is an important value, but the question in the euthanasia context is, What does it mean and how far should it extend? If it were a question of suicide, where a person takes their own life without assistance from another, that principle might be pertinent, at least for debate. But euthanasia is not that limited a matter. The self-determination in that case can only be effected by the moral and physical assistance of another. Euthanasia is thus no longer a matter only of self-determination, but of a mutual, social decision between two people, the one to be killed and the other to do the killing.

How are we to make the moral move from my right of self-determination to some doctor's right to kill me—from *my* right to *his* right? Where does the doctor's moral warrant to kill come from? Ought doctors to be able to kill anyone they want as long as permission is given by competent persons? Is our right to life just like a piece of property, to be given away or alienated if the price (happiness, relief of suffering) is right? And then to be destroyed with our permission once alienated?

In answer to all those questions, I will say this: I have yet to hear a plausible argument why it should be permissible for us to put this kind of power in the hands of another, whether a doctor or anyone else. The idea that we can waive our right to life, and then give to another the power to take that life, requires a justification yet to be provided by anyone.

Slavery was long ago outlawed on the ground that one person should not have the right to own another, even with the other's permission. Why? Because it is a fundamental moral wrong for one person to give over his life and fate to another, whatever the good consequences, and no less a wrong for another person to have that kind of total, final power. Like slavery, dueling was long ago banned on similar grounds: even free, competent individuals should not have the power to kill each other, whatever their motives, whatever the circumstances. Consenting adult killing, like consenting adult slavery or degradation, is a strange route to human dignity.

There is another problem as well. If doctors, once sanctioned to carry out euthanasia, are to be themselves responsible moral agents—not simply hired hands with lethal injections at the ready—then they must have their own *independent* moral grounds to kill those who request such services. What do I mean? As those who favor euthanasia are quick to point out, some people want it because their life has become so burdensome it no longer seems worth living.

The doctor will have a difficulty at this point. The degree and intensity to which people suffer from their diseases and their dying, and whether they find life more of a burden than a benefit, has very little directly to do with the nature or extent of their actual physical condition. Three people can have the same condition, but only one will find the suffering unbearable. People suffer, but suffering is as much a function of the values of individuals as it is of the physical causes of that suffering. Inevitably in that circumstance, the doctor will in effect be treating the patient's values. To be responsible, the doctor would have to share those values. The doctor would have to decide, on her own, whether the patient's life was “no longer worth living.”

But how could a doctor possibly know that or make such a judgment? Just because the patient said

so? I raise this question because, while in Holland at the euthanasia conference reported by Maurice de Wachter . . . , the doctors present agreed that there is no objective way of measuring or judging the claims of patients that their suffering is unbearable. And if it is difficult to measure suffering, how much more difficult to determine the value of a patient's statement that her life is not worth living?

However one might want to answer such questions, the very need to ask them, to inquire into the physician's responsibility and grounds for medical and moral judgment, points out the social nature of the decision. Euthanasia is not a private matter of self-determination. It is an act that requires two people to make it possible, and a complicit society to make it acceptable.

### Killing and Allowing to Die

Against common opinion, the argument is sometimes made that there is no moral difference between stopping life-sustaining treatment and more active forms of killing, such as lethal injection. Instead I would contend that the notion that there is no morally significant difference between omission and commission is just wrong. Consider in its broad implications what the eradication of the distinction implies: that death from disease has been banished, leaving only the actions of physicians in terminating treatment as the cause of death. Biology, which used to bring about death, has apparently been displaced by human agency. Doctors have finally, I suppose, thus genuinely become gods, now doing what nature and the deities once did.

What is the mistake here? It lies in confusing causality and culpability, and in failing to note the way in which human societies have overlaid natural causes with moral rules and interpretations. Causality (by which I mean the direct physical causes of death) and culpability (by which I mean our attribution of moral responsibility to human actions) are confused under three circumstances.

They are confused, first, when the action of a physician in stopping treatment of a patient with an underlying lethal disease is construed as *causing* death. On the contrary, the physician's omission can only bring about death on the condition that the patient's disease will kill him in the absence of

treatment. We may hold the physician morally responsible for the death, if we have morally judged such actions wrongful omissions. But it confuses reality and moral judgment to see an omitted action as having the same causal status as one that directly kills. A lethal injection will kill both a healthy person and a sick person. A physician's omitted treatment will have no effect on a healthy person. Turn off the machine on me, a healthy person, and nothing will happen. It will only, in contrast, bring the life of a sick person to an end because of an underlying fatal disease.

Causality and culpability are confused, second, when we fail to note that judgments of moral responsibility and culpability are human constructs. By that I mean that we human beings, after moral reflection, have decided to call some actions right or wrong, and to devise moral rules to deal with them. When physicians could do nothing to stop death, they were not held responsible for it. When, with medical progress, they began to have some power over death—but only its timing and circumstances, not its ultimate inevitability—moral rules were devised to set forth their obligations. Natural causes of death were not thereby banished. They were, instead, overlaid with a medical ethics designed to determine moral culpability in deploying medical power.

To confuse the judgments of this ethics with the physical causes of death—which is the connotation of the word *kill*—is to confuse nature and human action. People will, one way or another, die of some disease; death will have dominion over all of us. To say that a doctor “kills” a patient by allowing this to happen should only be understood as a moral judgment about the licitness of his omission, nothing more. We can, as a fashion of speech only, talk about a doctor *killing* a patient by omitting treatment he should have provided. It is a fashion of speech precisely because it is the underlying disease that brings death when treatment is omitted; that is its cause, not the physician’s omission. It is a misuse of the word *killing* to use it when a doctor stops a treatment he believes will no longer benefit the patient—when, that is, he steps aside to allow an eventually inevitable death to occur now rather than later. The only deaths that human beings invented

are those that come from direct killing—when, with a lethal injection, we both cause death and are morally responsible for it. In the case of omissions, we do not cause death even if we may be judged morally responsible for it.

This difference between causality and culpability also helps us see why a doctor who has omitted a treatment he should have provided has “killed” that patient while another doctor—performing precisely the same act of omission on another patient in different circumstances—does not kill her, but only allows her to die. The difference is that we have come, by moral convention and conviction, to classify unauthorized or illegitimate omissions as acts of “killing.” We call them “killing” in the expanded sense of the term: a culpable action that permits the real cause of death, the underlying disease, to proceed to its lethal conclusion. By contrast, the doctor who, at the patient’s request, omits or terminates unwanted treatment does not kill at all. Her underlying disease, not his action, is the physical cause of death; and we have agreed to consider actions of that kind to be morally licit. He thus can truly be said to have “allowed” her to die.

If we fail to maintain the distinction between killing and allowing to die, moreover, there are some disturbing possibilities. The first would be to confirm many physicians in their already too-powerful belief that, when patients die or when physicians stop treatment because of the futility of continuing it, they are somehow both morally and physically responsible for the deaths that follow. That notion needs to be abolished, not strengthened. It needlessly and wrongly burdens the physician, to whom should not be attributed the powers of the gods. The second possibility would be that, in every case where a doctor judges medical treatment no longer effective in prolonging life, a quick and direct killing of the patient would be seen as the next, most reasonable step, on grounds of both humanness and economics. I do not see how that logic could easily be rejected.

### **Calculating the Consequences**

When concerns about the adverse social consequences of permitting euthanasia are raised, its advocates tend to dismiss them as unfounded and

overly speculative. On the contrary, recent data about the Dutch experience suggests that such concerns are right on target. From my own discussions in Holland, and from the articles on that subject in this issue and elsewhere, I believe we can now fully see most of the *likely* consequences of legal euthanasia.

Three consequences seem almost certain, in this or any other country: the inevitability of some abuse of the law; the difficulty of precisely writing, and then enforcing, the law; and the inherent slipperiness of the moral reasons for legalizing euthanasia in the first place.

Why is abuse inevitable? One reason is that almost all laws on delicate, controversial matters are to some extent abused. This happens because not everyone will agree with the law as written and will bend it, or ignore it, if they can get away with it. From explicit admissions to me by Dutch proponents of euthanasia, and from the corroborating information provided by the Remmelink Report and the outside studies of Carlos Gomez and John Keown, I am convinced that in the Netherlands there are a substantial number of cases of nonvoluntary euthanasia, that is, euthanasia undertaken without the explicit permission of the person being killed. The other reason abuse is inevitable is that the law is likely to have a low enforcement priority in the criminal justice system. Like other laws of similar status, unless there is an unrelenting and harsh willingness to pursue abuse, violations will ordinarily be tolerated. The worst thing to me about my experience in Holland was the casual, seemingly indifferent attitude toward abuse. I think that would happen everywhere.

Why would it be hard to precisely write, and then enforce, the law? The Dutch speak about the requirement of “unbearable” suffering, but admit that such a term is just about indefinable, a highly subjective matter admitting of no objective standards. A requirement for outside opinion is nice, but it is easy to find complaisant colleagues. A requirement that a medical condition be “terminal” will run aground on the notorious difficulties of knowing when an illness is actually terminal.

Apart from those technical problems there is a more profound worry. I see no way, even in

principle, to write or enforce a meaningful law that can guarantee effective procedural safeguards. The reason is obvious yet almost always overlooked. The euthanasia transaction will ordinarily take place within the boundaries of the private and confidential doctor-patient relationship. No one can possibly know what takes place in that context unless the doctor chooses to reveal it. In Holland, less than 10 percent of the physicians report their acts of euthanasia and do so with almost complete legal impunity. There is no reason why the situation should be any better elsewhere. Doctors will have their own reasons for keeping euthanasia secret, and some patients will have no less a motive for wanting it concealed.

I would mention, finally, that the moral logic of the motives for euthanasia contain within them the ingredients of abuse. The two standard motives for euthanasia and assisted suicide are said to be our right of self-determination, and our claim upon the mercy of others, especially doctors, to relieve our suffering. These two motives are typically spliced together and presented as a single justification. Yet if they are considered independently—and there is no inherent reason why they must be linked—they reveal serious problems. It is said that a competent, adult person should have a right to euthanasia for the relief of suffering. But why must the person be suffering? Does not that stipulation already compromise the principle of self-determination? How can self-determination have any limits? Whatever the person's motives may be, why are they not sufficient?

Consider next the person who is suffering but not competent, who is perhaps demented or mentally retarded. The standard argument would deny euthanasia to that person. But why? If a person is suffering but not competent, then it would seem grossly unfair to deny relief solely on the grounds of incompetence. Are the incompetent less entitled to relief from suffering than the competent? Will it only be affluent, middle-class people, mentally fit and savvy about working the medical system, who can qualify? Do the incompetent suffer less because of their incompetence?

Considered from these angles, there are no good moral reasons to limit euthanasia once the

principle of taking life for that purpose has been legitimated. If we really believe in self-determination, then any competent person should have a right to be killed by a doctor for any reason that suits him. If we believe in the relief of suffering, then it seems cruel and capricious to deny it to the incompetent. There is, in short, no reasonable or logical stopping point once the turn has been made down the road to euthanasia, which could soon turn into a convenient and commodious expressway.

### **Euthanasia and Medical Practice**

A fourth kind of argument one often hears both in the Netherlands and in this country is that euthanasia and assisted suicide are perfectly compatible with the aims of medicine. I would note at the very outset that a physician who participates in another person's suicide already abuses medicine. Apart from depression (the main statistical cause of suicide), people commit suicide because they find life empty, oppressive, or meaningless. Their judgment is a judgment about the value of continued life, not only about health (even if they are sick). Are doctors now to be given the right to make judgments about the kinds of life worth living and to give their blessing to suicide for those they judge wanting? What conceivable competence, technical or moral, could doctors claim to play such a role? Are we to medicalize suicide, turning judgments about its worth and value into one more clinical issue? Yes, those are rhetorical questions.

Yet they bring us to the core of the problem of euthanasia and medicine. The great temptation of modern medicine, not always resisted, is to move beyond the promotion and preservation of health into the boundless realm of general human happiness and well-being. The root problem of illness and mortality is both medical and philosophical or religious. "Why must I die?" can be asked as a technical, biological question or as a question about the meaning of life. When medicine tries to respond to the latter, which it is always under pressure to do, it moves beyond its proper role.

It is not medicine's place to lift from us the burden of that suffering which turns on the meaning we assign to the decay of the body and its eventual death. It is not medicine's place to determine

when lives are not worth living or when the burden of life is too great to be borne. Doctors have no conceivable way of evaluating such claims on the part of patients, and they should have no right to act in response to them. Medicine should try to relieve human suffering, but only that suffering which is brought on by illness and dying as biological phenomena, not that suffering which comes from anguish or despair at the human condition.

Doctors ought to relieve those forms of suffering that medically accompany serious illness and the threat of death. They should relieve pain, do what they can to allay anxiety and uncertainty, and be a comforting presence. As sensitive human beings, doctors should be prepared to respond to patients who ask why they must die, or die in pain. But here the doctor and the patient are at the same level. The

doctor may have no better an answer to those old questions than anyone else; and certainly no special insight from his training as a physician. It would be terrible for physicians to forget this, and to think that in a swift, lethal injection, medicine has found its own answer to the riddle of life. It would be a false answer, given by the wrong people. It would be no less a false answer for patients. They should neither ask medicine to put its own vocation at risk to serve their private interests, nor think that the answer to suffering is to be killed by another. The problem is precisely that, too often in human history, killing has seemed the quick, efficient way to put aside that which burdens us. It rarely helps, and too often simply adds to one evil still another. That is what I believe euthanasia would accomplish. It is self-determination run amok.

## Active and Passive Euthanasia

JAMES RACHELS

In this famous essay, Rachels argues that the traditional distinction between killing and letting die is untenable, that “killing is not in itself any worse than letting die.” If so, then active euthanasia is no worse than passive euthanasia. Thus, doctors may have to distinguish between active and passive euthanasia for legal reasons, but “they should not give the distinction any added authority and weight by writing it into official statements of medical ethics.”

The distinction between active and passive euthanasia is thought to be crucial for medical ethics. The idea is that it is permissible, at least in some cases, to withhold treatment and allow a patient to die, but it is never permissible to take any direct action designed to kill the patient. This doctrine seems to be accepted by most doctors, and it is endorsed in a statement adopted by the House of Delegates of the American Medical Association on December 4, 1973:

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The intentional termination of the life of one human being by another—mercy killing—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association.

The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family.

However, a strong case can be made against this doctrine. In what follows I will set out some of the

relevant arguments, and urge doctors to reconsider their views on this matter.

To begin with a familiar type of situation, a patient who is dying of incurable cancer of the throat is in terrible pain, which can no longer be satisfactorily alleviated. He is certain to die within a few days, even if present treatment is continued, but he does not want to go on living for those days since the pain is unbearable. So he asks the doctor for an end to it, and his family joins in the request.

Suppose the doctor agrees to withhold treatment, as the conventional doctrine says he may. The justification for his doing so is that the patient is in terrible agony, and since he is going to die anyway, it would be wrong to prolong his suffering needlessly. But now notice this. If one simply withdraws treatment, it may take the patient longer to die, and so he may suffer more than he would if more direct action were taken and a lethal injection given. This fact provides strong reason for thinking that, once the initial decision not to prolong his agony has been made, active euthanasia is actually preferable to passive euthanasia, rather than the reverse. To say otherwise is to endorse the option that leads to more suffering rather than less, and is contrary to the humanitarian impulse that prompts the decision not to prolong his life in the first place.

Part of my point is that the process of being “allowed to die” can be relatively slow and painful, whereas being given a lethal injection is relatively quick and painless. Let me give a different sort of example. In the United States about one in 600 babies is born with Down’s syndrome. Most of these babies are otherwise healthy—that is, with only the usual pediatric care, they will proceed to an otherwise normal infancy. Some, however, are born with congenital defects such as intestinal obstructions that require operations if they are to live. Sometimes, the parents and the doctor will decide not to operate, and let the infant die. Anthony Shaw describes what happens then:

... When surgery is denied [the doctor] must try to keep the infant from suffering while natural forces sap the baby’s life away. As a surgeon whose natural inclination is to use the scalpel to fight off death, standing by and watching a salvageable baby die is the most emotionally exhausting experience I

know. It is easy at a conference, in a theoretical discussion, to decide that such infants should be allowed to die. It is altogether different to stand by in the nursery and watch as dehydration and infection wither a tiny being over hours and days. This is a terrible ordeal for me and the hospital staff—much more so than for the parents who never set foot in the nursery.\*

I can understand why some people are opposed to all euthanasia, and insist that such infants must be allowed to live. I think I can also understand why other people favor destroying these babies quickly and painlessly. But why should anyone favor letting “dehydration and infection wither a tiny being over hours and days”? The doctrine that says that a baby may be allowed to dehydrate and wither, but may not be given an injection that would end its life without suffering, seems so patently cruel as to require no further refutation. The strong language is not intended to offend, but only to put the point in the clearest possible way.

My second argument is that the conventional doctrine leads to decisions concerning life and death made on irrelevant grounds.

Consider again the case of the infants with Down’s syndrome who need operations for congenital defects unrelated to the syndrome to live. Sometimes, there is no operation, and the baby dies, but when there is no such defect, the baby lives on. Now, an operation such as that to remove an intestinal obstruction is not prohibitively difficult. The reason why such operations are not performed in these cases is, clearly, that the child has Down’s syndrome and the parents and doctor judge that because of that fact it is better for the child to die.

But notice that this situation is absurd, no matter what view one takes of the lives and potentials of such babies. If the life of such an infant is worth preserving, what does it matter if it needs a simple operation? Or, if one thinks it better that such a baby should not live on, what difference does it make that it happens to have an unobstructed intestinal tract? In either case, the matter of life and

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\*Shaw A: Doctor, Do we have a choice? *The New York Times Magazine*, January 30, 1972, p. 54.

death is being decided on irrelevant grounds. It is the Down's syndrome, and not the intestines, that is the issue. The matter should be decided, if at all, on that basis, and not be allowed to depend on the essentially irrelevant question of whether the intestinal tract is blocked.

What makes this situation possible, of course, is the idea that when there is an intestinal blockage, one can "let the baby die," but when there is no such defect there is nothing that can be done, for one must not "kill" it. The fact that this idea leads to such results as deciding life or death on irrelevant grounds is another good reason why the doctrine should be rejected.

One reason why so many people think that there is an important moral difference between active and passive euthanasia is that they think killing someone is morally worse than letting someone die. But is it? Is killing, in itself, worse than letting die? To investigate this issue, two cases may be considered that are exactly alike except that one involves killing whereas the other involves letting someone die. Then, it can be asked whether this difference makes any difference to the moral assessments. It is important that the cases be exactly alike, except for this one difference, since otherwise one cannot be confident that it is this difference and not some other that accounts for any variation in the assessments of the two cases. So, let us consider this pair of cases:

In the first, Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening while the child is taking his bath, Smith sneaks into the bathroom and drowns the child, and then arranges things so that it will look like an accident.

In the second, Jones also stands to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in planning to drown the child in his bath. However, just as he enters the bathroom Jones sees the child slip and hit his head, and fall face down in the water. Jones is delighted; he stands by, ready to push the child's head back under if it is necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally," as Jones watches and does nothing.

Now Smith killed the child, whereas Jones "merely" let the child die. That is the only difference

between them. Did either man behave better, from a moral point of view? If the difference between killing and letting die were in itself a morally important matter, one should say that Jones's behavior was less reprehensible than Smith's. But does one really want to say that? I think not. In the first place, both men acted from the same motive, personal gain, and both had exactly the same end in view when they acted. It may be inferred from Smith's conduct that he is a bad man, although that judgment may be withdrawn or modified if certain further facts are learned about him—for example, that he is mentally deranged. But would not the very same thing be inferred about Jones from his conduct? And would not the same further considerations also be relevant to any modification of this judgment? Moreover, suppose Jones pleaded, in his own defense, "After all, I didn't do anything except just stand there and watch the child drown. I didn't kill him; I only let him die." Again, if letting die were in itself less bad than killing, this defense should have at least some weight. But it does not. Such a "defense" can only be regarded as a grotesque perversion of moral reasoning. Morally speaking, it is no defense at all.

Now, it may be pointed out, quite properly, that the cases of euthanasia with which doctors are concerned are not like this at all. They do not involve personal gain or the destruction of normal healthy children. Doctors are concerned only with cases in which the patient's life is of no further use to him, or in which the patient's life has become or will soon become a terrible burden. However, the point is the same in these cases: the bare difference between killing and letting die does not, in itself, make a moral difference. If a doctor lets a patient die, for humane reasons, he is in the same moral position as if he had given the patient a lethal injection for humane reasons. If his decision was wrong—if, for example, the patient's illness was in fact curable—the decision would be equally regrettable no matter which method was used to carry it out. And if the doctor's decision was the right one, the method used is not in itself important.

The AMA policy statement isolates the crucial issue very well; the crucial issue is "the intentional termination of the life of one human being by

another." But after identifying this issue, and forbidding "mercy killing," the statement goes on to deny that the cessation of treatment is the intentional termination of a life. This is where the mistake comes in, for what is the cessation of treatment, in these circumstances, if it is not "the intentional termination of the life of one human being by another"? Of course it is exactly that, and if it were not, there would be no point to it.

Many people will find this judgment hard to accept. One reason, I think, is that it is very easy to conflate the question of whether killing is, in itself, worse than letting die, with the very different question of whether most actual cases of killing are more reprehensible than most actual cases of letting die. Most actual cases of killing are clearly terrible (think, for example, of all the murders reported in the newspapers), and one hears of such cases every day. On the other hand, one hardly ever hears of a case of letting die, except for the actions of doctors who are motivated by humanitarian reasons. So one learns to think of killing in a much worse light than of letting die. But this does not mean that there is something about killing that makes it in itself worse than letting die, for it is not the bare difference between killing and letting die that makes the difference in these cases. Rather, the other factors—the murderer's motive of personal gain, for example, contrasted with the doctor's humanitarian motivation—account for different reactions to the different cases.

I have argued that killing is not in itself any worse than letting die: if my contention is right, it follows that active euthanasia is not any worse than passive euthanasia. What arguments can be given on the other side? The most common, I believe, is the following:

"The important difference between active and passive euthanasia is that, in passive euthanasia, the doctor does not do anything to bring about the patient's death. The doctor does nothing, and the patient dies of whatever ills already afflict him. In active euthanasia, however, the doctor does something to bring about the patient's death: he kills him. The doctor who gives the patient with cancer a lethal injection has himself caused his patient's death: whereas if he merely ceases treatment, the cancer is the cause of the death."

A number of points need to be made here. The first is that it is not exactly correct to say that in passive euthanasia the doctor does nothing, for he does do one thing that is very important: he lets the patient die. "Letting someone die" is certainly different, in some respects, from other types of action—mainly in that it is a kind of action that one may perform by way of not performing certain other actions. For example, one may let a patient die by way of not giving medication, just as one may insult someone by way of not shaking his hand. But for any purpose of moral assessment, it is a type of action nonetheless. The decision to let a patient die is subject to moral appraisal in the same way that a decision to kill him would be subject to moral appraisal: it may be assessed as wise or unwise, compassionate or sadistic, right or wrong. If a doctor deliberately let a patient die who was suffering from a routinely curable illness, the doctor would certainly be to blame for what he had done, just as he would be to blame if he had needlessly killed the patient. Charges against him would then be appropriate. If so, it would be no defense at all for him to insist that he didn't "do anything." He would have done something very serious indeed, for he let his patient die.

Fixing the cause of death may be very important from a legal point of view, for it may determine whether criminal charges are brought against the doctor. But I do not think that this notion can be used to show a moral difference between active and passive euthanasia. The reason why it is considered bad to be the cause of someone's death is that death is regarded as a great evil—and so it is. However, if it has been decided that euthanasia—even passive euthanasia—is desirable in a given case, it has also been decided that in this instance death is no greater an evil than the patient's continued existence. And if this is true, the usual reason for not wanting to be the cause of someone's death simply does not apply.

Finally, doctors may think that all of this is only of academic interest—the sort of thing that philosophers may worry about but that has no practical bearing on their own work. After all, doctors must be concerned about the legal consequences of what they do, and active euthanasia is clearly forbidden

by the law. But even so, doctors should also be concerned with the fact that the law is forcing upon them a moral doctrine that may well be indefensible, and has a considerable effect on their practices. Of course, most doctors are not now in the position of being coerced in this matter, for they do not regard themselves as merely going along with what the law requires. Rather, in statements such as the AMA policy statement that I have quoted, they are endorsing this doctrine as a central point of medical ethics. In that statement, active euthanasia is condemned not merely as illegal but as “contrary to that for which the medical profession stands,”

whereas passive euthanasia is approved. However, the preceding considerations suggest that there is really no moral difference between the two, considered in themselves (there may be important moral differences in some cases in their *consequences*, but, as I pointed out, these differences may make active euthanasia, and not passive euthanasia, the morally preferable option). So, whereas doctors may have to discriminate between active and passive euthanasia to satisfy the law, they should not do any more than that. In particular, they should not give the distinction any added authority and weight by writing it into official statements of medical ethics.

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## Dying at the Right Time: Reflections on (Un)Assisted Suicide

JOHN HARDWIG

John Hardwig is a professor emeritus of the Department of Philosophy at the University of Tennessee. In this essay he argues that when “death comes too late,” we may have a duty to die or a duty to help someone else die. Severe, unrelieved pain is just one of several problems that could justify ending a life. Sometimes preserving a life can devastate the lives of those who care about the person. In particularly dire situations, there may be moral justification for unassisted suicide, family-assisted suicide, or physician-assisted suicide.

Let us begin with two observations about chronic illness and death:

1. Death does not always come at the right time. We are all aware of the tragedies involved when death comes too soon. We are afraid that it might come too soon for us. By contrast, we may sometimes be tempted to deny that death can come too late—wouldn’t everyone want to live longer? But in our more sober moments, most of us know perfectly well that death can come too late.

2. Discussions of death and dying usually proceed as if death came only to hermits—or others who are all alone. But most of the time, death is a death in the family. We are connected to family and loved ones. We are sustained by these connections. They are a major part of what makes life worth living for most of us.

Because of these connections, when death comes too soon, the tragedy is often two-fold: a tragedy both for the person who is now dead and for those of us to whom she was connected. We grieve both for our loved one who is gone and for ourselves who have lost her. On one hand, there is the unrealized good that life would have been for the dead person herself—what she could have become, what she

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could have experienced, what she wanted for herself. On the other, there is the contribution she would have made to others and the ways *their* lives would have been enriched by her.

We are less familiar with the idea that death can come too late. But here, too, the tragedy can be two-fold. Death can come too late because of what living on means to the person herself. There are times when someone does not (or would not) want to live like this, times when she believes she would be better off dead. At times like these, suicide or assisted suicide becomes a perfectly rational choice, perhaps even the best available option for her. We are then forced to ask, "Does someone have a right to die?" Assisted suicide may then be an act of compassion, no more than relieving her misery.

There are also, sadly, times when death comes too late because *others*—family and loved ones—would be better off if someone were dead. (Better off overall, despite the loss of a loved one.) Since lives are deeply intertwined, the lives of the rest of the family can be dragged down, impoverished, compromised, perhaps even ruined because of what they must go through if she lives on. When death comes too late because of the effect of someone's life on her loved ones, we are, I think, forced to ask, "Can someone have a duty to die?" Suicide may then be an attempt to do what is right; it may be the only loving thing to do. Assisted suicide would then be helping someone do the right thing.

Most professional ethicists—philosophers, theologians, and bioethicists—react with horror at the very idea of a duty to die. Many of them even argue that euthanasia and physician-assisted suicide should not be legalized because then some people might somehow get the idea that they have a duty to die. To this way of thinking, someone who got that idea could only be the victim of vicious social pressure or perverse moral reasoning. But when I ask my classes for examples of times when death would come too late, one of the first conditions students always mention is: "when I become a burden to my family." I think there is more moral wisdom here than in the dismay of these ethicists.

Death does not always come at the right time. I believe there are conditions under which I would prefer not to live, situations in which I would be

better off dead. But I am also absolutely convinced that I may one day face a duty or responsibility to die. In fact, as I will explain later, I think many of us will one day have this duty.

To my way of thinking, the really serious questions relating to euthanasia and assisted suicide are: Who would be better off dead? Who has a duty to die? *When* is the right time to die? And if my life should be over, who should kill me?<sup>1</sup> However, I know that others find much of what I have said here surprising, shocking, even morally offensive. So before turning to these questions that I want us to think about, I need to explain why I think someone can be better off dead and why someone can have a duty to die. (The explanation of the latter will have to be longer, since it is by far the less familiar and more controversial idea.)

### **When Someone Would Be Better Off Dead**

Others have discussed euthanasia or physician-assisted suicide when the patient would be better off dead.<sup>2</sup> Here I wish to emphasize two points often omitted from discussion: (1) Unrelieved pain is not the only reason someone would be better off dead. (2) Someone can be better off dead even if she has no terminal illness.

(1) If we think about it for even a little while, most of us can come up with a list of conditions under which we believe we would rather be dead than continue to live. Severe and unrelieved pain is one item on that list. Permanent unconsciousness may be another. Dementia so severe that we no longer recognize ourselves or our loved ones is yet another. There are some people who prefer not to live with quadriplegia. A future shaped by severe deterioration (such as that which accompanies MS, ALS, AIDS, or Huntington's chorea) is a future that some people prefer not to live out.

(Our lists would be different because our lives and values are different. The fact that some people would not or do not want to live with quadriplegia or AIDS, for example, does not mean that others should not want to live like that, much less that their lives are not worth living. That is very important. The point here is that almost all of us can make a list of conditions under which we would rather

not live, and that uncontrolled pain is not the only item on most of our lists.)

Focusing the discussion of euthanasia and assisted suicide on pain ignores the many other varieties of suffering that often accompany chronic illness and dying: dehumanization, loss of independence, loss of control, a sense of meaninglessness or purposelessness, loss of mental capabilities, loss of mobility, disorientation and confusion, sorrow over the impact of one's illness and death on one's family, loss of ability even to recognize loved ones, and more. Often, these causes of suffering are compounded by the awareness that the future will be even bleaker. Unrelieved pain is simply not the only condition under which death is preferable to life, nor the only legitimate reason for a desire to end one's life.

(2) In cases of terminal illness, death eventually offers the dying person relief from all her suffering. Consequently, things can be even worse when there is *NO* terminal illness, for then there is no end in sight. Both pain and suffering are often much worse when they are *not* accompanied by a terminal illness. People with progressive dementia, for example, often suffer much more if they are otherwise quite healthy. I personally know several old people who would be delighted to learn that they have a terminal illness. They feel they have lived long enough—long enough to have outlived all their loved ones and all sense of a purpose for living. For them, even daily existence is much worse because there is no end in sight.

Discussions of euthanasia and physician-assisted suicide cannot, then, be restricted to those with unrelieved pain and terminal illness. We must also consider requests made by those who have no untreatable pain and no terminal illness. Often, their case for relief is even more compelling.

Sometimes, a refusal of medical treatment will be enough to bring relief. Competent adults who are suffering from an illness have a well-established moral and legal right to decline any form of medical treatment, including life-prolonging medical treatment. Family members who must make medical decisions for incompetent people also have the right to refuse any form of medical treatment on their behalf, so long as they are acting in accordance with

the known wishes or best interests of their loved one. No form of medical treatment is compulsory when someone would be better off dead.<sup>3</sup>

But those who would be better off dead do not always have terminal illnesses; they will not always need any form of medical treatment, not even medically supplied food and water. The right to refuse medical treatment will not help these people. Moreover, death due to untreated illness can be agonizingly slow, dehumanizing, painful, and very costly, both in financial and emotional terms. It is often very hard. Refusing medical treatment simply will not always ensure a dignified, peaceful, timely death. We would not be having a national debate about physician-assisted suicide and euthanasia if refusal of medical treatment were always enough to lead to a reasonably good death. When death comes too late, we may need to do more than refuse medical treatment.

### **Religion and Ending a Life**

Some people can easily see that there are people who would be better off dead. But they still cannot accept suicide or physician-assisted suicide because they believe we have a duty to God not to take our own lives. For them, human life is a gift from God and it remains a gift no matter how much pain and suffering it may bring. It is a sin or an offense against God, the giver of life, to take your own life or to help someone else end theirs. Such believers may also feel that no one should be allowed to end their lives—every life is a gift from God, even the lives of those who do not believe that this is so.

I do not understand this position for two reasons. First, it involves the assumption that it is possible to take a human life (our own or someone else's) *before* God wants it ended, but we cannot possibly preserve it *after* God wants it ended. For if we do not make that assumption, we face *two dangers*—the danger that we are prolonging human life beyond its divine purpose, as well as the danger that we are ending it too soon. If we can extend life longer than God intends, suicide and physician-assisted suicide may be more in accord with God's wishes than attempts to preserve that life.

I can understand the view that everyone dies at precisely the right time, the moment God intends.

If that is so, people who commit suicide or who are intentionally killed by physicians also die at precisely the moment God wants them to die. I can also understand the view that we can take life before God wants it ended but we can also extend life longer than God wants it prolonged. But I cannot make sense of the view that we can end a human life too soon but not preserve it too long. Surely, God has given us both abilities or neither one.

I also have a second difficulty with this religious objection to suicide, assisted suicide and euthanasia. Suppose there is a right time to die, a divinely ordained moment when God wants each life to end. Even so, we have no right to assume that God will “take my life” when it’s the right time for me to die. In fact, we cannot even assume that God will send a terminal illness that will kill me at the right time. There could be a religious test—God may want me to take my own life and the question is whether I will meet this final challenge. Or a God who loves me might see that I would benefit spiritually from the process of coming to the conclusion that I should end my own life and then preparing to take it. That might be a fitting ending for me, the culminating step in my spiritual growth or development.

In short, a God not totally obsessed with the sheer quantity of our lives may well have purposes for us that are incompatible with longer life—even if we want to live longer. So, I think we should not believe that we always have a duty to God not to take our lives or to assist others in ending theirs. God may want me to step up and assume the responsibility for ending my own life or for seeing that someone else’s suffering is ended. This observation leads to our next question: Can there be a responsibility or duty to die?

### The Duty to Die

I may well one day have a duty to die, a duty most likely to arise out of my connections with my family and loved ones.<sup>4</sup> Sometimes preserving my life can only devastate the lives of those who care about me. I do not believe I am idiosyncratic, morbid or morally perverse in believing this. I am trying to take steps to prepare myself mentally and spiritually to make sure that I will be able to take my life if I should one day have such a duty. I need to prepare

myself; it might be a very difficult thing for me to do.

Our individualistic fantasy about ourselves sometimes leads us to imagine that lives are separate and unconnected, or that they could be so if we chose. If lives were unconnected, then things that happen in my life would not or need not affect others. And if others were not (much) affected by my life, I would have no duty to consider the impact of my life on others. I would then be morally free to choose whatever life and death I prefer for myself. I certainly would have no duty to die when I would prefer to live.

Most discussions of assisted suicide and euthanasia implicitly share this individualistic fantasy: they just ignore the fact that people are connected and lives intertwined. As a result, they approach issues of life or death as if the only person affected is the one who lives or dies. They mistakenly assume the pivotal issue is simply whether the person *herself* prefers not to live like this and whether *she herself* would be better off dead.<sup>5</sup>

But this is morally obtuse. The fact is we are not a race of hermits—most of us are connected to family and loved ones. We prefer it that way. We would not want to be all alone, especially when we are seriously ill, as we age, and when we are dying. But being with others is not all benefits and pleasures; it brings responsibilities, as well. For then what happens to us and the choices we make can dramatically affect the lives of our loved ones. It is these connections that can, tragically, generate obligations to die, as continuing to live takes too much of a toll on the lives of those connected to us.<sup>6</sup>

The lives of our loved ones can, we know, be seriously compromised by caring for us. The burdens of providing care or even just supervision 24 hours a day, 7 days a week, are often overwhelming.<sup>7</sup> But it can also be emotionally devastating simply to be married to a spouse who is increasingly distant, uncommunicative, unresponsive, foreign and unreachable. A local newspaper tells the story of a woman with Alzheimer’s who came running into her den screaming: “That man’s trying to have sex with me! He’s trying to have sex with me! Who IS that man?!” That man was her loving husband of more than 40 years who had devoted the past 10

years of his life to caring for her (Smith, 1995). How terrible that experience must have been for her. But how terrible those years must be for him, too.

We must also acknowledge that the lives of our loved ones can also be devastated just by having to *pay* for health care for us. A recent study documented the financial aspects of caring for a dying member of a family. Only those who had illnesses severe enough to give them less than a 50 percent chance to live six more months were included in this study. When these patients survived their initial hospitalization and were discharged, about one-third required considerable caregiving from their families; in 20 percent of cases a family member had to quit work or make some other major lifestyle change; almost one-third of these families lost all of their savings, and just under 30 percent lost a major source of income (Covinsky et al., 1994).

A chronic illness or debilitating injury in a family is a misfortune. It is, most often, nobody's fault; no one is responsible for this illness or injury. But then we face choices about how we will respond to this misfortune. That is where the responsibility comes in and fault can arise. Those of us with families and loved ones always have a responsibility not to make selfish or self-centered decisions about our lives. We should not do just what we want or just what is best for *us*. Often, we should choose in light of what is best for all concerned.

Our families and loved ones have obligations to stand by us and to support us through debilitating illness and death. They must be prepared to make sacrifices to respond to an illness in the family. We are well aware of this responsibility and most families meet it rather well. In fact, families deliver more than 80 percent of the long-term care in the US, almost always at great personal cost.

But responsibility in a family is not a one-way street. When we become seriously ill or debilitated, we too may have to make sacrifices. There are limits to what we can ask our loved ones to do to support us, even in sickness. There are limits to what they should be prepared to do for us—only rarely and for a limited period of time should they do all they can for us.

Somehow we forget that sick, infirm, and dying adults also have obligations to their families and

loved ones: a responsibility, for example, to try to protect the lives of loved ones from serious threats or greatly impoverished quality, or an obligation to avoid making choices that will jeopardize or seriously compromise their futures. Our obligations to our loved ones must be taken into consideration in making decisions about the end of life. It is out of these responsibilities that a duty to die can develop.

Tragically, sometimes the best thing you can do for your loved ones is to remove yourself from their lives. And the only way you can do that may be to remove yourself from existence. This is not a happy thought. Yet we must recognize that suicides and requests for assisted suicide may be motivated by love. Sometimes, it's simply the only loving thing to do.

### **Who Has a Duty to Die?**

Sometimes it is clear when someone has a duty to die. But more often, not. *WHO* has a duty to die? And *WHEN*—under what conditions? To my mind, these are the right questions, the questions we should be asking. Many of us may one day badly need answers to just these questions.

But I cannot supply answers here, for two reasons. In the first place, answers will have to be very particular and individualized . . . to the person, to the situation of her family, to the relationships within the family, etc. There will not be simple answers that apply to everyone.

Secondly and perhaps even more importantly, those of us with family and loved ones should not define our duties unilaterally. Especially not a decision about a duty to die. It would be isolating and distance-creating for me to decide without consulting them what is too much of a burden for my loved ones to bear. That way of deciding about my moral duties is not only atomistic, it also treats my family and loved ones paternalistically—*THEY* must be allowed to speak for themselves about the burdens my life imposes on them and how they feel about bearing those burdens.

I believe in family decision making. Important decisions for those whose lives are interwoven should be made *together*, in a family discussion. Granted, a conversation about whether I have a

duty to die would often be a tremendously difficult conversation. The temptations to be dishonest in such conversations could be enormous. Nevertheless, if we can, we should have just such an agonizing discussion—partly because it will act as a check on the information, perceptions and reasoning of all of us; but perhaps even more importantly, because it affirms our connectedness at a critical juncture in our lives. Honest talk about difficult matters almost always strengthens relationships.

But many families seem to be unable to talk about death at all, much less a duty to die. Certainly most families could not have this discussion all at once, in one sitting. It might well take a number of discussions to be able to approach this topic. But even if talking about death is impossible, there are always behavioral clues—about your caregiver's tiredness, physical condition, health, prevailing mood, anxiety, outlook, overall well-being, etc. And families unable to talk about death can often talk about those clues. There can be conversations about how the caregiver is feeling, about finances, about tensions within the family resulting from the illness, about concerns for the future. Deciding whether you have a duty to die based on these behavioral clues and conversation about them is more relational than deciding on your own about how burdensome this relationship and care must be.<sup>8</sup>

For these two reasons, I cannot say when someone has a duty to die. But I can suggest a few ideas for discussion of this question. I present them here without much elaboration or explanation.

1. There is more duty to die when prolonging your life will impose greater burdens—emotional burdens, caregiving, disruption of life plans, and, yes, financial hardship—on your family and loved ones. This is the fundamental insight underlying a duty to die.
2. There is greater duty to die if your loved ones' lives have already been difficult or impoverished (not just financially)—if they have had only a small share of the good things that life has to offer.
3. There is more duty to die to the extent that your loved ones have already made great contributions—perhaps even sacrifices—to make

your life a good one. Especially if you have not made similar sacrifices for their well-being.

4. There is more duty to die to the extent that you have *already* lived a full and rich life. You have already had a full share of the good things life offers.
5. Even if you have not lived a full and rich life, there is more duty to die as you grow older. As we become older, there is a diminishing chance that we will be able to make the changes that would now be required to turn our lives around. As we age, we will also be giving up less by giving up our lives, if only because we will sacrifice fewer years of life.
6. There is less duty to die to the extent that you can make a good adjustment to your illness or handicapping condition, for a good adjustment means that smaller sacrifice will be required of loved ones and there is more compensating interaction for them. (However, we must also recognize that some diseases—Alzheimer's or Huntington's chorea—will eventually take their toll on your loved ones no matter how courageously, resolutely, even cheerfully you manage to face that illness.)
7. There is more duty to die to the extent that the part of you that is loved will soon be gone or seriously compromised. There is also more duty to die when you are no longer capable of giving love. Part of the horror of Alzheimer's or Huntington's, again, is that it destroys the person we loved, leaving a stranger and eventually only a shell behind. By contrast, someone can be seriously debilitated and yet clearly still the person we love.

In an old person, “I am not ready to die yet” does not excuse one from a duty to die. To have reached the age of, say, 80 years without being ready to die is itself a moral failing, the sign of a life out of touch with life's basic realities.

A duty to die seems very harsh, and sometimes it is. But if I really do care for my family, a duty to protect their lives will often be accompanied by a deep desire to do so. I will normally *want* to protect

those I love. This is not only my duty, it is also my desire. In fact, I can easily imagine wanting to spare my loved ones the burden of my existence more than I want anything else.

### If I Should Be Dead, Who Should Kill Me?

We need to reframe our discussions of euthanasia and physician-assisted suicide. For we must recognize that pleas for assisted suicide are sometimes requests for relief from pain and suffering, sometimes requests for help in fulfilling one's obligations, and sometimes both. If I should be dead for either of these reasons, who should kill me?

Like a responsible life, a responsible death requires that we think about our choices in the context of the web of relationships of love and care that surround us. We must be sensitive to the suffering as well as the joys we cause others, to the hardships as well as the benefits we create for them. So, when we ask, "Who should kill me?" we must remember that we are asking for a death that will reduce the suffering of *both* me and my family as much as possible. We are searching for the best ending, not only for me, but for *everyone concerned*—in the preparation for death, the moment of death, and afterwards, in the memory and ongoing lives of loved ones and family.

Although we could perhaps define a new profession to assist in suicides—euthanasians??—there are now really only three answers to the question, "Who should kill me?" (1) I should kill myself. (2) A loved one or family member should kill me. (3) A physician should kill me. I will consider these three possibilities. I will call these *unassisted* suicide, *family-assisted* suicide, and *physician-assisted* suicide.

#### I Unassisted Suicide: I Should Kill Myself

The basic intuition here is that each of us should take responsibility for herself. I am primarily the one who wants relief from my pain and suffering, or it is fundamentally my own duty to die and *I* should be the one to do my duty. Moreover, intentionally ending a life is a very messy business—a heavy, difficult thing for anyone to have to do. If possible, I should not drag others into it. Often, I think, this is the right idea—I should be the one to kill myself.

But not always. We must remember that some people are physically unable to do so—they are too weak or incapacitated to commit suicide without assistance. Less persuasive perhaps are those who just can't bring themselves to do it. Without the assistance of someone, many lack the know-how or means to end their lives in a peaceful, dignified fashion. Finally, many attempted suicides—even serious attempts at suicide—fail or result in terrible deaths. Those who have worked in hospitals are familiar with suicide attempts that leave people with permanent brain damage or their faces shot off. There are also fairly common stories of people eating their own vomit after throwing up the medicine they hoped would end their lives.

Even more importantly, if I must be the one to kill myself, that may force me to take my life earlier than would otherwise be necessary. I cannot wait until I become physically debilitated or mentally incompetent, for then it will be too late for me to kill myself. I might be able to live quite comfortably for a couple more years, if I could count on someone else to take my life later. But if I cannot count on help from anyone, I will feel pressure to kill myself when unavoidable suffering for myself or my loved ones appears on the horizon, instead of waiting until it actually arrives.

Finally, many suicides are isolating—I can't die with my loved ones around me if I am planning to use carbon monoxide from automobile exhaust to end my life. For most of us, a meaningful end of life requires an affirmation of our connection with loved ones and so we do not want to die alone.

The social taboo against ending your own life promotes another type of isolation. The secrecy preceding many suicides creates conditions for misunderstanding or lack of understanding on the part of loved ones—Why did she do it? Why didn't I see that she was going to kill herself? Why didn't I do something to help? Secrecy and lack of understanding often compound the suffering family and loved ones go through when someone ends their life.

Unassisted suicide—I should kill myself—is not always the answer. Perhaps, then, my loved ones should participate in ending my life.

## 2 Family-Assisted Suicide: A Member of My Family Should Kill Me

At times, we may have a moral obligation to help others end their lives, especially those close to us, those we love. I can easily imagine myself having an obligation to help a loved one end her life and I hope my family will come to my assistance if my death does not come at the right time. What should be the role of family and loved ones in ending a life?

They might help me get information about reliable and peaceful methods for ending my life. They might also be able to help me get the drugs I need, if that is the method I choose. Like most people, I would also very much want my loved ones to participate, at least to the extent of being there with me when I die.

For reasons already mentioned, I would hope I could talk over my plans with my loved ones, both to reassure myself and check on my reasoning, and also to help them work through some of the emotional reaction to my death. Some people believe that families should not be involved in decisions about the end of life because they are in the grips of powerful emotions that lead to wildly inappropriate decisions. (A familiar example is the difficulty many families have in deciding to withdraw medical treatment even when their loved one is clearly dying.) Families will always be gripped by powerful emotions over a death in the family. But appropriate decisions are not necessarily unemotional or unininvolved decisions. And I think inappropriate reactions or decisions stem largely from lack of the discussions I advocate or from an attempt to compress them into one, brief, pressure-packed conversation, often in the uncomfortable setting of a hospital.

So, a good death for all concerned would usually involve my family—the preparation for taking my life, at least, would be family-assisted. My loved ones should know; they should, if possible, understand. They should not be surprised. Hopefully my loved ones could come to agree with my decision. They should have had time to come to terms with the fact that I plan to end my life. Indeed, I should have helped them begin to deal emotionally with my death. All that would help to ease their suffering and also my concern about how my death will affect

them. It would reaffirm our connectedness. It would also comfort me greatly to feel that I am understood and known by my loved ones as I take this important step.

More than this I cannot ask of them, for two related reasons. The first is that actually killing a loved one would usually be extremely difficult. It would be a searing and unforgettable experience that could well prove very hard to live with afterwards. Killing a loved one at her request *might* leave you feeling relieved—it could give you the satisfaction of feeling you had done what needed to be done. In cases of extreme debility or great suffering, family-assisted suicide might be experienced as a loving act of kindness, compassion and mercy. It would still be very hard. Much harder would be killing me because I have a duty to die, a duty to die because my life is too great a burden *for the one who now must kill me*. I cannot ask that of someone I love. I fear that they would suffer too much from taking my life.

I might be wrong about this, however. It might be that, though difficult indeed, being killed lovingly and with your consent by your spouse or your child would be a final testimonial to a solid, trusting, and caring relationship. There might be no more powerful reaffirmation of the strength of your relationship, even in the face of death. The traumatic experience for the family members who assist in the suicide might be a healing experience for them, as well. We know so little about family-assisted suicide.

But in any case, there is also a second reason: I cannot ask for family-assisted suicide because it is not legally protected—a loved one who killed me might well be charged with murder. I could not ask my family to subject themselves to such a risk. Moreover, unlike physician-assisted suicide, we would not want to legalize family-assisted suicide. The lives of families are just too complex and too often laced with strong negative emotions—guilt, resentment, hatred, anger, desire for revenge. Family members also often have multiple motives stemming from deeply conflicting interests. As a result, there would be just too many cases in which family-assisted suicide would be indistinguishable from murder.<sup>9</sup>

Finally, family members may also fail. They also may lack know-how or bungle the job. Caught in the compelling emotions of grief and/or guilt, they may be unable to end a life that should be ended.

All this notwithstanding, family-assisted suicide may be the right choice, especially if physician-assisted suicide is unavailable. But should it be unavailable?

### 3 Physician-Assisted Suicide: My Doctor Should Kill Me

There are, then, important difficulties with both unassisted suicide and family-assisted suicide. These difficulties are arguments for physician-assisted suicide and euthanasia. If my death comes too late, a physician is often the best candidate to kill me... or at the very least, to help me kill myself.

Perhaps the main argument for physician-assisted suicide grows out of the physician's extensive knowledge of disease and of dying. If it is a medical condition that leads me to contemplate ending my life, a key question for determining *when* or even *whether* I should end my life is: What is the prognosis? To what extent can my illness be treated or at least alleviated? How long do I have to live with my condition? How much worse will it get and how soon? What will life with that condition be like for me and my family? Few besides physicians possess all this critical information. I will be more likely to reach the right decision at the right time if a trusted physician is in on my plans to end my life.

A related point is physicians' knowledge of and access to drugs. Few of us know what drugs to take and in what amounts without the advice of a physician. Often, only a physician will know what to do to ensure that I do not vomit up the "suicide pill" or what to do if it fails. Physicians also have a monopoly on access to drugs. If my physician were more closely involved in the process, I could be more certain—and thus reassured—that my death will be peaceful and dignified, a death that permits reaffirmation of my connections with family and close friends.

A second argument for physician-assisted suicide grows out of physicians' greater experience with death and dying. Physicians know what to expect; those of us outside the health professions often do not. Granted, few physicians nowadays

will know *me* and *my* family. For this reason, physicians should seldom make unilateral decisions about assisted suicide. Still, most physicians could provide a rich source of information about death and about strategies to minimize the trauma, suffering, and agony of a death, both for the dying person and for the family.

Thirdly, physician-assisted suicide does not carry the same social stigma that unassisted suicide carries and physicians are not exposed to the legal risks involved in family-assisted suicide. Although many physicians are unwilling to take *any* risks to help someone end her life, there is really very little legal risk in physician-assisted suicide, especially if the family is in agreement. Physicians are also not morally censored the way family members would be for ending a life.

Finally, physicians ought not to abandon their patients, certainly not at the moment of death. Much has been made of the possibility that Americans would lose their trust in physicians if they knew that physicians sometimes kill. But many of us would trust our physicians *more* if we knew that we could count on them when death is needed or required (Quill and Cassell, 1995).

We have come, then, by a very round-about route to another argument for physician-assisted suicide. Often it is simply better—safer, more secure, more peaceful, less emotionally-damaging for others—than unassisted suicide or family-assisted suicide. If physicians refuse to assist or are not permitted to do so, families and seriously ill people will be forced back on their own resources. And many deaths will be much worse than they need to be. When death comes too late, a physician will often be the best candidate to kill me.

And yet, physician-assisted suicide is not always the answer, either. Many physicians take themselves to be sworn to preserve human life in all its forms. Also, many people want doctors who are sworn not to kill, for fear that physicians might start making presumptuous, single-handed decisions about when death comes too late. Moreover, in a time when most people lack a significant personal relationship with their physicians, physician-assisted suicide is often a death that is remote, isolated, disconnected from the relationships that gave

meaning to life. It is not always the best death. At times, then, family-assisted suicide and unassisted suicide remain the best answers.

### **Conclusion**

We have a long cultural tradition of attempts to deal with the problems of death that comes too soon. Modern medicine, with its dramatic high-tech rescue attempts in the emergency room and the intensive care unit, is our society's attempt to prevent death from coming too soon. On a more personal level, we are bombarded with advice about ways to avoid a death that would be too soon—sooner than we wished, before we were ready for it.

We have much less cultural wisdom about the problems of a death that comes too late. It is almost as if we had spent all our cultural resources trying to avoid deaths that come too soon, only to find that we then had no resources left to help us when death comes too late.

Deaths that come too soon usually raise no difficult moral problems, however difficult they may be in other ways. Such deaths normally occur despite our best attempts to prevent them. "There's nothing more we can do," we say to the dying person, her family, and ourselves. And there is ethical solace in this, despite the tragedy of the death itself. We admit our failure. But our failure is not a moral failure—we did what we could.

Deaths that come too late are ethically much more troubling. They call on us to assume responsibility—to make difficult decisions and to do difficult things. We can try to hide from this responsibility by claiming that we should always try to prolong life, no matter what. Or by not deciding anything. But we know that not to decide is to decide. And it is very often just not clear what we should do. The weight of life-or-death decision pushes down upon us.

The recognition that the lives of members of families are intertwined makes the moral problems of a death that comes too late even more difficult. For they deprive us of our easiest and most comfortable answers—"it's up to the individual," "whatever the patient wants." But we do know that measures to improve or lengthen one life often compromise the quality of the lives of those to whom that person is connected.

So, we are morally troubled by deaths that come too late. We don't know what to do. Beyond that, the whole idea is unfamiliar to us. But in other societies—primarily technologically primitive and especially nomadic societies—almost everyone knew that death could come too late. People in those cultures knew that if they managed to live long enough, death would come too late and they would have to do something about it. They were prepared by their cultural traditions to find meaning in death and to do what needed to be done.

We have largely lost those traditions. Perhaps we have supposed that our wealth and technological sophistication have purchased exemption for us from any need to worry about living too long, from any need to live less than every minute we enjoy living. For a while it looked that way. But we must now face the fact: deaths that come too late are only the other side of our miraculous life-prolonging modern medicine.

We have so far avoided looking at this dark side of our medical triumphs. Our modern medicine saves many lives and enables us to live longer. That is wonderful, indeed. But it thereby also enables more of us to survive longer than we are able to care for ourselves, longer than we know what to do with ourselves, longer than we even *are* ourselves. Moreover, if further medical advances wipe out many of today's "killer diseases"—cancers, AIDS, heart attacks, etc.—then most of us will one day find that death is coming too late. And there will be a very common duty to die.

Our political system and health-care reform (in the USA) are also moving in a direction that will put many more of us in the position of having a duty to die. Measures designed to control costs (for the government, and for employers who pay for retirement benefits and health insurance) often switch the burdens of care onto families. We are dismantling our welfare system and attempting to shift the costs of long-term health care onto families. One important consequence of these measures is that more of us will one day find ourselves a burden to our families and loved ones.<sup>10</sup>

Finally, we ourselves make choices that increase the odds that death will come too late. Patient autonomy gives us the right to make choices about our

own medical treatment. We use that right to opt again and again for life-prolonging treatment—even when we have chronic illnesses, when we are debilitated, and as we begin to die. Despite this autonomy, we may feel we really have no choice, perhaps because we are unable to find meaning in death or to bring our lives to a meaningful close. But if we repeatedly opt for life-prolonging treatment, we thereby also increase the chances that death will come too late. This is the cost of patient autonomy, combined with powerful life-prolonging medical technology and inability to give meaning to death or even to accept it.

Death is very difficult for us. I have tried here to speak about it in plain language; I have used hard words and harsh tones to try to make us attend to troubling realities. We may question the arguments and conclusions of this paper. We should do so. But this questioning must not be fueled by denial or lead to evasion. For one thing seems very clear: We had better start learning how to deal with the problems of a death that comes too late. Some day, many of us will find that we should be dead or that one of our loved ones should be dead. What should we do then? We had better prepare ourselves—mentally, morally, culturally, spiritually, and socially. For many of us, if we are to die at the right time, it will be up to us.

#### NOTES

I get by with a little help from my friends. I wish to thank Hilde and Jim Nelson, Mary English, Tom Townsend, and Hugh LaFollette for helpful comments on earlier versions of this essay. And more: these friends have been my companions and guides throughout my attempt to think through the meaning of love and family in our lives.

1. A note about language: I will be using “responsibility,” “obligation,” and “duty” interchangeably, despite significant differences in meaning. I generally use the word “duty” because it strikes me as a hard word for what can be a hard reality. (It also echoes Richard Lamm’s famous statement: “Old people have a duty to die and get out of the way to give the next generation a chance.”) Similarly, I use “kill” despite its connotations of destruction because I think we should not attempt to soften what we are doing. War and capital punishment

have already taught us too much about how to talk in sweet and attractive ways about what we do. So I have resisted talking about “bringing my life to a close” and similar expressions. I have tried to use the plain, hard words.

2. There are many articles on this topic. Perhaps the classic article is Rachels (1975). It has been widely reprinted. A good collection of articles can be found in the *Journal of Medicine and Philosophy* (June 1993), which was devoted to the topic, “Legal Euthanasia: Ethical Issues in an Era of Legalized Aid in Dying.” Recent anthologies include Beauchamp (1996) and Moreno (1995).

3. A few states in the US—currently (January 1996) New York, Missouri, Delaware, and Michigan—do require that family members be able to supply “clear and convincing evidence” that withdrawal of treatment is what their loved one would have wanted. This can be hard to prove. So it is especially important for those who live in these states to put their wishes about the kind of treatment they would want (if they become unable to decide for themselves) in writing. For information about the laws that apply in your state, write to Choice in Dying, 200 Varick Street, New York, NY 10014, or call them at 212-366-5540.

4. I believe we may also have a duty to ourselves to die, or a duty to the environment or a duty to the next generation to die. But I think for most of us, the strongest duty to die comes from our connections to family and loved ones, and this is the only source of a duty to die that I will consider here.

5. Most bioethicists advocate a “patient-centered ethics”—an ethics which claims only the patient’s interests should be considered in making medical treatment decisions. Most health-care professionals have been trained to accept this ethic and to see themselves as patient advocates. I have argued elsewhere that a patient-centered ethic is deeply mistaken. See Hardwig (1989, 1993).

6. I am considering only mentally competent adults. I do not think those who have never been competent—young children and those with severe retardation—can have moral duties. I do not know whether formerly competent people—e.g., those who have become severely demented—can still have moral duties. But if they cannot, I think some of us may face a duty to die even sooner—before we lose our moral agency.

7. A good account of the burdens of caregiving can be found in Brody (1990). To a large extent, care of the elderly is a women’s issue. Most people who live to be 75 or older are women. But care for the elderly is almost

always provided by women, as well—even when the person who needs care is the husband's parent.

8. Ultimately, in cases of deep and unresolvable disagreement between yourself and your loved ones, you may have to act on *your own* conception of your duty and your own conception of the burdens on them. But that is a fallback position to resort to when the better, more relational ways of arriving at a belief in a duty to die fail or are unavailable.

9. Although this is true, we also need to rethink our reactions to the motives of the family. Because lives are intertwined, if someone "wants Dad to be dead" and is relieved when he dies, this does not necessarily mean that she did not genuinely love him. Or that she is greedy, selfish, or self-centered. Her relief may stem from awareness of his suffering. It could also grow out of recognition of the sad fact that his life was destroying the lives of other family members whom she also loved. 10. Perhaps a more generous political system and a more equitable health-care system could counteract the trend toward a more and more common duty to die. For now, at least, we could pay for the care of those who would otherwise be a burden on their families. If we were prepared to do so, far fewer would face a duty to die. But we (in the US, at least) are not prepared to pay. Moreover, as medical advances enable more people to live longer (though also in various states of disability), it may be that the costs would overwhelm any society. Even if we could afford it, we should not continue to try to buy our way out of the problems of deaths that come

too late. We would be foolish to devote all our resources to creating a society dedicated solely to helping all of us live just as long as we want.

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## The Philosophers' Brief

RONALD DWORKIN, THOMAS NAGEL, ROBERT NOZICK, JOHN RAWLS,  
THOMAS SCANLON, AND JUDITH JARVIS THOMSON

In the 1997 Supreme Court cases *Vacco v. Quill* and *Washington v. Glucksberg*, six prominent philosophers presented this amicus brief, urging that states should recognize a right to assisted suicide. They argued that "individuals have a constitutionally protected interest in making those grave decisions [about their own deaths] for

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Brief for Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson as *Amici Curiae* in Support of Respondents at 2, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96–110), and *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95–1858).

themselves, free from the imposition of any religious or philosophical orthodoxy by court or legislature.” They conceded that states have a legitimate interest in protecting people from irrational or unstable decisions about their dying but asserted that states cannot deny people wishing to die a chance to demonstrate that their decisions are informed, stable, and free. They maintained that there is no morally significant difference between a physician deliberately withdrawing medical treatment to let a patient die from a natural process and a physician hastening the patient’s death by more active means.

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Amici are six moral and political philosophers who differ on many issues of public morality and policy. They are united, however, in their conviction that respect for fundamental principles of liberty and justice, as well as for the American constitutional tradition, requires that the decisions of the Courts of Appeals be affirmed.

### **Introduction and Summary of Argument**

These cases do not invite or require the Court to make moral, ethical, or religious judgments about how people should approach or confront their death or about when it is ethically appropriate to hasten one’s own death or to ask others for help in doing so. On the contrary, they ask the Court to recognize that individuals have a constitutionally protected interest in making those grave judgments for themselves, free from the imposition of any religious or philosophical orthodoxy by court or legislature. States have a constitutionally legitimate interest in protecting individuals from irrational, ill-informed, pressured, or unstable decisions to hasten their own death. To that end, states may regulate and limit the assistance that doctors may give individuals who express a wish to die. But states may not deny people in the position of the patient-plaintiffs in these cases the opportunity to demonstrate, through whatever reasonable procedures the state might institute—even procedures that err on the side of caution—that their decision to die is indeed informed, stable, and fully free. Denying that opportunity to terminally ill patients who are in agonizing pain or otherwise doomed to an existence they regard as intolerable could only be justified on the basis of a religious or ethical conviction about the value or meaning of life itself. Our Constitution forbids government to impose such convictions on its citizens.

Petitioners [i. e., the state authorities of Washington and New York] and the amici who support them offer two contradictory arguments. Some deny that the patient-plaintiffs have any constitutionally protected liberty interest in hastening their own deaths. But that liberty interest flows directly from this Court’s previous decisions. It flows from the right of people to make their own decisions about matters “involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy,” *Planned Parenthood v. Casey*, 505 U.S. 833, 851(1992).

The Solicitor General, urging reversal in support of Petitioners, recognizes that the patient-plaintiffs do have a constitutional liberty interest at stake in these cases. See Brief for the United States as Amicus Curiae Supporting Petitioners at 12, *Washington v. Vacco* (hereinafter Brief for the United States) (“The term ‘liberty’ in the Due Process Clause . . . is broad enough to encompass an interest on the part of terminally ill, mentally competent adults in obtaining relief from the kind of suffering experienced by the plaintiffs in this case, which includes not only severe physical pain, but also the despair and distress that comes from physical deterioration and the inability to control basic bodily functions.”); see also *id.* at 13 (“*Cruzan* . . . supports the conclusion that a liberty interest is at stake in this case.”)

The Solicitor General nevertheless argues that Washington and New York properly ignored this profound interest when they required the patient-plaintiffs to live on in circumstances they found intolerable. He argues that a state may simply declare that it is unable to devise a regulatory scheme that would adequately protect patients whose desire to die might be ill informed or unstable or foolish or not fully free, and that a state may therefore fall

back on a blanket prohibition. This Court has never accepted that patently dangerous rationale for denying protection altogether to a conceded fundamental constitutional interest. It would be a serious mistake to do so now. If that rationale were accepted, an interest acknowledged to be constitutionally protected would be rendered empty.

## Argument

### I. The Liberty Interest Asserted Here Is Protected by the Due Process Clause

The Due Process Clause of the Fourteenth Amendment protects the liberty interest asserted by the patient-plaintiffs here.

Certain decisions are momentous in their impact on the character of a person's life decisions about religious faith, political and moral allegiance, marriage, procreation, and death, for example. Such deeply personal decisions pose controversial questions about how and why human life has value. In a free society, individuals must be allowed to make those decisions for themselves, out of their own faith, conscience, and convictions. This Court has insisted, in a variety of contexts and circumstances, that this great freedom is among those protected by the Due Process Clause as essential to a community of "ordered liberty." *Palko v. Connecticut*, 302 U.S. 319, 325 (1937). In its recent decision in *Planned Parenthood v. Casey*, 505 U.S. 833, 851(1992), the Court offered a paradigmatic statement of that principle:

matters involving the most intimate and personal choices a person may make in a lifetime, choices central to a person's dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment.

That declaration reflects an idea underlying many of our basic constitutional protections. As the Court explained in *West Virginia State Board of Education v. Barnette*, 319 U.S. 624, 642 (1943):

If there is any fixed star in our constitutional constellation, it is that no official . . . can prescribe what shall be orthodox in politics, nationalism, religion, or other matters of opinion or force citizens to confess by word or act their faith therein.

A person's interest in following his own convictions at the end of life is so central a part of the more

general right to make "intimate and personal choices" for himself that a failure to protect that particular interest would undermine the general right altogether. Death is, for each of us, among the most significant events of life. As the Chief Justice said in *Cruzan v. Missouri*, 497 U.S. 261, 281 (1990), "[t]he choice between life and death is a deeply personal decision of obvious and overwhelming finality." Most of us see death—whatever we think will follow it—as the final act of life's drama, and we want that last act to reflect our own convictions, those we have tried to live by, not the convictions of others forced on us in our most vulnerable moment.

Different people, of different religious and ethical beliefs, embrace very different convictions about which way of dying confirms and which contradicts the value of their lives. Some fight against death with every weapon their doctors can devise. Others will do nothing to hasten death even if they pray it will come soon. Still others, including the patient-plaintiffs in these cases, want to end their lives when they think that living on, in the only way they can, would disfigure rather than enhance the lives they had created. Some people make the latter choice not just to escape pain. Even if it were possible to eliminate all pain for a dying patient—and frequently that is not possible—that would not end or even much alleviate the anguish some would feel at remaining alive, but intubated, helpless, and often sedated near oblivion.

None of these dramatically different attitudes about the meaning of death can be dismissed as irrational. None should be imposed, either by the pressure of doctors or relatives or by the fiat of government, on people who reject it. Just as it would be intolerable for government to dictate that doctors never be permitted to try to keep someone alive as long as possible, when that is what the patient wishes, so it is intolerable for government to dictate that doctors may never, under any circumstances, help someone to die who believes that further life means only degradation. The Constitution insists that people must be free to make these deeply personal decisions for themselves and must not be forced to end their lives in a way that appalls them, just because that is what some majority thinks proper.

## II. This Court's Decisions in *Casey* and *Cruzan* Compel Recognition of a Liberty Interest Here

**A. *Casey* Supports the Liberty Interest Asserted Here** In *Casey*, this Court, in holding that a state cannot constitutionally proscribe abortion in all cases, reiterated that the Constitution protects a sphere of autonomy in which individuals must be permitted to make certain decisions for themselves. The Court began its analysis by pointing out that “[a]t the heart of liberty is the right to define one’s own concept of existence, of meaning, of the universe, and of the mystery of human life.” 505 U.S. at 851. Choices flowing out of these conceptions, on matters “involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment.” *Id.* “Beliefs about these matters,” the Court continued, “could not define the attributes of personhood were they formed under compulsion of the State.” *Id.*

In language pertinent to the liberty interest asserted here, the Court explained why decisions about abortion fall within this category of “personal and intimate” decisions. A decision whether or not to have an abortion, “originat[ing] within the zone of conscience and belief,” involves conduct in which “the liberty of the woman is at stake in a sense unique to the human condition and so unique to the law.” *Id.* at 852. As such, the decision necessarily involves the very “destiny of the woman” and is inevitably “shaped to a large extent on her own conception of her spiritual imperatives and her place in society.” *Id.* Precisely because of these characteristics of the decision, “the State is [not] entitled to proscribe [abortion] in all instances.” *Id.* Rather, to allow a total prohibition on abortion would be to permit a state to impose one conception of the meaning and value of human existence on all individuals. This the Constitution forbids.

The Solicitor General nevertheless argues that the right to abortion could be supported on grounds other than this autonomy principle, grounds that would not apply here. He argues, for example, that the abortion right might flow from the great burden an unwanted child imposes on its mother’s life.

Brief for the United States at 14–15. But whether or not abortion rights could be defended on such grounds, they were not the grounds on which this Court in fact relied. To the contrary, the Court explained at length that the right flows from the constitutional protection accorded all individuals to “define one’s own concept of existence, of meaning, of the universe, and of the mystery of human life.” *Casey*, 505 U.S. at 851.

The analysis in *Casey* compels the conclusion that the patient-plaintiffs have a liberty interest in this case that a state cannot burden with a blanket prohibition. Like a woman’s decision whether to have an abortion, a decision to die involves one’s very “destiny” and inevitably will be “shaped to a large extent on [one’s] own conception of [one’s] spiritual imperatives and [one’s] place in society” *Id.* at 852. Just as a blanket prohibition on abortion would involve the improper imposition of one conception of the meaning and value of human existence on all individuals, so too would a blanket prohibition on assisted suicide. The liberty interest asserted here cannot be rejected without undermining the rationale of *Casey*. Indeed, the lower court opinions in the Washington case expressly recognized the parallel between the liberty interest in *Casey* and the interest asserted here. See *Compassion in Dying v. Washington*, 79 F.3d 790, 801 (9th Cir. 1996) (en banc) (“In deciding right-to-die cases, we are guided by the Court’s approach to the abortion cases. *Casey* in particular provides a powerful precedent, for in that case the Court had the opportunity to evaluate its past decisions and to determine whether to adhere to its original judgment.”), aff’g. 850 F. Supp. 1454, 1459 (W. D. Wash. 1994) (“[T]he reasoning in *Casey* [is] highly instructive and almost prescriptive . . .”). This Court should do the same.

**B. *Cruzan* Supports the Liberty Interest Asserted Here** We agree with the Solicitor General that this Court’s decision in “*Cruzan* . . . supports the conclusion that a liberty interest is at stake in this case.” Brief for the United States at 8. Petitioners, however, insist that the present cases can be distinguished because the right at issue in *Cruzan* was limited to a right to reject an unwanted invasion of one’s body.<sup>1</sup> But this Court repeatedly has held that in

appropriate circumstances a state may require individuals to accept unwanted invasions of the body. See, e.g., *Schmerber v. California*, 384 U.S. 757 (1966) (extraction of blood sample from individual suspected of driving while intoxicated, notwithstanding defendant's objection, does not violate privilege against self-incrimination or other constitutional rights); *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (upholding compulsory vaccination for smallpox as reasonable regulation for protection of public health).

The liberty interest at stake in *Cruzan* was a more profound one. If a competent patient has a constitutional right to refuse life-sustaining treatment, then, the Court implied, the state could not override that right. The regulations upheld in *Cruzan* were designed only to ensure that the individual's wishes were ascertained correctly. Thus, if *Cruzan* implies a right of competent patients to refuse life-sustaining treatment, that implication must be understood as resting not simply on a right to refuse bodily invasions but on the more profound right to refuse medical intervention when what is at stake is a momentous personal decision, such as the timing and manner of one's death. In her concurrence, Justice O'Connor expressly recognized that the right at issue involved a "deeply personal decision" that is "inextricably intertwined" with our notion of "self-determination." 497 U.S. at 287–89.

*Cruzan* also supports the proposition that a state may not burden a terminally ill patient's liberty interest in determining the time and manner of his death by prohibiting doctors from terminating life support. Seeking to distinguish *Cruzan*, Petitioners insist that a state may nevertheless burden that right in a different way by forbidding doctors to assist in the suicide of patients who are not on life-support machinery. They argue that doctors who remove life support are only allowing a natural process to end in death whereas doctors who prescribe lethal drugs are intervening to cause death. So, according to this argument, a state has an independent justification for forbidding doctors to assist in suicide that it does not have for forbidding them to remove life support. In the former case though not the latter, it is said, the state forbids an act of killing that is morally much more problematic than merely letting a patient die.

This argument is based on a misunderstanding of the pertinent moral principles. It is certainly true that when a patient does not wish to die, different acts, each of which foreseeably results in his death, nevertheless have very different moral status. When several patients need organ transplants and organs are scarce, for example, it is morally permissible for a doctor to deny an organ to one patient, even though he will die without it, in order to give it to another. But it is certainly not permissible for a doctor to kill one patient in order to use his organs to save another. The morally significant difference between those two acts is not, however, that killing is a positive act and not providing an organ is a mere omission, or that killing someone is worse than merely allowing a "natural" process to result in death. It would be equally impermissible for a doctor to let an injured patient bleed to death, or to refuse antibiotics to a patient with pneumonia—in each case the doctor would have allowed death to result from a "natural" process—in order to make his organs available for transplant to others. A doctor violates his patient's rights whether the doctor acts or refrains from acting, against the patient's wishes, in a way that is designed to cause death.

When a competent patient does want to die, the moral situation is obviously different, because then it makes no sense to appeal to the patient's right not to be killed as a reason why an act designed to cause his death is impermissible. From the patient's point of view, there is no morally pertinent difference between a doctor's terminating treatment that keeps him alive, if that is what he wishes, and a doctor's helping him to end his own life by providing lethal pills he may take himself, when ready, if that is what he wishes—except that the latter may be quicker and more humane. Nor is that a pertinent difference from the doctor's point of view. If and when it is permissible for him to act with death in view, it does not matter which of those two means he and his patient choose. If it is permissible for a doctor deliberately to withdraw medical treatment in order to allow death to result from a natural process, then it is equally permissible for him to help his patient hasten his own death more actively, if that is the patient's express wish.

It is true that some doctors asked to terminate life support are reluctant and do so only in deference to a patient's right to compel them to remove unwanted invasions of his body. But other doctors, who believe that their most fundamental professional duty is to act in the patient's interests and that, in certain circumstances, it is in their patient's best interests to die, participate willingly in such decisions: they terminate life support to cause death because they know that is what their patient wants. *Cruzan* implied that a state may not absolutely prohibit a doctor from deliberately causing death, at the patient's request, in that way and for that reason. If so, then a state may not prohibit doctors from deliberately using more direct and often more humane means to the same end when that is what a patient prefers. The fact that failing to provide life-sustaining treatment may be regarded as "only letting nature take its course" is no more morally significant in this context, when the patient wishes to die, than in the other, when he wishes to live. Whether a doctor turns off a respirator in accordance with the patient's request or prescribes pills that a patient may take when he is ready to kill himself, the doctor acts with the same intention: to help the patient die.

The two situations do differ in one important respect. Since patients have a right not to have life-support machinery attached to their bodies, they have, in principle, a right to compel its removal. But that is not true in the case of assisted suicide: patients in certain circumstances have a right that the state not forbid doctors to assist in their deaths, but they have no right to compel a doctor to assist them. The right in question, that is, is only a right to the help of a willing doctor.

### III. State Interests Do Not Justify a Categorical Prohibition on All Assisted Suicide

The Solicitor General concedes that "a competent, terminally ill adult has a constitutionally cognizable liberty interest in avoiding the kind of suffering experienced by the plaintiffs in this case." Brief for the United States at 8. He agrees that this interest extends not only to avoiding pain, but to avoiding an existence the patient believes to be one of intolerable indignity or incapacity as well. *Id.* at 12. The

Solicitor General argues, however, that states nevertheless have the right to "override" this liberty interest altogether, because a state could reasonably conclude that allowing doctors to assist in suicide, even under the most stringent regulations and procedures that could be devised, would unreasonably endanger the lives of a number of patients who might ask for death in circumstances when it is plainly not in their interests to die or when their consent has been improperly obtained.

This argument is unpersuasive, however, for at least three reasons. *First*, in *Cruzan*, this Court noted that its various decisions supported the recognition of a general liberty interest in refusing medical treatment, even when such refusal could result in death. 497 U.S. at 278–79. The various risks described by the Solicitor General apply equally to those situations. For instance, a patient kept alive only by an elaborate and disabling life-support system might well become depressed, and doctors might be equally uncertain whether the depression is curable: such a patient might decide for death only because he has been advised that he will die soon anyway or that he will never live free of the burdensome apparatus, and either diagnosis might conceivably be mistaken. Relatives or doctors might subtly or crudely influence that decision, and state provision for the decision may (to the same degree in this case as if it allowed assisted suicide) be thought to encourage it.

Yet there has been no suggestion that states are incapable of addressing such dangers through regulation. In fact, quite the opposite is true. In *McKay v. Bergstedt*, 106 Nev. 808, 801 P.2d 617 (1990), for example, the Nevada Supreme Court held that "competent adult patients desiring to refuse or discontinue medical treatment" must be examined by two nonattending physicians to determine whether the patient is mentally competent, understands his prognosis and treatment options, and appears free of coercion or pressure in making his decision. *Id.* at 827–28, 801 P.2d at 630. See also: *id.* (in the case of terminally ill patients with natural life expectancy of less than six months, [a] patient's right of self-determination shall be deemed to prevail over state interests, whereas [a] non-terminal patient's decision to terminate life-support systems must first be

weighed against relevant state interests by trial judge); [and] *In re Farrell*, 108 N.J. 335, 354, 529 A.2d 404, 413 (1987) ([which held that a] terminally-ill patient requesting termination of life-support must be determined to be competent and properly informed about [his] prognosis, available treatment options and risks, and to have made decision voluntarily and without coercion). Those protocols served to guard against precisely the dangers that the Solicitor General raises. The case law contains no suggestion that such protocols are inevitably insufficient to prevent deaths that should have been prevented.

Indeed, the risks of mistake are overall greater in the case of terminating life support. *Cruzan* implied that a state must allow individuals to make such decisions through an advance directive stipulating either that life support be terminated (or not initiated) in described circumstances when the individual was no longer competent to make such a decision himself, or that a designated proxy be allowed to make that decision. All the risks just described are present when the decision is made through or pursuant to such an advance directive, and a grave further risk is added: that the directive, though still in force, no longer represents the wishes of the patient. The patient might have changed his mind before he became incompetent, though he did not change the directive, or his proxy may make a decision that the patient would not have made himself if still competent. In *Cruzan*, this Court held that a state may limit these risks through reasonable regulation. It did not hold—or even suggest—that a state may avoid them through a blanket prohibition that, in effect, denies the liberty interest altogether.

*Second*, nothing in the record supports the [Solicitor General's] conclusion that no system of rules and regulations could adequately reduce the risk of mistake. As discussed above, the experience of states in adjudicating requests to have life-sustaining treatment removed indicates the opposite. The Solicitor General has provided no persuasive reason why the same sort of procedures could not be applied effectively in the case of a competent individual's request for physician-assisted suicide.

Indeed, several very detailed schemes for regulating physician-assisted suicide have been submitted to the voters of some states and one has been

enacted. In addition, concerned groups, including a group of distinguished professors of law and other professionals, have drafted and defended such schemes. See, e.g., Charles H. Baron, et. al, *A Model State Act to Authorize and Regulate Physician-Assisted Suicide*, 33 Harv. J. Legis. 1 (1996). Such draft statutes propose a variety of protections and review procedures designed to insure against mistakes, and neither Washington nor New York attempted to show that such schemes would be porous or ineffective. Nor does the Solicitor General's brief: it relies instead mainly on flat and conclusory statements. It cites a New York Task Force report, written before the proposals just described were drafted, whose findings have been widely disputed and were implicitly rejected in the opinion of the Second Circuit below. See generally *Quill v. Vacco*, 80 F.3d 716 (2d Cir. 1996). The weakness of the Solicitor General's argument is signaled by his strong reliance on the experience in the Netherlands which, in effect, allows assisted suicide pursuant to published guidelines. Brief for the United States at 23–24. The Dutch guidelines are more permissive than the proposed and model American statutes, however. The Solicitor General deems the Dutch practice of ending the lives of people like neonates who cannot consent particularly noteworthy, for example, but that practice could easily and effectively be made illegal by any state regulatory scheme without violating the Constitution.

The Solicitor General's argument would perhaps have more force if the question before the Court were simply whether a state has any rational basis for an absolute prohibition; if that were the question, then it might be enough to call attention to risks a state might well deem not worth running. But as the Solicitor General concedes, the question here is a very different one: whether a state has interests sufficiently compelling to allow it to take the extraordinary step of altogether refusing the exercise of a liberty interest of constitutional dimension. In those circumstances, the burden is plainly on the state to demonstrate that the risk of mistakes is very high, and that no alternative to complete prohibition would adequately and effectively reduce those risks. Neither of the Petitioners has made such a showing.

Nor could they. The burden of proof on any state attempting to show this would be very high. Consider, for example, the burden a state would have to meet to show that it was entitled altogether to ban public speeches in favor of unpopular causes because it could not guarantee, either by regulations short of an outright ban or by increased police protection, that such speeches would not provoke a riot that would result in serious injury or death to an innocent party. Or that it was entitled to deny those accused of crime the procedural rights that the Constitution guarantees, such as the right to a jury trial, because the security risk those rights would impose on the community would be too great. One can posit extreme circumstances in which some such argument would succeed. See, e.g., *Korematsu v. United States*, 323 U.S., 214 (1944) (permitting United States to detain individuals of Japanese ancestry during wartime). But these circumstances would be extreme indeed, and the *Korematsu* ruling has been widely and severely criticized.

Third, it is doubtful whether the risks the Solicitor General cites are even of the right character to serve as justification for an absolute prohibition on the exercise of an important liberty interest. The risks fall into two groups. The first is the risk of medical mistake, including a misdiagnosis of competence or terminal illness. To be sure, no scheme of regulation, no matter how rigorous, can altogether guarantee that medical mistakes will not be made. But the Constitution does not allow a state to deny patients a great variety of important choices, for which informed consent is properly deemed necessary, just because the information on which the consent is given may, in spite of the most strenuous efforts to avoid mistake, be wrong. Again, these identical risks are present in decisions to terminate life support, yet they do not justify an absolute prohibition on the exercise of the right.

The second group consists of risks that a patient will be unduly influenced by considerations that the state might deem it not in his best interests to be swayed by, for example, the feelings and views of close family members. Brief for the United States at 20. But what a patient regards as proper grounds for such a decision normally reflects exactly the judgments of personal ethics—of why his life is

important and what affects its value—that patients have a crucial liberty interest in deciding for themselves. Even people who are dying have a right to hear and, if they wish, act on what others might wish to tell or suggest or even hint to them, and it would be dangerous to suppose that a state may prevent this on the ground that it knows better than its citizens when they should be moved by or yield to particular advice or suggestion in the exercise of their right to make fateful personal decisions for themselves. It is not a good reply that some people may not decide as they really wish—as they would decide, for example, if free from the “pressure” of others. That possibility could hardly justify the most serious pressure of all—the criminal law which tells them that they may not decide for death if they need the help of a doctor in dying, no matter how firmly they wish it.

There is a fundamental infirmity in the Solicitor General’s argument. He asserts that a state may reasonably judge that the risk of “mistake” to some persons justifies a prohibition that not only risks but insures and even aims at what would undoubtedly be a vastly greater number of “mistakes” of the opposite kind—preventing many thousands of competent people who think that it disfigures their lives to continue living, in the only way left to them, from escaping that—to them—terrible injury. A state grievously and irreversibly harms such people when it prohibits that escape. The Solicitor General’s argument may seem plausible to those who do not agree that individuals are harmed by being forced to live on in pain and what they regard as indignity. But many other people plainly do think that such individuals are harmed, and a state may not take one side in that essentially ethical or religious controversy as its justification for denying a crucial liberty.

Of course, a state has important interests that justify regulating physician-assisted suicide. It may be legitimate for a state to deny an opportunity for assisted suicide when it acts in what it reasonably judges to be the best interests of the potential suicide, and when its judgment on that issue does not rest on contested judgments about “matters involving the most intimate and personal choices a person may make in a lifetime, choices central to personal

dignity and autonomy.” *Casey*, 505 U.S. at 851. A state might assert, for example, that people who are not terminally ill, but who have formed a desire to die, are, as a group, very likely later to be grateful if they are prevented from taking their own lives. It might then claim that it is legitimate, out of concern for such people, to deny any of them a doctor’s assistance [in taking their own lives].

This Court need not decide now the extent to which such paternalistic interests might override an individual’s liberty interest. No one can plausibly claim, however—and it is noteworthy that neither Petitioners nor the Solicitor General does claim—that any such prohibition could serve the interests of any significant number of terminally ill patients. On the contrary, any paternalistic justification for an absolute prohibition of assistance to such patients would of necessity appeal to a widely contested religious or ethical conviction many of them, including the patient-plaintiffs, reject. Allowing *that* justification to prevail would vitiate the liberty interest.

Even in the case of terminally ill patients, a state has a right to take all reasonable measures to insure that a patient requesting such assistance has made an informed, competent, stable and uncoerced decision. It is plainly legitimate for a state to establish procedures through which professional and administrative judgments can be made about these matters, and to forbid doctors to assist in suicide when its reasonable procedures have not been satisfied. States may be permitted considerable leeway in designing such procedures. They may be permitted, within reason, to err on what they take to be the side of caution. But they may not use the bare possibility of error as justification for refusing to establish any procedures at all and relying instead on a flat prohibition.

### **Conclusion**

Each individual has a right to make the “most intimate and personal choices central to personal dignity and autonomy.” That right encompasses the right to exercise some control over the time and manner of one’s death.

The patient-plaintiffs in these cases were all mentally competent individuals in the final phase

of terminal illness and died within months of filing their claims.

Jane Doe described how her advanced cancer made even the most basic bodily functions such as swallowing, coughing, and yawning extremely painful and that it was “not possible for [her] to reduce [her] pain to an acceptable level of comfort and to retain an alert state.” Faced with such circumstances, she sought to be able to “discuss freely with [her] treating physician [her] intention of hastening [her] death through the consumption of drugs prescribed for that purpose.” *Quill v. Vacco*, 80 F.2d 716, 720 (2d Cir. 1996) (quoting declaration of Jane Doe).

George A. Kingsley, in advanced stages of AIDS which included, among other hardships, the attachment of a tube to an artery in his chest which made even routine functions burdensome and the development of lesions on his brain, sought advice from his doctors regarding prescriptions which could hasten his impending death. *Id.*

Jane Roe, suffering from cancer since 1988, had been almost completely bedridden since 1993 and experienced constant pain which could not be alleviated by medication. After undergoing counseling for herself and her family, she desired to hasten her death by taking prescription drugs. *Compassion in Dying v. Washington*, 850 F. Supp. 1454, 1456 (1994).

John Doe, who had experienced numerous AIDS-related ailments since 1991, was “especially cognizant of the suffering imposed by a lingering terminal illness because he was the primary caregiver for his long-term companion who died of AIDS” and sought prescription drugs from his physician to hasten his own death after entering the terminal phase of AIDS. *Id.* at 1456–57.

James Poe suffered from emphysema which caused him “a constant sensation of suffocating” as well as a cardiac condition which caused severe leg pain. Connected to an oxygen tank at all times but unable to calm the panic reaction associated with his feeling of suffocation even with regular doses of morphine, Mr. Poe sought physician-assisted suicide. *Id.* at 1457.

A state may not deny the liberty claimed by the patient-plaintiffs in these cases without providing them an opportunity to demonstrate, in whatever way the state might reasonably think wise and

necessary, that the conviction they expressed for an early death is competent, rational, informed, stable, and uncoerced.

Affirming the decisions by the Courts of Appeals would establish nothing more than that there is such a constitutionally protected right in principle. It would establish only that some individuals, whose decisions for suicide plainly cannot be dismissed as irrational or foolish or premature, must be accorded a reasonable opportunity to show that their decision for death is informed and free. It is not necessary to decide precisely which patients are entitled to that opportunity. If, on the other hand, this Court reverses the decisions below, its decision could only be justified by the momentous proposition—a proposition flatly in conflict with the spirit and letter of the Court's past decisions—that an American citizen does not, after all, have the right,

even in principle, to live and die in the light of his own religious and ethical beliefs, his own convictions about why his life is valuable and where its value lies.

#### NOTE

1. In that case, the parents of Nancy Cruzan, a woman who was in a persistent vegetative state following an automobile accident, asked the Missouri courts to authorize doctors to end life support and therefore her life. The Supreme Court held that Missouri was entitled to demand explicit evidence that Ms. Cruzan had made a decision that she would not wish to be kept alive in those circumstances, and to reject the evidence the family had offered as inadequate. But a majority of justices assumed, for the sake of the argument, that a competent patient has a right to reject life-preserving treatment, and it is now widely assumed that the Court would so rule in an appropriate case.

## Legalizing Assisted Dying Is Dangerous for Disabled People

LIZ CARR

Liz Carr, a disabled person, sees a curious discrepancy in people's attitudes toward assisted suicide for healthy, nondisabled persons and assisted suicide for the disabled. In the former case, she says, suicide is seen as a tragedy, but in the latter, people seem much too eager to view assisted suicide as understandable under the circumstances. As she points out, "the sympathy we disabled people evoke can be used to justify support for us to kill ourselves while non-disabled people are told they have 'everything to live for.' . . . Please, don't wish death upon us because you feel pity for our condition." She argues that, given such attitudes toward disabled persons, legalizing assisted dying could be dangerous for them.

If I said I wanted to die, the press, celebrities and the public would support my choice, seeing it as rational and understandable. Hell, they would probably set up a go-fund-me campaign to help me make it happen.

Liz Carr, "Legalizing Assisted Dying Is Dangerous for Disabled People," *The Guardian*, September 9, 2016.

Yet when a healthy, non-disabled person wants to kill themselves it's seen as a tragedy, and support and prevention tools are provided. If nothing else convinces me that to legalise assisted suicide is not a safe option for many of us then this does. Suicide is not seen as socially desirable—so why is assisted suicide seen as compassionate when it's for ill or disabled people?

Marieke Vervoort, the 38-year-old Belgian Paralympian gold medallist, is only the most recent disabled person to announce that she is considering euthanasia, saying her “body is exhausted.” She is not imminently dying. Yet no one seems to be trying to persuade her that life is worthwhile. Would Usain Bolt be met with the same reaction if he announced his decision to end it all after his last Olympics?

Although proponents of assisted suicide legislation say it's only for those with six months or less to live, they propagandise with cases like that of Daniel James, the 23-year-old man paralysed (but not dying) following a rugby accident, who killed himself at the Swiss clinic Dignitas after he said he did not want to live a “second-class” (that is, disabled) life. Jeffrey Spector, a 54-year-old man also not imminently dying, also killed himself at Dignitas.

The Netherlands, which legalised euthanasia to provide relief for the terminally ill, now regularly provides euthanasia for disabled people who can demonstrate “unbearable suffering.” Canada, the most recent nation to legalise euthanasia and assisted suicide, allows it for “serious and incurable illness, disease or disability.”

Usually, the two sides of the argument are characterised as “religious” (opposed to legalisation) or “secular” (in favour). But it's not that simple.

Frustrated by the lack of opportunity to have the voices of people like me—of disabled people—heard on this issue, I have decided to combine my activism with my career as a performer.

I've never seen a piece of art or theatre which expresses opposition to legalising assisted suicide from a disabled person's perspective—so I decided to try to rectify that. The result is *Assisted Suicide: The Musical*—a show which premieres this weekend at the Royal Festival Hall, London, and marks the first anniversary of the defeat of the assisted dying bill in parliament.

There were of course religious people there with me and many others outside Westminster, on Friday 11 September 2015. But MPs who glanced out the window would have seen more Not Dead Yet (NDY) T-shirts and banners than religious ones. NDY is made up of disabled people opposed to a change in the law. Every major disabled group in

the UK, it should be stressed, is opposed to this legislation.

Suicide is, of course, an individual choice. Disabled people who are determined to take their lives may even find it easier to do so than abled people, given the often precarious nature of their existences. But that does not mean that when a fellow human being—disabled or abled—expresses the wish to die because their life is shit, that we should agree with them. The value of a life is not just in its physicality but in our relationships with those around us.

The bill, had it passed, would have licensed doctors to assist in the deaths of terminally-ill people who had less than six months to live, were mentally competent and requested such assistance. But the direction legislation has taken in other countries shows that the sympathy we disabled people evoke can be used to justify support for us to kill ourselves while non-disabled people are told they have “everything to live for.” How many times has someone come up to me and said how much they admired me just for existing because they could not, in my condition?

There is a fine line between those who are terminally ill and those who are disabled in public perception and the emotional power behind the campaign for assisted suicide is based on misplaced pity. Rather than telling us we have everything to live for—and we do—we are helped to the proverbial cliff edge and offered a push.

People—disabled and not, with many years or only a few months ahead of them—become suicidal for many, many reasons. We know from surveys in Oregon, one of just four states in the US where assisted suicide is legal, that the reasons people choose this option have little to do with pain, although this is always the emphasis of supporters of assisted dying.

In fact, loss of dignity, loss of autonomy, loss of ability to do daily activities, and fear of being a burden—reasons which are essentially more about the realities of living with a disability in our society—are all more important than pain.

It is worth keeping in mind, too, that, in the context of economic arguments about a health service overly concerned with “waste” of resources,

disabled people may be seen as a drain, just like the elderly. We also know from the US that some people have been denied life-extending treatments because they are too costly while the cheaper assisted suicide option has been offered as an alternative. Think this won't happen here? Medical rationing is the reality of our overstretched NHS.

No one wants us, those we love or even those we don't to suffer and die in pain. But shouldn't we try to get end-of-life care right before we throw physician-assisted killing into the mix? Currently

hospices and palliative care are only available to the few, and hospices continue to rely on donations for their survival.

Please, don't wish death upon us because you feel pity for our condition. It is demoralising when disabled people like Vervoort express—understandably—exhaustion with the everyday struggle of existence and discouragement with life and are met with sad, understanding nods. On Saturday, it is world suicide prevention day. Can we be included in suicide prevention efforts, too, please?

## **"For Now Have I My Death" I: The "Duty to Die" Versus the Duty to Help the Ill Stay Alive**

FELICIA ACKERMAN

Felicia Ackerman criticizes the view of John Hardwig, who argues that if you are old and had made sacrifices for your family and are now ill, and if keeping you alive takes a great deal of your family's time and money (for example, most or all of your spouse's free time and much of the money that you had previously set aside for your child's college education), you have a duty to die (maybe a duty to commit suicide) to avoid burdening your family. Ackerman argues that Hardwig's assumptions in such cases are dubious. She recognizes that laying down hard and fast rules saying exactly what people's obligations are in such situations is not possible. But she nevertheless thinks the right answer is that the family should sacrifice to keep their loved one alive. "A teenager," she says, "should work and borrow his way through college in order to free up money to prolong the life of a beloved parent who raised him and sacrificed for him. A spouse should forgo tennis lessons . . . in order to take care of the beloved partner 'that he promised his faith unto.' Sometimes, it's simply the only loving thing to do."

For the last three days he screamed incessantly. It was unendurable. I cannot understand how I bore it; you could hear him three rooms off. Oh, what I have suffered!<sup>12</sup>

Suppose you are a sixty-year-old who has worked hard and made sacrifices for your family. Now you

From Felicia Ackerman, "For Now Have I My Death," *Midwest Studies in Philosophy* XXIV (2000).

are ill and the care necessary to keep you alive is taking up a lot of time and money, including almost all your spouse's free time and much of the money you previously set aside for your child's college education. You and your family still love one another, but you all have strong self-interested desires as well. You want to stay alive as long as possible. Your spouse, a dedicated amateur athlete who used to spend much time playing tennis, is tired of being your caregiver. Your child wants to go to college. Who has a duty to do what? Here are four possible answers.

1. You have a duty to die (possibly including a duty to commit suicide) in order to avoid burdening your family.
2. Your spouse has a duty to accept the loss of leisure time and take care of you (that is why “in sickness and in health” is in the marriage vows) and your child has a duty to accept the loss of your financial contribution to his education, in order to avoid burdening you with the premature loss of your life.
3. Either course of action can be justified; it is not a matter of duty.
4. It depends.

John Hardwig has recently argued in favor of (1), at least in some circumstances. This paper will criticize his views and argue for alternatives.

One way Hardwig seeks to support his view is by pointing out that

[M]any older people report that their one remaining goal in life is not to be a burden to their loved ones. Young people feel this, too: when I ask my undergraduate students to think about whether their death could come too late, one of their very first responses always is, “Yes, when I become a burden to my family or loved ones.”<sup>3</sup>

Hardwig thinks this reflects “moral wisdom.”<sup>4</sup> He does not consider the possibility that it reflects our society’s bias against systematic devaluation of the old and ill, a devaluation some old people accept uncritically, just as many women used to accept the idea that women should be subordinate to men. After all, it would hardly be surprising to discover that fifty years ago, most married women reported that they did not want careers that would burden their families. But people (or at least liberals) nowadays would have second thoughts about calling this moral wisdom, let alone using it to support an argument that married women had a duty to avoid careers that would burden their families. We now recognize two factors. First, fifty years ago there was so much social pressure on married women, if they worked outside the home at all, not to let their work inconvenience their families that any woman who dissented from this outlook risked being instantly condemned as selfish (which is not to deny that some women genuinely felt this way). Second, there

was bias involved in seeing women’s careers, but not men’s, as a burden to their families. Many people recognize these things nowadays. But how many recognize that the same factors apply to Hardwig’s uncritical report of present-day expressions of attitudes toward old age and illness? To illustrate the first factor, imagine the social reaction to a sick old person who said, “I’m sorry if it burdens my family, but my life comes first.” The fact that sick old people do make “burdensome” choices often enough to give the question of a duty to die practical as well as theoretical interest suggests that many of the old and ill are less self-sacrificing than the sentiments they pay lip service to may suggest. To illustrate the second factor, consider the (deliberate) oddness of my formulation of (2), above. Sick old people are routinely called burdens to their families, but college-bound teenagers are not. It is surprising that someone who believes “life without connection is meaningless”<sup>5</sup> would think it shows moral wisdom for people to talk as though they did not realize that accepting the burdens of taking care of one another is part of what a family is all about. If Hardwig really holds, as much of his writing claims, the more moderate position that there are limits to the burdens families can be expected to assume (although I will argue that his limits are unacceptably stringent), then why does he think it shows moral wisdom to speak as though any burden, no matter how small, would be unacceptable?

Similar concerns apply to Hardwig’s use of such loaded words as ‘individualistic’ and ‘selfish.’ I doubt that anyone actually believes what he condemns as “the individualistic fantasy . . . that the patient is the only one affected by decisions about her medical treatment.”<sup>6</sup> And few would find fault, except on grounds of triteness, with his claim that “[t]hose of us with families and loved ones always have a duty not to make selfish . . . decisions about our lives.”<sup>7</sup> We normally use the pejorative term ‘selfish’ only for things we want to condemn. But in order to see what sorts of decisions Hardwig condemns as selfish or unduly individualistic, we must look at the family burdens he thinks can give rise to a duty to die. He says:

The lives of our loved ones can be seriously compromised by caring for us. The burdens of

providing care or even just supervision twenty-four hours a day, seven days a week are often overwhelming. When this kind of caregiving goes on for years, it leaves the caregiver exhausted, with no time for herself or life of her own. Ultimately, even her health is often destroyed. But it can also be emotionally devastating simply to live with a spouse who is increasingly distant, uncommunicative, unresponsive, foreign, and unreachable. Other family members' needs often go unmet as the caring capacity of the family is exceeded. Social life and friendships evaporate, as there is no opportunity to go out to see friends and the home is no longer a place suitable for having friends in.

We must also acknowledge that the lives of our loved ones can be devastated just by having to pay for health care for us. One part of [a] recent . . . study documented the financial aspects of caring for a dying member of a family. Only those who had illnesses severe enough to give them less than a 50 percent chance to live six more months were included in this study. When these patients survived their initial hospitalization and were discharged about one-third required considerable caregiving from their families; in 20 percent of cases a family member had to quit work or make some other major lifestyle change; almost one-third of these families lost all of their savings; and just under 30 percent lost a major source of income.

If talking about money sounds venal or trivial, remember that much more than money is normally at stake here. When someone has to quit work, she may well lose her career. Savings decimated late in life cannot be recouped in the few remaining years of employability, so the loss compromises the quality of the rest of the caregiver's life. For a young person, the chance to go to college may be lost to the attempt to pay debts due to an illness in the family, and this decisively shapes an entire life.<sup>8</sup>

These remarks cry out for critical examination. For one thing, Hardwig's conception of what can constitute an unacceptable family burden seems astonishingly weak. Several questions immediately arise. Should being "distant, uncommunicative, unresponsive, foreign, and unreachable" really be a capital offense anywhere, let alone in a "loving" family? Does a loving family really welcome a beloved member's suicide in order to keep a young person from having to work and/or borrow his way

through college? Does the view that you have a duty to spend your hard-earned money to put your able-bodied child through college rather than to prolong your own life reflect a devaluation of the old and the ill that will someday be as offensive to liberals as 1950s attitudes toward women are today?

Hardwig's bias is also reflected in his failure to extend his criticism of selfishness and individualism to a teenager's decision to accept the college tuition money that could be used to extend his father's life or to a husband's self-interested encouragement of the suicide of his ailing wife. Such failure illustrates how terms like 'selfish' and 'individualistic' can serve in a worldview promoting not altruism, but the favoring of the interests of some *individuals* over those of others. Hardwig says, "We fear death too much."<sup>9</sup> But to the extent that his views are widespread, I think that what we fear too much is having our lives and plans disrupted by the medical needs of our loved ones. This fear may cause us to magnify such disruptions out of proportion, to the point where having to work and borrow one's way through college or live with a distant and uncommunicative spouse seems so terrible that the sick person's death seems preferable and perhaps even obligatory.

There are other elements of bias in the quoted passage. The burden of providing "care or even just supervision twenty-four hours a day, seven days a week," far from being unbearable or unique to caretakers of the ill, is routine for many stay-at-home single mothers of babies and toddlers (and for stay-at-home married mothers with unhelpful husbands).<sup>10</sup> It is likewise common for "a family member [to have] to quit work or make some other major lifestyle change" or for a family to lose "a major source of income" when a baby is born. (Of course, people are aware of such needs when they choose to have children, but people who choose to marry are likewise aware of the strong possibility that their spouse will someday be ill and need care. I will discuss this matter more in the next section.) And Hardwig's claim that "[s]ocial life and friendships evaporate, as there is no opportunity to go out to see friends and the home is no longer a place suitable for having friends in" raises three questions. First, hasn't Hardwig ever heard of the telephone or

e-mail? Why is he so ready to see the hardships of taking care of a sick person as reasons why that sick person has a duty to die, rather than as practical problems open to practical remedies? Second, precisely why is a home with a seriously ill person “no longer a place suitable for having friends in”? Suppose that person is unpredictable and incontinent. Is a home with a rambunctious toddler who is not yet toilet trained no longer a suitable place for having friends in? Third, does a loving spouse really welcome the suicide of a beloved partner in order to preserve the spouse’s social life? What sort of values and what sort of love would this priority indicate?

The foregoing may make Hardwig look like a bigot with respect to age and health. So it is important to consider other aspects of his arguments, including the following case:

An 87-year-old woman was dying of congestive heart failure. [The prognosis was] that she had less than a 50 percent chance to live for another six months. She was lucid, assertive, and terrified of death. She very much wanted to live and kept opting for rehospitalization and the most aggressive life-prolonging treatment possible. That treatment successfully prolonged her life (though with increasing debility) for nearly two years. Her 55-year-old daughter was her only remaining family, her caregiver, and the main source of her financial support. The daughter duly cared for her mother. But before her mother died, her illness had cost the daughter all of her savings, her home, her job, and her career.<sup>11</sup>

I will return to this case after looking at some general features of Hardwig’s views.

## II

Hardwig’s approach has one great strength: he acknowledges the existence of genuine conflicts of interest between patients and their families. This contrasts favorably with the sentimentality of the hospice approach, on which “[p]atients, their families and loved ones are the unit of care.”<sup>12</sup> In contrast, Hardwig points out that “[t]he conflicts of interests, beliefs, and values among family members are often too real and too deep to treat all members as ‘the patient.’”<sup>13</sup> He also refuses to hide behind the claim that many of the conditions he

thinks can generate a duty to die can also impair patients’ lives to the point where they have self-interested reasons for wanting to die. He recognizes that the most problematic cases are those where the burdensome patient wants to live.<sup>14</sup> I follow him in focusing on such cases. In fact, unless otherwise specified, I assume as a background condition that the patient *greatly* wants to stay alive, and that the family’s competing wants are equally strong.

Elsewhere, however, Hardwig is not so clear-headed. He uses the phrase ‘duty to die’ indiscriminately to apply to a duty to eschew aggressive life-prolonging medical care and a duty to commit suicide.<sup>15</sup> He holds that “[t]here can be a duty to die before one’s illness would cause death, even if treated only with palliative measures,”<sup>16</sup> and that “there may be a fairly common responsibility to end one’s life in the absence of any terminal illness at all,”<sup>17</sup> and he offers a detailed discussion of whether a person with a duty to die should carry out his own suicide or solicit suicide assistance from his loving family or from doctors.<sup>18</sup>

Hardwig’s use of the phrase ‘duty to die’ to cover both a duty to commit suicide and a duty to eschew aggressive life-prolonging medical treatment leads him to exaggerate the originality and daringness of his position. The view that sick people can have a duty to commit suicide may indeed strike people as “just too preposterous to entertain. Or too threatening.”<sup>19</sup> But this is hardly true of the view that the old and/or terminally ill have a duty not to burden their families and society by insisting on the most aggressive life-prolonging treatment possible, regardless of financial and other costs. This latter view is popular nowadays to the point of cliché. It occurs with varying degrees of explicitness in numerous newspaper and magazine pieces, as well as in highly praised, widely read, and widely influential books by Daniel Callahan<sup>20</sup> and Sherwin B. Nuland,<sup>21</sup> the latter a National Book Award winner. The *denial* of this latter view is what strikes people as “just too preposterous to entertain. Or too threatening.” (When did you last hear anyone, bioethicist or otherwise, say that terminally ill old people are entitled to extend their lives as long as possible and by the most aggressive care possible, regardless of the cost to their families and

society?)<sup>22</sup> Hardwig is conventional, not original, when he says that “we must now face the fact: deaths that come too late are only the other side of our miraculous, life-prolonging modern medicine.”<sup>23</sup> What is amazing is his claim (in 1996!) that “[w]e have so far avoided looking at this dark side of our medical triumphs.”<sup>24</sup>

Unsurprisingly, Daniel Callahan, who is hostile to aggressive life-extending care for the old and ill but to whom suicide is anathema, has criticized Hardwig’s moral equation of suicide and the refusal of aggressive life-prolonging medical care. Since I accept neither Callahan’s views about suicide nor his views about aggressive life-prolonging medical care, I will not defend this sort of criticism. Instead, I find Callahan and Hardwig similar in the low value they place on the lives of the old and the ill. Callahan’s objection to Hardwig that

it trivializes the relationship of family members to each other to act as if their mutual obligations to each other are to be judged by some benefit-burden calculus. Hardwig seems to be saying in effect: “for better or worse, in sickness and in health—well, sort of, it all depends”<sup>25</sup>

should be read in light of things he says elsewhere. For example:

It is not improper for people to worry about being a burden on their families. A family member should reject [a technologically extended death] for the sake of the family’s welfare after he or she is gone.<sup>26</sup>

Callahan even says that “the *primary* aspiration of the old [should be] to serve the young.”<sup>27</sup> He also says, “We do not need a . . . set of moral values that will impose upon families the drain of extended illness and death.”<sup>28</sup> (Note the bias in Callahan’s use of “we” here. Who are the “we” who do not need such a set of moral values? Families eager to free themselves of burdensome sick “loved ones” do not need such a set of moral values, but the sick people themselves may, if they want to stay alive. What “we” (i.e., such actual and potential sick people) do not need is a set of moral values that impose on us the drain of being pressured to forgo high-tech life-extending care and die sooner than necessary, in order to avoid burdening our families—a description of the situation that is no more biased than

Callahan’s own. “We” old people also do not need a set of moral values that tell us our primary aspiration should be to serve the young.) Callahan’s real objection thus seems to be to suicide, rather than to a benefit-burden calculation.<sup>29</sup> In contrast, I have only a practical reason for finding Hardwig’s views about the duty to commit suicide more objectionable than Callahan’s views about the duty to refuse aggressive life-prolonging medical care: the former duty casts a much wider net. This paper will not distinguish further between these two possible duties, but will follow Hardwig’s practice of using ‘duty to die’ to apply indiscriminately to both.

Hardwig’s second conflation is also interesting. He makes no distinction between the duty to die in order to avoid burdening your children and the duty to die in order to avoid burdening your spouse. (Interestingly, none of his examples mentions young adults with a duty to die in order to avoid burdening their caregiving parents.) But there are obvious differences between parental and “adult child” cases, on the one hand, and spousal cases on the other. Parents have often made great sacrifices for their children, including an approximation of the hyperbolically described “twenty-four hours a day, seven days a week” care that Hardwig considers so onerous in the case of the old and the ill. There is a large literature on what, if anything, grown children owe their parents, but, to my mind, nothing that refutes Joel Feinberg’s “My benefactor once freely offered me his services when I needed them . . . But now circumstances have arisen in which he needs help, and I am in a position to help him. Surely I owe him my services now, and he would be entitled to resent my failure to come through.”<sup>30</sup> He would also be entitled to resent my hypocrisy if I claimed to love him. (What if I have significant obligations elsewhere? This issue will be touched upon later.)

Marriages differ from parent-child relationships in two ways that are relevant here. First, they do not normally begin with a long period of one-sided caregiving, let alone one-sided caregiving by the party most likely to need care later on. Second, marriages are freely entered into by both parties. This gives couples the opportunity for prenuptial discussions and agreements that will generate their own

agreed-upon caregiving duties. Of course, such an approach has its own problems. The first, which also applies to living wills, is that it may be virtually impossible for many healthy young people to enter imaginatively into hypothetical situations in which they would be seriously ill and debilitated. As Ellen Goodman puts it, “No one . . . wants to live to be senile. But once senile, he may well want to live.”<sup>31</sup> The second problem, which also applies to prenuptial financial agreements, is that such an arrangement may seem cold-blooded and destructive to the loving spirit of the marriage. Hardwig also advocates discussions in families. He even advocates having them once a person is ill, which avoids the first problem and enables people to consider the “particular and contextual”<sup>32</sup> details of their actual situation. But it enormously intensifies the second problem. Hardwig’s sentimental claim that “[h]onest talk about difficult matters almost always strengthens relationships”<sup>33</sup> raises the question of just how it would strengthen a relationship to say to your father, even in response to his query, “Well, Dad, you’re not pleasant to have around anymore, and if you don’t die soon, your care will use up all the money you saved for my college education, so I’d really appreciate it if you killed yourself now or at least stopped getting treatment.” This may be a crude formulation, but what could be a better one of such a crude thought? The plain fact is that letting your father know you value his life less than your college tuition is unlikely to strengthen your relationship. It is surprising that someone hard headed enough to see that the slogan “the patient is the family” glosses over genuine conflicts of interest (see the material leading up to note 13) would slip into the sentimentality of supposing that honest discussion of such conflicts will almost always strengthen relationships. Prenuptial agreements may seem cold-blooded, but at least they do not involve the cruelty of telling a sick and vulnerable person that you would welcome his death. Prenuptial discussions also give a couple the option of calling off the wedding if they find that their values are too far apart.

### III

Hardwig realizes that a duty to die may seem harsh. “And yet,” he says, “a duty to die will not always be

as harsh as we might assume. If I love my family, I will want to protect them and their lives. I will not want to make choices that compromise their futures.”<sup>34</sup> But if he loves his ill wife, will he want to protect her and her life? Will he want to avoid compromising her future by encouraging her to commit suicide so he will be free of the burden of caregiving? Hardwig says that “there is something deeply insulting in . . . an ethic that . . . [treats] me as if I had no moral responsibilities when I am ill or debilitated.”<sup>35</sup> Will he also be insulted if his ill wife commits suicide because she thinks he is the sort of person who would rather have her dead than take care of her? I would be enormously insulted if a loved one had such a view of me. Hardwig tells us that his “own grandfather committed suicide after his heart attack as a final gift to his wife—he had plenty of life insurance but not nearly enough health insurance, and he feared that she would be left homeless and destitute if he lingered on in an incapacitated state.”<sup>36</sup> Hardwig does not tell us whether his grandmother appreciated this “gift.” What sort of person would she be if she did? If she welcomed this sacrifice, how could she be worth it? What sort of love could she have felt for her husband? What sort of love could he have thought she felt for him? And was there no one else in this loving family who could help his grandmother so she would not have to be left “homeless and destitute” if her husband lingered on?

This brings me to a discussion of what I have elsewhere called “the paradox of the selfless invalid.”<sup>37</sup> In its most extreme form, the paradox goes as follows. Either the patient’s loved ones want him to die quickly in order to save money or otherwise make their lives easier, or they do not. If they do not, the patient does not respect them by dying for their sake. If they do, then why is the patient sacrificing what would otherwise be left of his life for people who love him so little that they value his life less than money and/or freedom from encumbrance? Wouldn’t a truly loving family find such a sacrifice appalling? Of course, families can have mixed feelings, which include both the desire to have the patient stay alive and the self-interested desire to get it all over with and to keep expenses down.<sup>38</sup> But the basic point remains. Decent and

loving families, as part of their decency and lovingness, will recognize the latter desire as ignoble and, on balance, will not want patients to pander to it.

This extreme view is itself open to objections. Just as it is inhumane to suppose a sick person has a duty to forgo an extra year of life in order to conserve money for a child's college tuition, it is unreasonable to suppose there are no limits to what a loving family can be expected to do for a sick member, even to the point of selling literally everything they own in order to give him a minute of extra life. The devil is in the details, or, as Hardwig puts it, "the really serious moral questions are . . . how far family and friends can be asked to support and sustain the patient."<sup>39</sup> I have argued that some of Hardwig's answers are ludicrous. Where should we draw the line? I hardly have an exact answer, nor does Hardwig. But here are his general guidelines.

1. A duty to die is more likely when continuing to live will impose significant burdens—emotional burdens, extensive caregiving, destruction of life plans, and yes, financial hardship—on your family and loved ones. This is the fundamental insight underlying a duty to die.
2. A duty to die becomes greater as you grow older. As we age, we will be giving up less by giving up our lives, if only because we will sacrifice fewer remaining years of life and a smaller portion of our life plans. After all, it's not as if we would be immortal and live forever if we could just manage to avoid a duty to die. To have reached the age of, say, seventy-five or eighty years without being ready to die is itself a moral failing, the sign of a life out of touch with life's basic realities.
3. A duty to die is more likely when you have already lived a full and rich life. You have already had a full share of the good things life offers.
4. There is a greater duty to die if your loved ones' lives have already been difficult or impoverished, if they have had only a small share of the good things that life has to offer (especially if through no fault of their own).
5. A duty to die is more likely when your loved ones have already made great contributions—perhaps even sacrifices—to make your life a good one. Especially if you have not made similar sacrifices for their well-being or for the well-being of other members of your family.
6. To the extent that you can make a good adjustment to your illness or handicapping condition, there is less likely to be a duty to die. A good adjustment means that smaller sacrifices will be required of loved ones and there is more compensating interaction for them. Still, we must also recognize that some diseases—Alzheimer or Huntington's chorea—will eventually take their toll on your loved ones no matter how courageously, resolutely, even cheerfully you manage to face that illness.
7. There is less likely to be a duty to die if you can still make significant contributions to the lives of others, especially your family. The burdens to family members are not only or even primarily financial, neither are the contributions to them. However, the old and those who have terminal illnesses must also bear in mind that the loss their family members will feel when they die cannot be avoided, only postponed.
8. A duty to die is more likely when the part of you that is loved will soon be gone or seriously compromised. Or when you soon will no longer be capable of giving love. Part of the horror of dementing disease is that it destroys the capacity to nurture and sustain relationships, taking away a person's agency and the emotions that bind her to others.
9. There is a greater duty to die to the extent that you have lived a relatively lavish lifestyle instead of saving for illness or old age. . . . It is a greater wrong to come to your family for assistance if your need is the result of having chosen leisure or a spendthrift lifestyle.<sup>40</sup>

I suggest we reconceptualize the problem by asking how these and related conditions might affect the duty to make sacrifices in order to extend

the life of a burdensomely ill loved one. I will call this “a duty to aid.” Here are nine conditions parallel to Hardwig’s.

1. A duty to aid is more likely when failing to do so will impose significant burdens when the ill loved one wants very much to go on living and needs your help. This is the fundamental insight underlying a duty to aid.
2. Perhaps a duty to aid becomes greater as you grow older, because you will be sacrificing a smaller portion of your life plans. Alternatively, a duty to aid may be greater when you are young, because you have more stamina as well as more life ahead of you, with more opportunity to recoup your losses. At any rate, to have reached adulthood without being ready to undertake major financial burdens and changes in “lifestyle” in order to aid a seriously ill loved one is itself a moral failing, a sign of a life out of touch with life’s basic realities.
3. A duty to aid is more likely when you have already lived a full and rich life. You have already had a full share of the good things life offers.
4. There is a greater duty to aid if your ill loved one’s life has already been difficult or impoverished, if he has had only a small share of the good things that life has to offer (especially if through no fault of his own).
5. A duty to aid is more likely when your loved one has already made great contributions—perhaps even sacrifices—to make your life a good one. Especially if you have not made similar sacrifices for his well-being. This imbalance frequently exists between grown children and the parents who raised them.
6. To the extent that there are others able to share the burden of aiding, there is less you have a duty to do. To the extent that you cannot make a good adjustment to the duty of aiding, there is less of a duty to aid. Still, we must also recognize that unwillingness to make a good adjustment does not constitute inability to do so, nor does making a good adjustment mean you must enjoy aiding.
7. There is less of a duty to aid if you have significant obligations elsewhere. However, you must also bear in mind that your obligations to your children do not automatically outweigh your obligations to your parents. The popular slogan “The best thing you can do for your parents is to take good care of their grandchildren” is obviously false if your father needs and wants a heart transplant, which he cannot afford without your help, and your son “needs” and wants four years at Yale.
8. A duty to aid is more likely when your loved one is painfully aware that the part of him that was loved will soon be gone or seriously compromised and is terrified that his loved ones will abandon him. And if you genuinely love your “loved one,” then to the extent that the part that is loved is not compromised, you will have a strong self-interested reason for wanting to help him stay alive; you would hate never seeing him again.
9. There is a greater duty to provide physical care to the extent that you have lived a relatively lavish “lifestyle” that has prevented you from saving enough to provide financial help.

These guidelines are not formally incompatible with Hardwig’s. He grants that families “must be prepared to make significant sacrifices to respond to an illness in the family,”<sup>41</sup> although his examples I quoted earlier of what can constitute an intolerable family burden raise the question of just what sort of “significant sacrifices” he has in mind. His statement “I cannot imagine that it would be morally permissible for me to . . . compromise the quality of [my grandchildren’s] lives simply because I wish to live a little longer”<sup>42</sup> illustrates the importance of this question. What deprivation could *not* be said to compromise the quality of one’s grandchildren’s lives? Going without private schooling? Going without summer camp? Going without tennis lessons? At any rate, my guidelines and Hardwig’s reflect (although they do not entail) different orientations. Hardwig believes we can find meaning in death by recognizing our duty to die, thus engaging in an “affirmation of connections.”<sup>43</sup>

I am less inclined to find meaning in death at all. I find Malory's "Let me lie down and wail with you"<sup>44</sup> a much more humane response to adversity than today's relentless tendency to insist we turn adversity into an opportunity for "growth," a tendency Hardwig at any rate follows very selectively. His selectivity reflects his characteristic bias. After all, if we are going to urge people to regard death and dying as opportunities for growth and "affirmation of connections," why not urge families to seize the opportunity to grow and "affirm connections" by making loving sacrifices to prolong the life of a seriously ill loved one? Hardwig says, "Caring for the sick or aged can foster growth . . . But it would be irresponsible to blithely assume that this always happens, that it will happen in my family, or that it will be the fault of my family if they cannot manage to turn my illness into a positive experience."<sup>45</sup> He does not criticize such unsuccessful families for having a "sense of community [that] is so weak."<sup>46</sup> He reserves this harsh judgment for old and/or ill people who are unwilling to unburden their families by dying (although he does grant that "man who can leave his wife the day after she learns she has cancer, on the grounds that he has his own life to live, is to be deplored").<sup>47</sup>

Hardwig's guidelines, as well as his whole approach, raise another question. Why does he fail to consider cases where the sacrificial suicide of someone who is healthy and far from old could benefit his (not overly) loving family? Suppose you are a forty-year-old mid-level executive who has been downsized. The only job you can get pays the minimum wage, not enough to support your family, even with the added income of your wife, who now has to work fifty hours a week as a home health aide, doing the caregiving Hardwig finds so onerous when done for a family member. Your family is about to lose their home; you will all have to move to a rat-infested apartment in an unsafe inner-city neighborhood. "For [your children], the chance to go to college [will] be lost"<sup>48</sup> (if we assume, as Hardwig inexplicably does in cases involving illness, that young people's working and/or borrowing their way through college is not an option). There is, however, a solution. Like Hardwig's grandfather, you have excellent life

insurance. (If your life insurance has the common two-year "suicide clause" denying payment if the insured person commits suicide within two years of purchasing the policy, that clause has long since expired.) In accord with Hardwig's guidelines, we can build in that your life so far has been rich and full, your wife has had a difficult, impoverished childhood, and your family has made sacrifices for your career (your wife sacrificed her own career and also spent much time in the tedious pseudosocializing necessary to further your ambitions, and your children endured the dislocation of frequent moves). We can even say that you lost your job not through downsizing but through your own fault and that you have little in the way of savings because you lived a "relatively lavish lifestyle instead of saving." Would Hardwig then say you could have a duty to commit suicide instead of burdening your family by depriving them of your life insurance money? If not, why not?

Like Hardwig, I cannot lay down a series of precise rules saying who owes whom what when a sick family member needs care. In Hardwig's case of the eighty-seven-year-old woman, for example, I think much hinges on her prior relationship with her daughter. How much did that mother sacrifice for her daughter? Did the mother pay, and make sacrifices to pay, for the education that enabled the daughter to have the career Hardwig is so distressed about her losing? What was their relationship like once the daughter grew up? Did the mother, like many parents nowadays, give her daughter some of the money that enabled the daughter to buy the home Hardwig is so distressed about her losing? What happened after the mother died? Did the daughter ever find another job? Hardwig does not tell us any of these things.<sup>49</sup> But I think it is clear that in my own example with which I opened this paper, alternative (2) is the right answer. A teenager should work and borrow his way through college in order to free up money to prolong the life of a beloved parent who raised him and sacrificed for him. A spouse should forgo tennis (even if it is not a trivial recreation but an important part of his life) in order to take care of the beloved partner "that he promised his faith unto."<sup>50</sup> "Sometimes, it's simply the only loving thing to do."<sup>51</sup>

## NOTES

1. Sir Thomas Malory, *Le Morte D'Arthur* (London: Penguin, 1969), v.2, 515. As for the subtitle, for simplicity of exposition I will focus my discussion on the ill and their families. But note that the same issues can arise when people are severely enough disabled to need care, even when the disability arises not from illness, but from some other source, such as an injury. (Some disability rights activists set great store by the fact that they are disabled, not ill, and feel insulted when considered on a par with the ill. For examples of this attitude, see Joseph Shapiro, *No Pity* [New York: Times Books, 1993, 21, 22, and 49]. I consider this attitude to be morally on a par with that of a dark-skinned Caucasian who sets great store by the fact that he is white and feels insulted when considered on a par with blacks.)
2. Leo Tolstoy, *The Death of Ivan Ilych* (New York: New American Library of World Literature, 1960), 10. Tolstoy, of course, intended this remark (by a cancer patient's widow) to show monumental selfishness and callousness.
3. John Hardwig, "Is There a Duty to Die?" *Hastings Center Report* 27, no. 2 (1997), 36.
4. John Hardwig, "Dying at the Right Time: Reflections on (Un)assisted Suicide," in Hugh La Follette (ed.), *Ethics in Practice* (Cambridge, MA: Blackwell, 1996), 54.
5. Hardwig, "Is There a Duty to Die?" 41. Hardwig's book, *Is There a Duty to Die? and Other Essays in Bioethics* (New York: Routledge, 2000), was published too late for general discussion in this paper, but I will be reviewing it in a forthcoming issue of the *American Philosophical Association Newsletter on Philosophy and Medicine*. One point can be mentioned here, though. Hardwig praises a list of "Responsibilities of Those Facing the End of Life" (*ibid.*, 197–99) compiled by a group of old people in a discussion he led. One item on the list is "Don't live so long that your loved ones will wish you were dead" (198). This treats life as a dinner party where the "loved ones" are hosts and the elderly are guests who should not be so rude as to overstay their welcome. Note that the complete lack of qualification entails that the elderly should honor *every* reason their loved ones may have for wishing them dead. Such a low valuation of the lives of the elderly is hard to take seriously. What if your loved ones wish you were dead so they can inherit your money and buy a Jaguar?
6. *Ibid.*, 35.
7. *Ibid.*, 36.
8. *Ibid.*
9. *Ibid.*, 40.
10. Or, more accurately, this burden is as closely approximated in both sorts of cases. Hardwig's description is, of course, hyperbole. No one actually provides care or supervision "twenty-four hours a day." (When would he sleep? Even someone whose caregiving tasks often interrupt his sleep does not actually provide care or supervision "twenty-four hours a day.") This is not a trivial stylistic point, but an illustration of Hardwig's tendency to exaggerate the horrors of taking care of the ill.
11. *Ibid.*, 37.
12. See B. Manard and C. Perrone, *Hospice Care: An Introduction and Review of the Evidence* (Arlington, VA: National Hospice Organization, 1994), 4.
13. John Hardwig, "What About the Family?" *Hastings Center Report* (March/April 1990), 5.
14. See Hardwig, "Is There a Duty to Die?" 35.
15. See the letters to the editor from Larry Churchill, Elizabeth A. Linehan, and Daniel G. Flory, *Hastings Center Report* (November/December 1997), 4–6.
16. Hardwig, "Is There a Duty to Die?" 35.
17. *Ibid.*
18. See Hardwig, "Dying at the Right Time."
19. Hardwig, "Is There a Duty to Die?" 34.
20. See Daniel Callahan, *Setting Limits* (Washington, DC: Georgetown University Press, 1987), *What Kind of Life* (Washington, DC: Georgetown University Press, 1990), and *The Troubled Dream of Life* (New York: Simon and Schuster, 1993).
21. Sherwin B. Nuland, *How We Die* (New York: Knopf, 1994).
22. Hardwig claims that "bioethicists advocate a 'patient-centered ethics'—an ethics which claims only the patient's interests should be considered in making medical treatment decisions. Most health care professionals have been trained to accept this ethic and to see themselves as patient advocates" ("Is There a Duty to Die?" note 3, p. 42). These claims overlook the enormous influence of Daniel Callahan. They also fail to take account of the huge (and hugely influential) hospice movement, one of whose basic principles is the above-quoted "Patients, their families and loved ones are the unit of care" (Manard and Perrone, *Hospice Care*, 4). Elsewhere, however, as I have indicated (see note 13), Hardwig distinguishes the hospice sort of approach from his own.
23. Hardwig, "Dying at the Right Time," 63.
24. *Ibid.*
25. Callahan, letter to the editor, *Hastings Center Report* (November/December 1997), 4.

26. Callahan, *The Troubled Dream of Life*, 218–9.
27. Callahan, *Setting Limits*, 43 (italics in original).
28. Callahan, *The Troubled Dream of Life*, 218–9.
29. See my “Death, Dying, and Dignity,” in K. Brinkmann (ed.), *Proceedings of the Twentieth World Congress of Philosophy. Vol. 1: Ethics* (Bowling Green, OH: Philosophy Documentation Center, 1999), 196, for another example of how Callahan professes disdain for quality-of-life considerations, but freely uses them when the issue is “letting die.”
30. Joel Feinberg, “Duties, Rights, and Claims,” *American Philosophical Quarterly* 3, no. 2 (1966), 139 (italics in original). Obviously, this general claim leaves much unanswered. Feinberg is not specifically discussing parents and children, but Callahan cites this passage in that context in *Setting Limits*, 91. The general issue of what grown children owe their parents has many complexities that I lack space to go into here. For more discussion of the issue, see Jane English, “What Do Grown Children Owe Their Parents?” in La Follette, *Ethics in Practice*, 174–8; Christina Hoff Sommers, “Filial Morality,” *Journal of Philosophy* (1986), 439–56; and Norman Daniels, *Am I My Parents’ Keeper? An Essay on Justice Between the Young and the Old* (New York: Oxford University Press, 1988).
31. Ellen Goodman, “Who Lives? Who Dies? Who Decides?” in E. Goodman, *At Large* (New York: Simon and Schuster, 1981), 161. (The first part of Goodman’s statement is false. I want to live to be senile. I would rather be mentally intact than senile, of course, but I would rather be senile than dead.)
32. Hardwig, “Is There a Duty to Die?” 38.
33. Ibid., 38. He gives a less sanguine picture in his earlier paper, “What About the Family?” 10. See also his reply to the letter from Daniel Callahan, *Hastings Center Report* (November/December 1997), 6.
34. Hardwig, “Is There a Duty to Die?” 40.
35. Ibid., 40–1.
36. Hardwig, “What About the Family?” 6.
37. For further discussion of this paradox, see my “Assisted Suicide, Severe Disability, Terminal Illness, and the Double Standard,” in M. P. Battin et al. (eds.), *Physician-Assisted Suicide: Expanding the Debate* (New York: Routledge, 1998), 156, and my “Goldilocks and Mrs. Ilych: A Critical Look at the ‘Philosophy of Hospice,’” *Cambridge Quarterly of Healthcare Ethics*, 6 (1997), 319.
38. I owe this point to Sara Ann Ketchum.
39. Hardwig, “What About the Family?” 6.
40. Hardwig, “Is There a Duty to Die?” 3, 8–9. With respect to the third sentence of his second guideline, note that attempts to postpone death normally reflect people’s (frequently attainable) goal of living *longer*, rather than the obviously unattainable goal of immortality. A similar point applies to Elizabeth A. Linehan’s speculation about the “denial of mortality” (letter to the editor, *Hastings Center Report*, November/December 1997, 5) in Hardwig’s case of the eighty-seven-year-old mother (discussed above) who insisted on the most aggressive possible treatment for her congestive heart failure. Like young diabetics who take insulin, this old woman was trying to prolong her life. The term ‘denial of mortality’ is no more appropriate to her case than to theirs, however much one may begrudge this sick old lady the extra time she craved.
41. Hardwig, “Is There a Duty to Die?” 37.
42. Ibid., 38.
43. Ibid., 41.
44. Malory, *Le Morte D’Arthur*, v. 2, 172. Malory himself, as a devout Catholic, found a completely different sort of meaning in death as a passage to a better world, but when believers and disbelievers in an afterlife talk about death, what they take themselves to be talking about is very different.
45. Hardwig, “Is There a Duty to Die?” 36.
46. Ibid., 42.
47. Hardwig, “What About the Family?” 7.
48. Hardwig, “Is There a Duty to Die?” 36.
49. In “SUPPORT and the Invisible Family” (Special Supplement, *Hastings Center Report*, 25, no. 6, 1995, S23–5), Hardwig discusses a real-life case of this sort but considers none of these questions. He also expresses great sympathy and concern for the daughter, whom he identifies as a personal friend, but none for the mother.
50. Malory, *Le Morte D’Arthur*, v. 2, 426.
51. This is a claim Hardwig makes about killing yourself in order to avoid burdening your loved ones: “Dying at the Right Time,” 57.

## Vacco v. Quill

UNITED STATES SUPREME COURT

At issue in this case is whether a ban on assisted suicide enacted in New York State is constitutional—specifically whether the prohibition violates the Equal Protection Clause of the Fourteenth Amendment. The Court finds that it does not, that in fact there is no constitutional right to a physician's help in dying. But each state may establish its own policy on the issue.

In New York, as in most States, it is a crime to aid another to commit or attempt suicide, but patients may refuse even lifesaving medical treatment. The question presented by this case is whether New York's prohibition on assisting suicide therefore violates the Equal Protection Clause of the Fourteenth Amendment. We hold that it does not.

Petitioners are various New York public officials. Respondents Timothy E. Quill, Samuel C. Klagsbrun, and Howard A. Grossman are physicians who practice in New York. They assert that although it would be "consistent with the standards of [their] medical practice[s]" to prescribe lethal medication for "mentally competent, terminally ill patients" who are suffering great pain and desire a doctor's help in taking their own lives, they are deterred from doing so by New York's ban on assisting suicide. Respondents, and three gravely ill patients who have since died, sued the State's Attorney General in the United States District Court. They urged that because New York permits a competent person to refuse life-sustaining medical treatment, and because the refusal of such treatment is "essentially the same thing" as physician-assisted suicide, New York's assisted-suicide ban violates the Equal Protection Clause.

The District Court disagreed: "[I]t is hardly unreasonable or irrational for the State to recognize a difference between allowing nature to take its course, even in the most severe situations, and intentionally using an artificial death-producing device." The court noted New York's "obvious legitimate

interests in preserving life, and in protecting vulnerable persons," and concluded that "[u]nder the United States Constitution and the federal system it establishes, the resolution of this issue is left to the normal democratic processes within the State."

The Court of Appeals for the Second Circuit reversed. The court determined that, despite the assisted-suicide ban's apparent general applicability, "New York law does not treat equally all competent persons who are in the final stages of fatal illness and wish to hasten their deaths," because "those in the final stages of terminal illness who are on life-support systems are allowed to hasten their deaths by directing the removal of such systems; but those similarly situated except for the previous attachment of life-sustaining equipment, are not allowed to hasten death by self-administering prescribed drugs." In the court's view, "[t]he ending of life by [the withdrawal of life-support systems] is *nothing more nor less than assisted suicide*" (emphasis added). The Court of Appeals then examined whether this supposed unequal treatment was rationally related to any legitimate state interest, and concluded that "to the extent that [New York's statutes] prohibit a physician from prescribing medications to be self-administered by a mentally competent, terminally-ill person in the final stages of his terminal illness, they are not rationally related to any legitimate state interest." We granted certiorari and now reverse.

The Equal Protection Clause commands that no State shall "deny to any person within its jurisdiction the equal protection of the laws." This provision creates no substantive rights. Instead, it embodies a general rule that States must treat like

cases alike but may treat unlike cases accordingly. If a legislative classification or distinction “neither burdens a fundamental right nor targets a suspect class, we will uphold [it] so long as it bears a rational relation to some legitimate end.”

New York’s statutes outlawing assisting suicide affect and address matters of profound significance to all New Yorkers alike. They neither infringe fundamental rights nor involve suspect classifications. These laws are therefore entitled to a “strong presumption of validity.”

On their faces, neither New York’s ban on assisting suicide nor its statutes permitting patients to refuse medical treatment treat anyone differently than anyone else or draw any distinctions between persons. *Everyone*, regardless of physical condition, is entitled, if competent, to refuse unwanted life-saving medical treatment; *no one* is permitted to assist a suicide. Generally speaking, laws that apply even-handedly to all “unquestionably comply” with the Equal Protection Clause.

The Court of Appeals, however, concluded that some terminally ill people—those who are on life-support systems—are treated differently than those who are not, in that the former may “hasten death” by ending treatment, but the latter may not “hasten death” through physician-assisted suicide. This conclusion depends on the submission that ending or refusing lifesaving medical treatment “is nothing more nor less than assisted suicide.” Unlike the Court of Appeals, we think the distinction between assisting suicide and withdrawing life-sustaining treatment, a distinction widely recognized and endorsed in the medical profession and in our legal traditions, is both important and logical: it is certainly rational. (“When the basic classification is rationally based, uneven effects upon particular groups within a class are ordinarily of no constitutional concern.”)

The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology, but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication.

Furthermore, a physician who withdraws, or honors a patient’s refusal to begin, life-sustaining

medical treatment purposefully intends, or may so intend, only to respect his patient’s wishes and “to cease doing useless and futile or degrading things to the patient when [the patient] no longer stands to benefit from them.” Assisted Suicide in the United States, Hearing before the Subcommittee on the Constitution of the House Committee on the Judiciary, 104th Cong., 2d Sess., 368 (1996) (testimony of Dr. Leon R. Kass). The same is true when a doctor provides aggressive palliative care; in some cases, painkilling drugs may hasten a patient’s death, but the physician’s purpose and intent is, or may be, only to ease his patient’s pain. A doctor who assists a suicide, however, “must, necessarily and indubitably, intend primarily that the patient be made dead.” *Id.*, at 367. Similarly, a patient who commits suicide with a doctor’s aid necessarily has the specific intent to end his or her own life, while a patient who refuses or discontinues treatment might not.

The law has long used actors’ intent or purpose to distinguish between two acts that may have the same result. Put differently, the law distinguishes actions taken “because of” a given end from actions taken “in spite of” their unintended but foreseen consequences. (“When General Eisenhower ordered American soldiers onto the beaches of Normandy, he knew that he was sending many American soldiers to certain death. . . . His purpose, though, was to . . . liberate Europe from the Nazis.”)

Given these general principles, it is not surprising that many courts, including New York courts, have carefully distinguished refusing life-sustaining treatment from suicide. In fact, the first state court decision explicitly to authorize withdrawing lifesaving treatment noted the “real distinction between the self-infliction of deadly harm and a self-determination against artificial life support.” . . .

Similarly, the overwhelming majority of state legislatures have drawn a clear line between assisting suicide and withdrawing or permitting the refusal of unwanted lifesaving medical treatment by prohibiting the former and permitting the latter. And “nearly all states expressly disapprove of suicide and assisted suicide either in statutes dealing with durable powers of attorney in health-care situations, or in ‘living will’ statutes.” Thus, even as the States move to protect and promote patients’

dignity at the end of life, they remain opposed to physician-assisted suicide.

New York is a case in point. The State enacted its current assisted-suicide statutes in 1965.<sup>1</sup> Since then, New York has acted several times to protect patients common-law right to refuse treatment. In so doing, however, the State has neither endorsed a general right to “hasten death” nor approved physician-assisted suicide. Quite the opposite: The State has reaffirmed the line between “killing” and “letting die.” More recently the New York State Task Force on Life and the Law studied assisted suicide and euthanasia and, in 1994, unanimously recommended against legalization. When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context vii (1994). In the Task Force’s view, “allowing decisions to forego life-sustaining treatment and allowing assisted suicide or euthanasia have radically different consequences and meanings for public policy.” *Id.*, at 146.

This Court has also recognized, at least implicitly, the distinction between letting a patient die and making that patient die. In *Cruzan v. Director, Mo. Dept. of Health* (1990), we concluded that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions,” and we assumed the existence of such a right for purposes of that case. But our assumption of a right to refuse treatment was grounded not, as the Court of Appeals supposed, on the proposition that patients have a general and abstract “right to hasten death,” but on well established, traditional rights to bodily integrity and freedom from unwanted touching. In fact, we observed that “the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide.” *Cruzan* therefore provides no support for the notion that refusing life-sustaining medical treatment is “nothing more nor less than suicide.”

For all these reasons we disagree with respondents’ claim that the distinction between refusing lifesaving medical treatment and assisted suicide is “arbitrary” and “irrational.”<sup>2</sup> Granted, in some cases, the line between the two may not be clear, but certainty is not required, even were it possible. Logic

and contemporary practice support New York’s judgment that the two acts are different, and New York may therefore, consistent with the Constitution, treat them differently. By permitting everyone to refuse unwanted medical treatment while prohibiting anyone from assisting a suicide, New York law follows a longstanding and rational distinction.

New York’s reasons for recognizing and acting on this distinction—including prohibiting intentional killing and preserving life; preventing suicide; maintaining physicians’ role as their patients’ healers; protecting vulnerable people from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards euthanasia—are discussed in greater detail in our opinion in *Glucksberg, ante*. These valid and important public interests easily satisfy the constitutional requirement that a legislative classification bear a rational relation to some legitimate end.

The judgment of the Court of Appeals is reversed.

#### NOTES

1. It has always been a crime, either by statute or under the common law, to assist a suicide in New York.
2. Respondents also argue that the State irrationally distinguishes between physician-assisted suicide and “terminal sedation,” a process respondents characterize as “induc[ing] barbiturate coma and then starv[ing] the person to death.” Petitioners insist, however, that “[a]lthough proponents of physician-assisted suicide and euthanasia contend that terminal sedation is covert physician-assisted suicide or euthanasia, the concept of sedating pharmacotherapy is based on informed consent and the principle of double effect.” Reply Brief for Petitioners 12 (quoting P. Rousseau, Terminal Sedation in the Care of Dying Patients, 156 Archives Internal Med. 1785, 1785–1786 [1996]). Just as a State may prohibit assisting suicide while permitting patients to refuse unwanted lifesaving treatment, it may permit palliative care related to that refusal, which may have the foreseen but unintended “double effect” of hastening the patient’s death. See New York Task Force, “When Death is Sought,” at 163 (“It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient’s death, if the medication is intended to alleviate pain and severe discomfort, not to cause death”).



# Justice and Health Care

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## Dividing Up Health Care Resources

In this land of plenty, many are rich; many are poor. Many are healthy; many are not. Many who are afflicted by disease, disability, or injury can get the health care they need; many cannot—and they suffer and die for its lack. For any sensitive observer (and any decent society), these cold inequalities are surely cause for concern, dismay, even alarm. They also raise ethical questions of the most basic kind. To what are the less fortunate entitled, and what is society obligated to give? Are the needy due only the health care they can afford to buy for themselves, even if they can afford nothing? Or is society obligated to provide more? Is society obliged to provide everyone with access to health care regardless of ability to pay? Or is the claim on society's resources even stronger: Do people have a *right* to health care? If so, to what exactly are they entitled? To a guarantee of a state of well-being equal to that of everyone else? To an equal share of health care resources? To the best health care available? Or to something more modest—a decent minimum amount of health care? And what, exactly, is a decent minimum?

These are moral concerns on a larger scale than most of those we have grappled with in previous chapters. Here we ask not what is right or good in the person-to-person dramas of moral conflict; rather, we ask what is good or right in the policies and actions of society or government. The central issue is: Who should get health care, who should provide it, and who should pay for it? In other words, *what is just?* In the painful, complicated task of dividing up society's health care resources (including medical treatment, disease prevention, emergency care, and public health measures), what does justice demand?

Whatever answer is devised, it must take into account some hard realities. No system can provide maximum health care for everyone; there are limits—sometimes severe—to what any system can provide. Costs restrict how much health care can be delivered and how much can be obtained, and they can rise rapidly enough to destroy the best laid plans for fair access. Moreover, a society's finite resources must be allocated to satisfy many needs besides health care—education, defense, transportation, law enforcement, and others. Some kinds of health care can increase the well-being of more people to a greater degree than others, so considerations of efficiency will have to shape the allocation of resources. And somehow these quantitative factors must be reconciled with freedom of choice. In a free society, this value is paramount and cannot be entirely discarded for the sake of a more rational distribution of health care.

Most careful thinkers on the subject believe that a just apportioning of health care is possible. But how?

### HEALTH CARE IN TROUBLE

Regardless of their political views, most tend to think that in this free and prosperous nation, all citizens should somehow have access to health care. But many people go without. Health care is so expensive that many can't afford it unless they have some type of health insurance, which is itself expensive—so expensive in fact that the high cost is the main reason for lack of coverage. In 2010, almost 49 million people under the age of 65 were uninsured, and almost 8 million of those were children. Nearly

a third of the under-65 population—almost 90 million people—had no health insurance for at least part of 2006 or 2007.<sup>1</sup> In 2013, just before the Affordable Care Act (ACA, or “Obamacare”) began to take effect, more than 44 million people under age 65 were without coverage. But by 2014, the ACA had expanded government health insurance (Medicaid), and many people were able to get tax credits to buy coverage from an ACA health insurance marketplace. Millions of people took advantage of these programs, but millions more were still left without coverage. By 2016, there were still 26.7 million people under 65 who had no health insurance coverage.<sup>2</sup> In 2019, the number climbed to 28.9 million. The reasons for lack of coverage were the same then as they are today: high cost of insurance, the absence of coverage acquired through employment, and ineligibility for public coverage.

The consequences of going without health coverage are just what you might expect. The uninsured are less likely than the insured to get needed medical treatment, prescription drugs, preventive tests (pap smears and prostate exams, for example), and follow-up care when they do manage to see a doctor. Not surprisingly, researchers have estimated that the risk of death is 25 percent higher for the uninsured than the insured, resulting in about 18,000 more deaths in 2000 among those aged 25 to 64.<sup>3</sup>

Of course, being without health insurance is a major financial burden as well as a health risk. A nonpartisan research organization explains the problem like this:

For many uninsured people, the costs of health insurance and medical care are weighed against equally essential needs, like housing, food, and transportation to work, and many uninsured adults report being very or moderately worried about paying basic monthly expenses such as rent or other housing costs and normal monthly bills. When uninsured people use health care, they may be charged for the full cost of that care (versus insurers, who negotiate discounts) and

often face difficulty paying medical bills and potential medical debt. Providers absorb some of the cost of care for the uninsured, and while uncompensated care funds cover some of those costs, these funds do not fully offset the cost of care for the uninsured.<sup>4</sup>

Traditionally most people under age 65 got health coverage as a benefit of employment, but a smaller percentage of them are now obtaining insurance this way—69 percent in 2000 down to 57 percent in 2013, and 50 percent in 2019. Fewer employers are offering this benefit, and even when they do, many employees are either not eligible for it or cannot afford to pay their portion of the insurance premium. Over 75 percent of the uninsured are members of families with full-time workers.<sup>5</sup>

People who are age 65 and older and some adults under 65 with permanent disabilities are covered by the public health insurance program known as Medicare. It collects payroll taxes from workers during their employment years and provides coverage when they turn 65, paying many health care expenses, including physician and hospital services and prescription drugs. Medicaid, another publicly supported program, covers some under-65 low-income people, including children and the disabled. But coverage varies from state to state and, because of eligibility rules, does not extend to millions of people below the federal poverty level.

Critics of the U.S. health care system point to discrepancies between the huge expenditures for health care and surprisingly low grades on standard measures of national health. According to 2019 data, the country’s per capita spending on health care was more than \$10,000—far more than the amount spent by the richest nations in the world. (The list of the richest comprises 30 democracies in the Organization for Economic Cooperation and Development [OECD], including France, Germany, Switzerland, Denmark, Canada, the United Kingdom, Norway, and Japan.) The countries coming

closest to that level of spending were Switzerland at \$7,317 and Norway at \$6,187. The United Kingdom, Japan, Australia, Canada, Iceland, and France all spent about half of what the United States did.

Yet in the United States, life expectancy at birth (81.1 years) was lower than that of most of the other economically advanced OECD countries, including Canada (83.9), France (85.5), Japan (87.1), the United Kingdom (83), Switzerland (85.6), Iceland (84.1), Australia (84.6), and Spain (86.3). The infant mortality rate in the United States was also higher than the OECD average—5.9 deaths per 1,000 live births compared to an average of 3.9. In fact, it was higher than the rate of any other developed country except Mexico.<sup>6</sup>

Though the United States spends more on health care than any other country, the quality of the care is not obviously better overall than that of other countries. The U.S. system outshines them in some ways, but lags behind in others. For example, it excels in the development and use of medical technologies and in some important measures of health care quality:

- 30-day mortality for heart attacks and ischemic stroke is lower in the United States than in comparable countries.
- Obstetric trauma during vaginal delivery is less common in the United States than in some comparable countries.
- Five-year survival rates for certain cancers (colorectal, breast, and cervical, ages 15 and over) are higher in the United States than in comparable countries.
- Mortality rates for breast and colorectal cancer in the United States are lower than in comparable countries.

But on other measures the quality of U.S. health care falls short:

- The United States has the highest rate of deaths amenable to health care among comparable countries.

- Disease burden (disability) is higher in the United States than in comparable countries.
- Hospital admissions for preventable diseases are more frequent in the United States than in comparable countries.
- The United States has higher rates of medical, medication, and lab errors than comparable countries.
- The mortality rate for respiratory diseases is higher in the United States than in comparably wealthy countries.
- Adults in most comparable countries have quicker access to a doctor or nurse when they need care.
- Use of the emergency department in place of regular doctor visits is more common in the United States than in most comparable countries.<sup>7</sup>

In the United States most health care is allocated through **managed care**, a system for providing care to a particular group of patients (members of the system) using regulatory restraints to control costs and increase efficiency. People who enroll in a managed care plan—such as a health maintenance organization (HMO) or a preferred provider organization (PPO)—get health care at discounted prices from the plan's network of providers (physicians, hospitals, etc.). Managed care plans try to control costs by influencing the kind and amount of care that providers offer and by restricting the choices that members have. Though cost control and efficiency are laudable goals, many critics worry that they are at odds with patient welfare. The concern is that for the sake of economical medicine, providers may cut corners, decide not to order necessary tests, pay less attention to patients' needs, or refuse to treat certain serious health problems. Some charge that managed care as it is currently practiced forces physicians to try to serve the patient and provide organizational efficiency, an impossible task that weakens the patient's trust in the physician.

In 2010 this troubling picture of American health care began to change when President Barack Obama signed into law the Patient Protection and Affordable Care Act (ACA). It was an attempt to provide health coverage to many more Americans and to contain the insidious rise of health care costs. Getting the law through Congress was a wrenching ordeal of high-stakes partisan brawling that seemed to arise largely from diverging answers to fundamental philosophical questions: What duties does the state have toward its citizens? How much should the state do to ensure the well-being of its people? What benefits do citizens have a right to expect from a government that is supposed to “promote the general welfare”?

Here's a rundown of the legislation's major provisions summarized by a nonpartisan foundation:

- Most individuals will be required to have health insurance beginning in 2014.
- Individuals who do not have access to affordable employer coverage will be able to purchase coverage through a health insurance exchange with premium and cost-sharing credits available to some people to make coverage more affordable. Small businesses will be able to purchase coverage through a separate exchange.
- Employers will be required to pay penalties for employees who receive tax credits for health insurance through the exchange, with exceptions for small employers.
- New regulations will be imposed on all health plans that will prevent health insurers from denying coverage to people

## Fact File U.S. Health Care

- In 2019, 28.9 million Americans under age 65 had no health insurance.
- In 2019, 74 percent of uninsured adults said the main reason they were uninsured was because the cost was too high.
- Enrollment in ACA coverage corresponds with large declines in the uninsured rate. Between 2013 and 2014, the uninsured rate dropped significantly, from 16.2 percent in the last quarter of 2013 to 12.1 percent in the last quarter of 2014. The uninsured rate in 2019 was 10.9 percent.

Hispanic people and Native Hawaiians and Other Pacific Islander people experienced the largest increases in the uninsured in 2019.

- Many people do not have access to coverage through a job, and some people, particularly poor adults in states that did not expand Medicaid under ACA, remain ineligible for public coverage.
- In 2019, over 73 percent of uninsured people were in a family with a full-time worker.
- The United States has earned surprisingly low grades on several standard measures of the quality of health care.

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From Kaiser Family Foundation, “Key Facts about the Uninsured Population,” November 6, 2020, <https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/>; Peterson-Kaiser, Health System Tracker, “How Does the Quality of the U.S. Healthcare System Compare to Other Countries?,” September 30, 2021, <https://www.healthsystemtracker.org/chart-collection/quality-u-s-healthcare-system-compare-countries/>; the Kaiser Commission on Medicaid and the Uninsured, “The Uninsured: A Primer,” Kaiser Family Foundation, October 2010, <http://www.kff.org/uninsured/7451.cfm>.

for any reason, including health status, and from charging higher premiums based on health status and gender.

- Medicaid will be expanded to 133 percent of the federal poverty level (\$14,404 for an individual and \$29,327 for a family of four in 2009) for all individuals under age 65.

The provisions of the law were implemented over the next few years. In the meantime it has been repeatedly challenged in the federal courts, and the partisan divide over it remains as wide as ever.

In 2012, in the case of *National Federation of Independent Business v. Sebelius*, the Supreme Court held that the ACA was constitutional but that states could opt out of the law's requirement to expand Medicaid. In 2014, the Court ruled that under the law, employers with religious objections are not required to cover contraceptives. In 2015, the Court upheld the legality of the ACA's mandate to provide health insurance subsidies to all qualifying Americans. But in 2017, Congress got rid of the mandate. Yet despite repeated attempts by Republicans in Congress to kill the ACA, it is still substantially intact.

## THEORIES OF JUSTICE

All these difficulties bring us around again to the question of what is just. Justice in the most general sense refers to people getting what is fair or what is their due (see Chapter 1). At the heart of every plausible notion of justice is the principle that equals should be treated equally—that people should be treated the same unless there is a morally relevant reason for treating them differently. When we ask what justice demands in society's allocation of health care, we are dealing with matters of **distributive justice**—justice regarding the fair distribution of society's advantages and disadvantages, or benefits and burdens, including income, property, employment, rights, taxes, and public service.

Debates about ethical allocations of health care resources rely heavily on general theories of justice. To justify a particular scheme of allocation, philosophers, politicians, and others may appeal to a theory of justice, and those who criticize the scheme may do so by arguing against that underlying theory of justice or by offering an alternative theory they believe to be superior. Three types of theories have had—and continue to have—an enormous impact on the discussions: libertarian, utilitarian, and egalitarian.

According to **libertarian theories of justice**, the benefits and burdens of society should be distributed through the fair workings of a free market and the exercise of liberty rights of noninterference. The role of government is to protect the rights of individuals to freely pursue their own interests in the economic marketplace without violations of their liberty through coercion, manipulation, or fraud. Government may use coercion, but only to preserve liberty. Beyond these protections, the government has no obligation to adjust the distribution of benefits and burdens among people; the distribution is the responsibility of free and autonomous individuals. People may have equal rights or equal worth, but that does not entitle them to an equal distribution of society's benefits. The government acts unjustly if it coercively redistributes those benefits.

On this view, no one has a right to health care, and a government program using tax dollars to provide universal health care or even health care only for low-income families would be unjust. Such a program would be a coercive violation of people's right to use their resources as they see fit. The libertarian would accept a system of health care only if it is freely endorsed and financed by those who participate in it. So health insurance acquired through free choice by a group of private citizens to meet their own health care needs is acceptable. State-supported health insurance financed by taxes is not. But none of this would rule out voluntary charity by well-off citizens to provide health care for the poor.

## IN DEPTH

### COMPARING HEALTH CARE SYSTEMS: UNITED STATES, CANADA, AND GERMANY

#### UNITED STATES

The U.S. health system is a mix of public and private, for-profit and nonprofit insurers and health care providers. The federal government provides funding for the national Medicare program for adults age 65 and older and some people with disabilities as well as for various programs for veterans and low-income people, including Medicaid and the Children's Health Insurance Program [CHIP]. States manage and pay for aspects of local coverage and the safety net. Private insurance, the dominant form of coverage, is provided primarily by employers. . . .

The United States does not have universal health insurance coverage. . . .

The federal government has only a negligible role in directly owning and supplying providers, except for the Veterans Health Administration and Indian Health Service. The ACA established "shared responsibility" among government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance. The U.S. Department of Health and Human Services is the federal government's principal agency involved with health care services.

The states cofund and administer their CHIP and Medicaid programs according to federal regulations. States set eligibility thresholds, patient cost-sharing requirements, and much of the benefit package. They also help finance health insurance for state employees, regulate private insurance, and license health professionals. Some states also manage health insurance for low-income residents, in addition to Medicaid.

#### CANADA

Canada has a decentralized, universal, publicly funded health system called Canadian Medicare.

Health care is funded and administered primarily by the country's 13 provinces and territories. Each has its own insurance plan, and each receives cash assistance from the federal government on a per-capita basis. Benefits and delivery approaches vary. All citizens and permanent residents, however, receive medically necessary hospital and physician services free at the point of use. To pay for excluded services, including outpatient prescription drugs and dental care, provinces and territories provide some coverage for targeted groups. In addition, about two-thirds of Canadians have private insurance.

Canadian Medicare—Canada's universal, publicly funded health care system—was established through federal legislation originally passed in 1957 and in 1966. The Canada Health Act of 1984 replaces and consolidates the two previous acts and sets national standards for medically necessary hospital, diagnostic, and physician services. To be eligible to receive full federal cash contributions for health care, each provincial and territorial (P/T) health insurance plan needs to comply with the five pillars of the Canada Health Act. . . .

Canadian P/T governments have primary responsibility for financing, organizing, and delivering health services and supervising providers. The jurisdictions directly fund physicians and drug programs, and contract with delegated health authorities (either a single provincial authority or multiple subprovincial, regional authorities) to deliver hospital, community, and long-term care, as well as mental and public health services.

The federal government cofinances P/T universal health insurance programs and administers a range of services for certain populations, including eligible First Nations and Inuit peoples, members of the Canadian Armed Forces, veterans, resettled refugees and some refugee claimants, and inmates in federal penitentiaries. It also regulates the safety and efficacy of medical devices, pharmaceuticals, and natural health products, funds health research and some information technology systems, and administers several public health functions on a national scale.

*(continued)*

## GERMANY

Health insurance is mandatory in Germany. Approximately 86 percent of the population is enrolled in statutory health insurance, which provides inpatient, outpatient, mental health, and prescription drug coverage. Administration is handled by non-governmental insurers known as sickness funds. Government has virtually no role in the direct delivery of health care. Sickness funds are financed through general wage contributions (14.6 percent) and a dedicated, supplementary contribution (1 percent of wages, on average), both shared by employers and workers. Copayments apply to inpatient services and drugs, and sickness funds offer a range of deductibles. Germans earning more than \$68,000 can opt out of SHI and choose private health insurance instead. There are no government subsidies for private insurance.

Chancellor Otto von Bismarck's Health Insurance Act of 1883 established the first social health insurance system in the world. At the beginning, health insurance coverage was restricted to blue-collar workers. In 1885, 10 percent of the population was insured and entitled to cash benefits in case of illness (50 percent of wages for a maximum of 13 weeks), death, or childbirth. While initially limited, coverage gradually expanded. The final step toward universal health coverage occurred in 2007, when health insurance, either statutory or private, was mandated for all citizens and permanent residents. Today's system provides coverage for the entire population, along with a generous benefit package.

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From The Commonwealth Fund, "International Health Care Systems Profiles," June 5, 2020, <https://www.commonwealthfund.org/international-health-policy-center/countries/united-states>.

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In utilitarian theories of justice, a just distribution of benefits and burdens is one that maximizes the net good (utility) for society. Some allocations (or principles of allocation) of society's resources are more beneficial overall than others, and these are what utilitarian justice demands. A utilitarian may grant some principles of allocation the status of rights—rules that can be enforced by society and that can override considerations of utility in specific situations. But the ultimate justification of the rules is utilitarian (actually, rule-utilitarian): consistently following the rules may maximize utility generally, although rule adherence in some instances may not produce a net good.

On a utilitarian view, a just allocation of health care can take several forms depending on the facts about society's resources and needs and the likely effects of various allocation policies and programs. Thus, depending on calculations of net benefits, a utilitarian might endorse a system of universal health care insurance, or a qualified right to health care, or a two-tiered plan (like the U.S. arrangement) in which

government-supported health insurance is combined with the option of privately purchased health coverage for those who can afford it.

Egalitarian theories of justice affirm that important benefits and burdens of society should be distributed equally. To achieve greater equality, the egalitarian (unlike the libertarian) would not be averse to mandating changes to the distribution of society's goods or to interfering in the workings of a free market. And the egalitarian (unlike the utilitarian) would not allow utility to be the ultimate overriding consideration in a system of distribution. From egalitarian premises, theorists have derived several schemes for allocating health care, including systems that give equal access to all legitimate forms of health care, that offer a guaranteed minimal level of health care for everyone, or that provide care only to those most in need.

Besides these familiar theories of justice, there is another entirely different perspective on justice and health care: the *human rights approach*. The idea is that we can best achieve just

distributions of health and health care by ensuring that human rights in general are respected. Respecting human rights (which encompass fair treatment, freedom from coercion, nondiscrimination, protection from abuse, equality, and other entitlements) contributes to well-being and health (including access to health care), and these positive contributions to health depend on respect for human rights. According to proponents of this view,

Health and human rights are not distinct but intertwined. Viewed as a universal aspiration, the notion of health as the attainment of physical, mental, and social well-being implies its dependency on and contribution to the realization of human rights. From the same perspective, the enjoyment by everyone of the highest attainable standard of physical and mental health is in itself a recognized human right. From a global normative perspective, health and human rights are closely intertwined in many international treaties and declarations supported by mechanisms of monitoring and accountability (even as their effectiveness can be questioned) that draw from both fields.<sup>9</sup>

### A RIGHT TO HEALTH CARE

No matter what theory of justice people accept, they are likely to agree that it would be good for everyone to have adequate health care, or that beneficence may justify society's providing health care to the neediest, or that making particular kinds of health care available to certain groups may produce a net benefit for society. But some assert a much stronger claim: People have a moral *right* to health care. A right is an entitlement, a *bona fide* claim, to something. A person's rights impose duties on others—either (1) duties not to interfere with that person's obtaining something or (2) duties to help that person in her efforts to get something. Rights entailing the former obligations are called *negative rights*; those entailing the latter are called *positive rights*. Those who insist that an individual has a

right to health care are referring to a positive right and are claiming that society has an obligation to provide that benefit in some way.

Libertarians are likely to deny that there is a right to health care, for generally they accept negative rights and disallow positive rights. Utilitarians can admit a right to health care, though it would be what some have called a *derivative right*, a rule ultimately justified by assessments of utility. Others, including egalitarians, can accommodate a right to health care and interpret it in the strong sense of being an entitlement that ultimately outweighs calculations of maximized utility.

But what reasons are there for believing that there is such a strong right to health care? Norman Daniels believes that such a right can be derived from one of the principles of justice articulated by John Rawls, specifically the right to "fair equality of opportunity."<sup>10</sup> Rawls maintains that everyone is entitled to an equal chance to obtain the basic goods of society, though there is no guarantee of an equal share of them (see the discussion of Rawls's theory in Chapter 2). A just society would ensure equal opportunities to its citizens. Daniels argues that disease and disability diminish people's "normal species functioning" and thus restrict the range of opportunities open to them. But "health care in all its forms, whether public health or medical, preventive or acute or chronic, aims to keep people functioning as close to normally as possible. . . . Health care thus preserves for us the range of opportunities we would have, were we not ill or disabled, given our talents and skills."<sup>11</sup> Since people are entitled to fair equality of opportunity, and adequate health care can protect or restore their normal range of opportunities, they have a positive right to adequate health care.

A pivotal question that confronts every serious advocate of a moral right to health care is what health care resources it includes. Some have thought the right encompasses universal equal access to all available health care resources. But this arrangement is not technically or economically feasible; a right to health care, it seems, must

have limits. Recognizing this, many have argued for a weaker right to a “decent minimum” level of health care. On this view, everyone would have access to a minimal, basic array of health care resources. This tier of care would be universally available, publicly supported, and guaranteed for all in need. A second tier of additional health care services (elective or nonessential therapies, for example) would be available in the free market-place for those who can afford them.

Allen Buchanan rejects the idea of a right to a decent minimum of care, but he understands its attractions:

First, the notion that people have a right to a decent minimum or adequate level, rather than to *all* health care that produces any net benefit, clearly acknowledges that, because not all health care is of equal importance, allocational priorities must be set within health care and that resources must also be allocated to goods other than health care. Second, this [decent minimum] position is also consonant with the intuitively plausible conviction that our obligations to the less fortunate, although fundamental enough to be expressed in the language of rights, are nonetheless *not unlimited*. Third, the decent minimum is a floor beneath

### IN DEPTH PUBLIC HEALTH AND BIOETHICS

Public health is bioethics on a large scale. Most of the time bioethics concerns ethics as it applies to individuals and personal morality, but it also encompasses morality as it pertains to the health of whole populations. This is *public health*. It focuses on communities, from neighborhoods to countries to the world, working to prevent disease and disabilities, promoting health and well-being, tracking the incidence of illness, and intervening when the health of a community is imperiled.

Public health involves agencies of the government but also many professionals and nonprofessionals in the community. It can function locally, nationally, or globally. Public health programs provide vaccinations, promote healthful habits such as handwashing and not smoking, guide the treatment of wastewater, distribute condoms to prevent the spread of sexually transmitted diseases, help insure the safety of food and water, investigate pandemics and other disease outbreaks, provide early warning of emerging public health hazards, prevent epidemics after natural disasters, and much more.

*Public health ethics*, like any other area of applied ethics, deals with the application and reconciliation of moral norms. The same moral principles and concepts that inform the whole field of bioethics also do work in the subfield of public health. In public health, we still must strive to respect autonomy, avoid harming others, act with beneficence, maximize utility, behave justly, protect privacy and confidentiality, deal honestly with others, and keep promises. The proper balancing of these demands—a job that falls to both professionals and ordinary citizens—is often difficult and controversial. Implementing these ideas is a separate job that is frequently even more challenging.

Moral norms can conflict in public health ethics just as they do in personal ethics. Suppose public health officials quarantine or treat a man against his will because he has contracted a deadly communicable disease. Here respect for the man’s autonomy clashes with the need to protect the public from harm. In other cases the need to protect the public might conflict with people’s right to privacy or with fairness or with confidentiality. Suppose the state mandates that all adults must be vaccinated against a lethal, spreading infection. A key issue is whether the government is wrongfully infringing on the population’s personal liberty. Disputes like these can (and do) happen in nearly every public health endeavor, and disagreement is frequently widespread.

which no one should be allowed to fall, not a ceiling above which the better-off are prohibited from purchasing services if they wish.<sup>12</sup>

But the implications of the decent-minimum standard have been extremely difficult to specify in a plausible way. What is, after all, a *decent minimum* of health care? We may assume it includes such things as immunizations, annual physical exams, and “routine” medical care. Should it also include heart transplants, treatments for rare or orphan diseases, cosmetic surgery, expensive but marginally effective care for very elderly or dying patients, and costly lifelong therapies for mentally impaired persons who will never reach “normal” functioning?

Buchanan believes that although there is no right to a decent minimum of health care, there are good reasons for supposing that society should nevertheless provide the kind and amount of health care that a decent-minimum right would demand. That is, there is no individual right, but there may be a societal duty. Among these reasons are arguments that people have special rights (as opposed to universal rights) to health care—rights of restitution to certain groups for past wrongs, rights of compensation for “those who have suffered unjust harm or who have been unjustly exposed to health risks by the assignable actions of private individuals or corporations,” and rights to health care for honorable service to society (for wounded soldiers, for instance). There are also prudential arguments, Buchanan says, such as that “the availability of certain basic forms of health care make for a more productive labor force or improve the fitness of the citizenry for national defense.” Arguments for what he calls “enforced beneficence” can also be made out. To maximize the practical effect of our moral obligations of charity or beneficence regarding health care for those in need, “an enforced decent minimum principle is needed to achieve coordinated joint effort.”<sup>13</sup> Thus, for example, the government could levy taxes to provide health care to the poor—not in the name of egalitarian justice, but for the sake of beneficence.

## THE ETHICS OF RATIONING

*Rationing* has been a dirty word in debates about health care, laden as it is with images of extreme measures of last resort for managing a dearth of resources. But in health care, rationing—in the broad sense of parceling out important limited goods—has always been with us and probably always will be. People’s health care needs are virtually boundless, yet the supply of health care resources is ever limited. So we ration: Medicare and Medicaid allot health care to the elderly and the poor; HMOs limit medical procedures, tests, and access to doctors to control costs; hospitals restrict the use of intensive care units (ICUs), cardiac surgical teams, emergency departments, hospital beds, and expensive drugs; organ transplants are doled out to the few because of shortages of usable organs; and the health care system as a whole rations a great deal of care by people’s ability to pay for it. (See Chapter 12 on rationing health care resources during a pandemic.)

Thus, the tough choices of rationing fall hard upon us, and we are forced to ask: Who should get what share of limited health care goods and services? In countless troubling instances, the question reduces to this: Who should live and who must die? In nearly the same breath we have to ask: On what ethical grounds do we make these choices? The fundamental issue of the proper allocation of insufficient resources troubles on several levels at once. It arises both on the scale of the total health care system (concerning what portion of society’s resources should go to health care and how this allotment should be used—so-called *macroallocation*) and on the scale of individual patients and providers (regarding who should receive specific resources—known as *microallocation*).

Let’s consider just a few of the smaller scale (*microallocation*) questions raised by one of our scarcest life-saving resources—organ transplants. Transplant operations are incredibly expensive, organs are in very short supply, and transplants are desperately needed by far more

people than can be accommodated. The waiting list for transplants is long, and thousands die every year for their lack. Screening committees at transplant centers decide whether someone should be placed on the waiting list and what ranking they should receive. They use various criteria to make these decisions, some explicit, some informal or unspoken, some plausible (such as the patient's need and likelihood of benefit), and some controversial (such as ability to pay, social worthiness, and health habits).

But what criteria *should* be used? What rationing policy for transplants is morally justified? Many proposed criteria are utilitarian, concerned with maximizing benefits to the patient and society. Many are egalitarian, focusing on justice and the moral equality of persons. Some philosophers propose rationing policies that emphasize one or the other, while some try systematically to accommodate both.<sup>13</sup> No policy is completely satisfactory, but some seem to capture our moral intuitions better than others.

One utilitarian approach to rationing care to patients is to measure objectively the benefits that a treatment is likely to give each patient and then selectively treat particular patients or conditions to maximize total benefits. The objective measure of benefits that has often been used in such calculations is known as a QALY, or quality-adjusted life year. One QALY is equivalent to one year of life in good health, and a year of life in poor health is equal to less than 1 QALY. The lower the quality of life for a person in poor health, the lower the QALY value. A transplant operation that allows a patient to live seven years without disability or suffering is worth 7 QALYs; if it results in the patient's living seven years burdened by severe pain, it is worth less than 7 QALYs. Thus, QALYs gauge a treatment's impact by, plausibly, trying to take into account both the length of life and its quality. Intuitively this seems right because both quality of life and length of life matter to people. Most would probably rather enjoy a few years of good health than suffer through many years of terrible illness or disability. Suppose, then, that three people are awaiting heart transplants, without which they

will die within six months, and only two transplants are possible. Two of the potential recipients are young, so a transplant for either one of them would yield 10 QALYs. The third person is much older; a transplant for her would yield only 5 QALYs. So a transplant selection committee using the QALY standard alone would likely allocate the available transplants to the two younger patients, maximizing total benefits.

The utilitarian purpose behind using QALYs is to do the most good with the resources available. But critics have charged that relying on QALYs to allocate or ration health care can lead to morally unacceptable decisions. John Harris argues, for example, that QALYs discriminate against older people:

Maximizing QALYs involves an implicit and comprehensive ageist bias. For saving the lives of younger people is, other things being equal, always likely to be productive of more QALYs than saving older people. Thus on the QALY arithmetic we always have a reason to prefer, for example, neonatal or paediatric care to all "later" branches of medicine. This is because any calculation of the life-years generated for a particular patient by a particular therapy, must be based on the life expectancy of that patient. The older a patient is when treated, the fewer the life-years that can be achieved by the therapy.<sup>14</sup>

QALYs, he says, are also unfair to the disabled:

Suppose for example that if an accident victim were treated, he would survive, but with paraplegia. This might always cash out at fewer QALYs than a condition which with treatment would give a patient perfect remission for about five years after which the patient would die. Suppose that both candidates wanted to go on living as long as they could and so both wanted, equally fervently, to be given the treatment that would save their lives. Is it clear that the candidate with most QALYs on offer should always and inevitably be the one to have priority? To judge so would be to count the paraplegic's desire to live the life that was available to him as of less value than his rival's.<sup>15</sup>

**CLASSIC CASE FILE****Christine deMeurers**

The era of managed care has changed health care in the United States radically—for the worse, many say. Whatever the case, it has surely set off a host of conflicts that were previously unimagined: clashes between patients and their insurance companies, between physicians and their cost-conscious managed care employers, and between the physicians' duty to put the patient's welfare first and the economic incentives to put it last. Out of this maelstrom many unsettling stories have come, including this one.

In 1992, Christine deMeurers—a 32-year-old wife, mother of two, and schoolteacher—found out that she had breast cancer. She fought back promptly and aggressively, enduring a radical mastectomy, radiation therapy, and chemotherapy. But in May 1993, a bone scan revealed that the cancer had spread and now rated the ominous label of Stage IV metastatic breast cancer. Every standard therapy available had been used against her disease with no apparent effect. She was running out of time.

Harris and others contend that a crucial failing of QALYs is that these objective measurements cannot accommodate the subjective nature of people's assessments of the value of their own lives. A paraplegic may value his life and think its quality extremely high despite his disability. A perfectly healthy person may think her life miserable despite a lack of physical ailments. The subjective valuation seems to be the important one; the objective measurement seems to be beside the point.

Policies for rationing transplants to a particular group of patients generally try to take into account the probability of transplant success or the urgency of the patients' needs. Both factors can be morally relevant. Regarding the former, because transplants are a scarce resource,

Christine and her husband, Alan, were subscribers in an HMO, Health Net of Woodland Hills, California. They got the insurance through their employer (they both were teachers at the same school) and had opted for the least expensive coverage.

After the standard treatments failed, the deMeurerses thought they had no options left, but Christine's oncologist, Dr. Mahesh Gupta, was hopeful. He held out the possibility that she could benefit from a promising new treatment, a bone marrow transplant. Its effectiveness against Christine's type of cancer was unproven, but it had been used successfully on other kinds of malignancies. In violation of Health Net rules on referrals, Dr. Gupta referred Christine directly to an expert he knew, an oncologist at the Scripps Clinic in La Jolla.

According to the deMeurerses, the Scripps doctor was reluctant to help them or even to provide them with information about the bone marrow transplant. So they flew to Denver, where Christine was examined by Dr. Roy B. Jones at the University of

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fairness seems to demand that they be given to those who are likely to benefit from them—otherwise the resource will be wasted, and people will be deprived of a treatment that could have saved them. Regarding the latter, giving transplants to those who cannot survive for much longer without them fulfills a duty to preserve lives.

Nevertheless, some maintain that allocating resources in light of one of these considerations while disregarding the other is a mistake:

For example, although heart-transplant surgeons sometimes list their patients as urgent priority candidates for an available heart because the patients will soon die if they do not receive a transplant, some of these patients are virtually certain

Colorado. He told them that the bone marrow procedure might be beneficial to Christine. But about the time that the deMeureresaes consulted with Dr. Jones, Health Net resolved that the company would not pay for the transplant because it was disallowed under the investigational clause in Christine's contract.

Increasingly desperate, the deMeureresaes started trying to raise the thousands of dollars needed to pay for the procedure, and they hired a lawyer to appeal Health Net's ruling. They also got permission to see another oncologist. He, too, encouraged Christine to consider the bone marrow transplant and referred her to the UCLA Medical Center, where Dr. John Glaspy presented the operation as an option and agreed to perform it.

This encounter between the deMeureresaes and Dr. Glaspy was strained by mutual ignorance of some significant facts. Wary of possible interference from Health Net, they did not tell Dr. Glaspy that they were Health Net subscribers and told him instead that they would pay for the transplant out of pocket. At the same time the deMeureresaes did not know that Dr. Glaspy was on the Health Net committee that

had voted recently not to cover bone marrow transplants for Stage IV breast cancer patients.

Later, news came that Health Net had rejected the appeal filed by the deMeureresaes' lawyer.

Dr. Glaspy found himself caught between conflicting loyalties. As the deMeureresaes' physician, he felt a responsibility to help Christine get the transplant. But as a Health Net physician, he was required to uphold the regulations of the HMO, some of which he had helped make. Discussions ensued between Health Net administrators and UCLA physicians and officials. Finally, a way out of the conflict appeared when UCLA agreed that it would pay for Christine's operation.

Christine began the treatment on September 22, 1993, at UCLA Medical Center. She died on March 10, 1995. Health Net officials expressed doubt that the treatment helped much. Alan deMeurers said that it gave Christine four disease-free months.

Eventually an arbitration panel ruled that Health Net should have paid for Christine's transplant and that the company had improperly interfered in the doctor-patient relationship.

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to die even if they do receive the heart. High quality candidates are passed over in the process. A classification and queuing system that permits urgent need to determine priority exclusively is as unjust as it is inefficient.<sup>16</sup>

Neither probability of success nor urgent need seems to be as controversial as another kind of criterion: the *social value* of people's lives. Here the question is which potential recipients—if given the chance to live—are expected to contribute most to the good of society. To state the issue concretely: All things being equal, should the medical student get the transplant instead of the poet or prostitute? Nicholas Rescher thinks this question of social utility important and morally relevant:

In “choosing to save” one life rather than another, “the society,” through the mediation of the particular medical institution in question—which should certainly look upon itself as a trustee for the social interest—is clearly warranted in considering the likely pattern of future *services to be rendered* by the patient (adequate recovery assumed), considering his age, talent, training, and past record of performance. In its allocations of [exotic life-saving therapy], society “invests” a scarce resource in one person as against another and is thus entitled to look to the probable prospective “return” on its investment.<sup>17</sup>

Others reject this line altogether, arguing from an egalitarian or Kantian perspective that all

persons have equal worth. Morally, the medical student is not worth more than the poet or prostitute, and vice versa. Education, achievement, occupation, and the like are not morally relevant.

Nevertheless, while generally taking this view, some philosophers maintain that in very rare cases, social worth can outweigh egalitarian concerns. It seems reasonable that in a natural disaster involving mass casualties, injured physicians or nurses should be treated first if they can aid the other survivors. We can imagine analogous situations involving organ transplants, says Walter Glannon:

Suppose that Nelson Mandela needed a liver transplant in 1992. This was the time when he was leading the transition from apartheid to democracy in South Africa. The transition turned out to be peaceful; but the political situation was potentially volatile. Mandela was essential to maintaining social stability. Suppose further that a younger individual also needed a liver and would have at least as good an outcome with a transplant. In the light of the political and social circumstances, Mandela should have been given priority over the younger patient in receiving a liver. His survival would have ensured the social stability of the country. It would have ensured that many people would not suffer a loss of welfare or life from the social instability that might have resulted otherwise. Mandela's social worth was a function of the dependence of many people's welfare and lives on his survival. That worth would have been a decisive factor in giving the organ to him rather than to another person with the same need.<sup>18</sup>

### KEY TERMS

distributive justice  
egalitarian theories of justice  
libertarian theories of justice  
managed care  
utilitarian theories of justice

### SUMMARY

The U.S. system of health care has been ailing—or failing, as some would say—for years. Its most obvious symptoms are 47 million uninsured

people under age 65, soaring costs, and low grades on some measures of national health, such as infant mortality rates.

Debates about ethical allocations of health care resources often reduce to clashes between theories of distributive justice—that is, theories regarding the fair distribution of society's benefits and burdens. Libertarian theories of justice say that the benefits and burdens of society should be distributed through the fair workings of a free market and the exercise of liberty rights of noninterference. The role of government is to protect the rights of individuals to freely pursue their own interests in the economic marketplace without violations of their liberty through coercion, manipulation, or fraud. On this view, no one has a right to health care. In utilitarian theories of justice, a just distribution of benefits and burdens is one that maximizes the net utility for society. Depending on calculations of net benefits, a utilitarian might endorse a system of universal health care insurance, or a qualified right to health care, or a two-tiered plan. Egalitarian theories of justice say that important benefits and burdens of society should be distributed equally. To achieve greater equality, the egalitarian would not be averse to mandating changes to the distribution of society's goods or to interfering in the workings of a free market. Egalitarian theorists could consistently endorse several schemes for allocating health care, including systems that give equal access to all legitimate forms of health care, that offer a guaranteed minimal level of health care for everyone, or that provide care only to those most in need.

Some theorists assert the strong claim that people have a positive moral right to health care. Libertarians would reject this view, utilitarians could endorse a derivative right to health care, and egalitarians could favor a bona fide entitlement to a share of society's health care resources. Some of the latter argue for a right to a decent minimum of health care.

Because people's health care needs are virtually limitless and the supply of resources is always bounded, rationing of health care in

some form is ever with us. The dilemmas of rationing arise most visibly and acutely on the level of individual patients and providers who must contend with scarce life-saving resources such as organ transplants. The central moral issue in these cases is what criteria should be used to decide which patients get transplants and who should make the decisions.

## Cases for Evaluation

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### CASE I

#### Black Market in Organ Transplants

(*San Francisco Chronicle*)—Tears well up in P. Guna's eyes as he stares at a long scar running down his side. A year ago, he attempted to stave off mounting debt by swapping one of his healthy kidneys for quick cash.

"Humans don't need two kidneys, I was made to believe," he said. "I can sell my extra kidney and become rich, I thought."

At the time, an organ trader promised Guna, 38, a motorized-rickshaw driver with a fourth-grade education, \$2,500 for the kidney, of which he eventually received only half. Since then, he has experienced excruciating pain in his hip that has kept him from working full time and pushed him deeper in debt.

In recent years, many Indian cities—like Chennai in southern India—have become hubs of a murky business in kidney transplants, despite a 1994 nationwide ban on human organ sales (the Transplant of Human Organ Act states only relatives of patients can donate kidneys).

An influx of patients, mainly foreigners, seeking the transplants has made the illicit market a lucrative business. Some analysts say the business thrives for the same reasons that have made India a top destination for medical tourism: low cost and qualified doctors. In fact, medical tourism is expected to reach \$2.2 billion by 2012, according to government estimates.

Not surprisingly, an organized group of organ traders in cahoots with unscrupulous doctors is constantly on the prowl for donors like Guna.

In Gurgaon, a posh New Delhi suburb, police last month busted an illegal organ racket, which included doctors, nurses, pathology clinics, and hospitals. In the past 14 years, the participants allegedly removed kidneys from about 500 day laborers, the majority of them abducted or conned, before selling the organs to wealthy clients.

Police say the doctor believed to be the mastermind behind the operation, Amit Kumar, searched for donors by cruising in luxury cars outfitted with medical testing machines, and kept sophisticated surgical equipment in a residential apartment. In his office, police found letters and e-mail messages from 48 people from nine countries inquiring about transplants.

On Thursday, police arrested Kumar in Chitwan, a Nepalese jungle resort. Local news reports said he was identified by a hotel employee who recognized him from Indian television broadcasts seen in Nepal. "I have not duped anybody," Kumar later told reporters in Kathmandu, according to the Associated Press.

Nepalese authorities say they won't extradite Kumar until they finish an investigation on whether he violated currency laws by not declaring \$230,000 in cash and a check for \$24,000 that he was carrying when arrested. He is scheduled to appear in a Nepalese court Sunday.

In another high-profile arrest, a renowned Chennai surgeon, Palani Ravichandran, was arrested in October in Mumbai for involvement in a kidney racket. He admitted to arranging organ transplants for wealthy foreigners—mainly from Persian Gulf states and Malaysia, whom he charged up to \$25,000. Mumbai police say Ravichandran had performed between 40 and 100 illegal transplants since 2002.

Police say kidney donors can earn between \$1,250 and \$2,500, while recipients pay as much as \$25,000, according to ActionAid India, an antipoverty organization that has worked with kidney trade victims in the southern state of Tamil Nadu.

The same procedure can cost as much as \$70,000 in China and \$85,000 in the United States.

"These middlemen act more like cut-and-grab men whose only interest is to hack out the organ," said Annie Thomas, a field co-coordinator for

ActionAid in Chennai, formerly known as Madras. "This is a reprehensible abuse of the poor, and this practice needs to be curbed."

Thomas says many middlemen typically masquerade the donors as relatives to circumvent the law while many foreigners in need of a kidney arrive on tourist visas rather than the required medical visas; some resort to false documents.\*

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*Is it morally permissible to sell your own organs? Is it morally permissible to buy organs from consenting adult donors? Should organ selling be illegal in all cases? Are the Indian organ donors described in this article being exploited? How? Give reasons for your answers.*

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\*Anuj Chopra, "Organ-Transplant Black Market Thrives in India," *SFGate*, February 9, 2008, <http://www.sfgate.com>.

## CASE 2

### Expensive Health Care for a Killer

(*Statesman Journal*)—Oregon taxpayers are shelling out more than \$120,000 a year to provide life-saving dialysis for a condemned killer.

Horacio Alberto Reyes-Camarena was sent to death row six years ago for stabbing to death an 18-year-old girl and dumping her body near the Oregon Coast.

At the Two Rivers Correctional Institution in Eastern Oregon, Reyes-Camarena, 47, gets hooked up to a dialysis machine for four hours three times a week to remove toxins from his blood.

Without dialysis, he would die because his kidneys are failing.

Each dialysis session costs \$775.80 for treatment and medication, according to Corrections Department figures. At that rate, his dialysis costs \$121,025 a year.

As the state keeps Reyes-Camarena alive, thousands of older, poor, sick and disabled Oregonians are trying to survive without medications and care that vanished amid state budget cuts.

Some Oregon hospitals are considering closing dialysis units because of Medicaid-related reductions.

Reyes-Camarena said he wants to sever his ties to the dialysis machine. The convicted killer wants to be the first Oregon inmate to receive a taxpayer-financed organ transplant.

"It's much better for me, and them, too," Reyes-Camarena said, referring to his desire for a kidney transplant, a procedure sought by nearly 57,000 Americans.

The prisoner cited medical reports indicating that transplant costs prove to be cheaper than dialysis in the long run.

Even so, transplant surgery is costly: \$80,000 to \$120,000. It also requires \$500 to \$1,200 a month in lifelong drugs to keep the recipient from rejecting the new organ.

Studies have found that the death rate for dialysis patients is about 23 percent a year. A successful transplant reduces that risk to about 3 percent a year.

But the number of transplants is severely limited by a national scarcity of available organs. As of this month, 56,895 Americans, including 192 Oregonians, were waiting for kidney transplants, according to the Virginia-based United Network for Organ Sharing, which maintains the nation's waiting list for organs.

Because the waiting list is long and there aren't enough organs to go around, some people die before a transplant becomes available.

Overall, 86,157 Americans are waiting for organ transplants—mostly kidneys, livers, pancreases and lungs. Officials estimate that about 700 will die this year while waiting.

Lifesaving care for Reyes-Camarena raises questions about the bounds of medical treatment for prisoners.\*

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*Is society obligated to prolong the life of felons like Reyes-Camarena? As thousands of dollars are spent each year by the state to provide him with health care, many lawful citizens cannot afford critical care and die as a result. Is this arrangement just? Do prisoners have a right to health care? Does anyone have a right to health care? Explain your answers.*

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\*Alan Gustafson, "Death Row Inmate Seeks Organ Transplant," *Statesman Journal*, April 28, 2003, <http://news.statesmanjournal.com/article.cfm?i=59,756>.

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**CASE 3**

## Should We Have Universal Health Care?

(TCU360)—Since the dawn of the twentieth century, a debate over health care has raged in America.

The debate centers around the argument over whether the federal government is obligated to ensure that its citizens have health care, thus preventing them from economic headaches associated with rising costs of basic medical care.

Historian and sociologist Paul Starr wrote in his book, *Remedy and Reaction: The Peculiar American Struggle over Health Care Reform*, that efforts to “provide all Americans access to medical care and protect them from economic ruin” have long been a “liberal inspiration.”

Beginning in the early decades of the twentieth century, reform from the Progressive Era gave Americans antitrust laws, labor legislation, the Federal Reserve and workers’ compensation, but reforming health care proved to be more challenging.

Reform has come slowly. After the New Deal, Social Security was passed to give seniors a fiscal safety net in their later years. Along with Social Security came the GI Bill and the minimum wage.

For decades liberals sought a system of universal health care that would protect all Americans from the pain of illness and burdensome medical bills.

With the establishment of Medicare and Medicaid, progressives hoped they had broken through—not so.

Starr wrote that “if Americans came to know one thing about the history of battles over health insurance, it was that a government program to make health care a right of citizenship had always been defeated.”

Early ideas for government-led health insurance programs came from Europe.

British national health care and German sickness funds were unpopular and never gained traction in America. Workers compensation shows similarities to German sickness funds, but the idea

of national health care similar to Britain was, to the chagrin of progressives, politely frowned upon in the States.

In 1912, progressives within the Republican Party established the Progressive Party that included in its platform support for social health insurance.

Canada boasts a single payer system with striking similarities to the United States’ Medicare system. Progressives had hoped that the Medicare system would serve as a precursor to a more wide-reaching program to establish a system for all Americans, offering insurance akin to the coverage offered to seniors by Medicare. . . .

In reality, none of the proposals in the United States even closely resembles true government health care like Britain’s universal health care system.

Reality shows that Democrats largely played on Republican turf.

Coupling reform with deficit reduction, championing the originally Republican idea of the individual mandate and dropping advocacy for a government-run “public option” meant that Democrats sought compromise on the bill.

They sought agreement on one of the most divisive issues in America’s history. Agreement may have been sought, but discord was found.

Perhaps the fact that the debate requires Americans to draw upon deep-seated ethical principles precludes agreement.

Or perhaps the problem is deeper.

Perhaps Americans are truly divided over the role government should play in people’s lives.\*

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*Should the United States establish a system of universal health care? Why or why not? What moral principle seems to underpin opposition to such a system? What moral principle seems to favor it? What would be the negative effects of having universal health care? What would be the positive effects?*

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\*Alex Apple, “Universal Health Care Debate a Controversial Topic for the United States,” TCU360 (Texas Christian University), November 22, 2012, <https://www.tcu360.com/>.

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**READINGS**

## **Is There a Right to Health Care and, If So, What Does It Encompass?**

NORMAN DANIELS

Daniels argues for a strong right to health care, deriving it from John Rawls's justice principle of "fair equality of opportunity." He reasons that disease and disability diminish people's "normal species functioning" and thus restrict the range of opportunities open to them. Since people are entitled to fair equality of opportunity, and adequate health care can protect or restore their normal range of opportunities, they have a positive right to adequate health care.

### **Is There a Right to Health Care?**

#### **Legal Versus Moral Rights to Health Care**

One way to answer this question is to adopt the stance of legal positivists, who claim that there are no rights except those that are embodied in actual institutions through law. We would then be able to reply that in nearly every advanced industrial democracy in the world, there is a right to health care, since institutions exist in them that assure everyone access to needed services regardless of ability to pay. The notable exception is the United States, where many poor and near poor people have no insurance coverage for, and thus no assured access to, medically necessary services, although by law they cannot be denied emergency services.

The legal right to health care is embodied in a wide variety of types of health-care systems. These range from national health services, where the government is the provider of services, as in Great Britain, to public insurance schemes, where the government finances services, as in Canada, to mixed public and private insurance schemes, as in Germany and the Netherlands. Despite these differences in the design of systems, there is a broad overlap in the scope or content of the legal right to

health care in these countries. Most cover "medically necessary" services, including a broad range of preventive, curative, rehabilitative and long-term care for physical and mental diseases, disorders and disabilities. Most exclude uses of medical technologies that enhance otherwise normal functioning or appearance, such as purely cosmetic surgery. The legal rights vary in significant ways, however, for example, in the degree to which they cover new reproductive technologies, or in the types of mental health and long-term care services that are offered.

In the context of rising costs and the rapid dissemination of new technologies there is growing debate in many countries about how to set limits on the scope of a right to health care. This debate about the scope of rights to health care pushes moral deliberation about such a right into the forefront, even where a legal right is recognized. Legal entitlements, most people believe, should reflect what society is morally obliged to provide by way of medical services. What, then, is the basis and scope of a moral right to health care?

#### **Positive Versus Negative Rights**

A right to health care is a *positive* as opposed to a *negative* right. Put quite simply, a positive right requires others to do something beneficial or enabling for right-bearers, whereas a negative right requires others to refrain from doing something, usually harmful or restrictive, to right-bearers. To say that

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others are required to do something or to refrain from doing something is to say they must so act or refrain even if they could produce more good or improve the world by not doing so (Thomson, 1990). For example, a negative right to free expression requires others to refrain from censuring the expression of the right-bearer even if censuring this speech would make a better world. Some public-health measures that protect people against interference with their health, such as environmental protections that protect people against polluters of air, water and food sources, might be construed as requirements of a negative right. More generally, however, a right to health care imposes an obligation on others to assist the right-bearers in obtaining needed and appropriate services. Specifically, claiming a right to health care includes these other claims; society has the duty to its members to allocate an adequate share of its total resources to health-related needs; society has the duty to provide a just allocation of different types of health-care services, taking into account the competing claims of different types of health-care needs; each person is entitled to a fair share of such services, where a "fair share" includes an answer to the question, who should pay for the services (Daniels, 1985)? Health-care rights thus form a part of a broader family of positive "welfare" rights that includes rights to education and to income support. Because positive rights require other people to contribute their resources or skills to benefit right-bearers, rather than merely refraining from interfering with them, they have often been thought more difficult to justify than negative rights, and their scope and limits have been harder to characterize.

### Theories of Justice and Rights to Health Care

If we are to think of a right to health care as a requirement of justice, then we should look to more general theories of justice as a way to specify the scope and limits of that right. On some theories of justice, however, there is little basis for requiring people to assist others by meeting their health care or other needs. Libertarians, for example, believe that fundamental rights to property, including rights to personal assets, such as talents and skills,

are violated if society coerces individuals into providing "needed" resources or skills (Nozick, 1974). Libertarians generally recognize an "imperfect" duty to act beneficently or charitably, but this duty involves discretion. It can be discharged in different ways that are matters of choice. People denied charity have no right to it and have no complaint against people who act charitably in other ways. Though some have argued that the difficulty of coordinating the delivery of charitable assistance might justify coercive measures (Buchanan, 1984), and others have tried to show that even libertarians must recognize some forms of welfare rights (Sterba, 1985), most libertarians resist any weakening of the property rights at the core of their view (Brennan and Friedman, 1981).

A spectre sometimes raised by libertarians against the idea of a right to health care is that such a right is a "bottomless pit." Since new technologies continuously expand the scope of "medical needs," a right to health care would give rise to unlimited claims on the resources of others (Fried, 1969; Engelhardt, 1986). Protecting such an expansive right to health care would thus not be compatible with the function of a libertarian "minimal state" to assure the non-violation of rights to liberty and property.

Though there remains controversy about whether utilitarians can provide a basis for recognizing true moral rights, there are strong utilitarian arguments in favour of governments assuring access to at least some broad range of effective medical services. Preventing or curing disease or disability reduces suffering and enables people to function in ways that contribute to aggregate welfare. In addition, knowing that health-care services are available increases personal security and strengthens the ties of community. Utilitarians can also justify redistributing the burden of delivering these benefits to society as a whole, citing the decreasing marginal utility of money to support progressive financing of healthcare services (Brandt, 1979).

Beneath these quite general arguments, however, there lies a more specific controversy about the scope of utilitarian entitlements to health care. There seems to be little utilitarian justification for

investing resources in health care if those resources would produce more net welfare when invested in other things, yet many people believe they have moral obligations to assist others with their health-care needs even at a net cost in utility. For example, some highly expensive and effective medical treatments that most people believe should be offered to people might not be “cost beneficial” and thus not defensible on utilitarian grounds. Similarly, many forms of long-term care, especially for those who cannot be restored to productive social activity, are also difficult to defend on utilitarian grounds, yet we insist our health-care systems are obliged to provide such services.

Lack of moral acceptance of the distributive implications of utilitarianism makes many uncomfortable with the use of methods, such as cost-effectiveness analysis, that are intended to guide decisions about resource allocation in health care. For example, an assumption of cost-effectiveness analysis is that a unit of health benefit, such as a quality-adjusted life year (QALY), is of equal value or importance regardless of where it is distributed. But this assumption does not capture the concerns many people have about how much priority to give to the sickest patients, or when aggregating modest benefits to large numbers of people it outweighs the moral importance of delivering more significant benefits to fewer people (Nord, 1993; Daniels, 1993).

Two points about a utilitarian framework for a right to health care are worth noting. Recognizing a right to health care is compatible with recognizing limits on entitlements that result from resource scarcity and the fact that there are competing uses of those resources. Consequently, recognizing a right to health care need not open a bottomless pit. Second, just what entitlements to services follow from a right to health care cannot be specified outside the context of a *system* properly designed to deliver health care in a way that promotes aggregate utility. For the utilitarian, entitlements are *system-relative*. The same two points apply to other accounts of the foundations and limits of a right to health care.

Because many people reject the utilitarian rationales for health care (and other welfare) rights, theorists have explored other ways to ground such

rights. Some claim that these rights are presupposed as enabling conditions for the exercise of other rights or liberties, or as practical presuppositions of all views of justice (Braybrooke, 1987) or as a way of avoiding vulnerability and exploitation (Goodin, 1988). One approach that has been developed in some detail views a right to health care as a special case of a right to equality of opportunity (Daniels, 1985). This approach shows how the most important contractarian theory of justice, Rawls’ (1971) account of justice as fairness, can be extended to the problem of health care, since that theory gives prominence to a principle protecting equality of opportunity (Rawls, 1993). Without endorsing that account here, we shall use it to illustrate further the complexity surrounding the concept of a right to health care.

### Equal Opportunity and a Right to Health Care

The central observation underlying this account of a right to health care is that disease and disability restrict the range of opportunities that would otherwise be open to individuals. This is true whether they shorten our lives or impair our ability to function, including through pain and suffering. Health care in all its forms, whether public health or medical, preventive or acute or chronic, aims to keep people functioning as close to normally as possible. Since we are complex social creatures, our normal functional capabilities include our capabilities for emotional and cognitive functioning and not just physical capabilities. Health care thus preserves for us the range of opportunities we would have, were we not ill or disabled, given our talents and skills.

The significant contribution health care makes to protecting the range of opportunities open to individuals is nevertheless *limited* in two important ways. It is limited because other things, such as the distribution of wealth and income and education, also profoundly affect equality of opportunity. It is also limited because health care, by restricting its aim to protecting normal functioning, leaves the normal distribution of talents and skills unmodified. It aims to help us function as “normal” competitors, not strictly equal ones.

Some argue that an equal opportunity account of health care should abandon the limit set by a focus on normal functioning (see Arneson, 1988; G. A. Cohen, 1989; Sen, 1992). They claim our concerns about equality, including equality of opportunity, require us to use health-care technologies whenever doing so would equalize opportunity for welfare or equalizes capabilities. For example, if through medical intervention we can “enhance” the otherwise normal capabilities of those who are at a competitive disadvantage, then our commitment to equality of opportunity requires us to do so. Obviously, this version of an equal opportunity account would vastly expand the moral requirements on medicine, yielding a right to health care much more expansive than any now embodied in actual systems and, arguably, one that would make administration of a health-care system unwieldy (Sabin and Daniels, 1994).

This expansive version of the appeal to equal opportunity ignores an important fact about justice: our concern for equality must be reconciled with considerations of liberty and efficiency in arriving at the overall requirements of justice (see Sen, 1992; Cohen, 1995; Daniels, 1996). Such a reconciliation seems to underlie the limits we commonly accept when we appeal to equality of opportunity. We generally believe that rights to equal opportunity are violated only if unfair social practices or preventable or curable diseases or disabilities interfere with the pursuit of reasonable plans of life within our society by making us lose competitive advantage. We accept, however, the fact that the natural distribution of talents and skills, working in an efficient market for them, will both enhance the social product and lead to inequalities in social outcomes. A just society will try to mitigate the effects of these inequalities in competitive advantage in other ways than by eliminating all eliminable differences in capabilities. For example, on Rawls’ account, transfers that make the worst off as well off as they can be mitigate the effects on equality of allowing the natural distribution of talents and skills to enhance productivity. In what follows, the account of a right to health care rests on a more limited appeal to equal opportunity, one that takes the maintenance of normal functioning as a reasonable limit.

## What Does a Right to Health Care Include?

### System-Relative Entitlements

By making the right to health care a special case of rights to equality of opportunity, we arrive at a reasonable, albeit incomplete and imperfect, way of restricting its scope while still recognizing its importance. The account does not give individuals a basic right to have all of their health-care needs met. At the same time, there are social obligations to design a health-care system that protects opportunity through an appropriate set of health-care services. If social obligations to provide appropriate health care are not met, then individuals are definitely wronged. For example, if people are denied access—because of discrimination or inability to pay—to a basic tier of services adequate to protect normal functioning, injustice is done to them. If the basic tier available to people omits important categories of services without consideration of their effects on normal functioning, for example, whole categories of mental health or long-term care or preventive services, their rights are violated.

Still, not every medical need gives rise to an entitlement to services. The scope and limits of rights to health care, that is, the entitlements they actually carry with them, will be relative to certain facts about a given system. For example, a health-care system can protect opportunity only within the limits imposed by resource scarcity and technological development within a society. We cannot make a direct inference from the fact that an individual has a right to health care to the conclusion that this person is entitled to some specific health-care service, even if the service would meet a health-care need. Rather the individual is entitled to a specific service only if, in the light of facts about a society’s technological capabilities and resource limitations, it should be a part of a system that appropriately protects fair equality of opportunity. The equal opportunity account of a right to health care, like the utilitarian account, makes entitlements to health care system-relative.

### Effective Treatment of Disease and Disability

The health care we have strongest claim to is care that effectively promotes normal functioning by

reducing the impact of disease and disability, thus protecting the range of opportunities that would otherwise be open to us. Just what counts as “effective,” however? And what should we do about hard cases on the boundary between treatment of disease or disability and enhancement of capabilities?

It is a common feature of public and private insurance systems to limit care to treatments that are not “experimental” and have some “proven effectiveness.” Unfortunately, many services that count as standard treatment have little direct evidence about outcomes to support their use (Hadorn, 1992). They are often just customary treatment. Furthermore, it is often controversial just when new treatments or technologies should count as “safe and efficacious.” What counts as “reasonably effective” is then a matter of judgement and depends on the kind of condition and the consequences of not correcting it. We might, for example, want to lower our standards for effectiveness when we face a treatment of last resort, or raise them if resource scarcity is very great. On the other hand, we do not owe people a chance to obtain miracles through whatever unproven procedures they prefer to try.

By focusing a right to health care on the maintenance of normal functioning, a line is drawn between uses of medical technologies that count as legitimate “treatments” and those that we may want but which do not meet our “health-care needs.” Although we may want medical services that can enhance our appearance, like cosmetic (as opposed to reconstructive) plastic surgery, or that can optimize our otherwise normal functioning, like some forms of counselling or some uses of Prozac, we do not truly need these services to maintain normal functioning. We are obliged to help others achieve normal functioning, but we do not “owe” each other whatever it takes to make us more beautiful or strong or completely happy (Daniels, 1985).

Though this line is widely used in both public and private insurance practices, it leaves us with hard cases. Some of the hardest issues involve reproductive technologies. Abortion, where there is no preventive or therapeutic need, does not count as “treatment” because an unwanted pregnancy is not a disease or disability. Some nevertheless insist that requirements of justice, including a right to

control one’s body, means that non-therapeutic abortion should be included as an entitlement in a health-care system. Some national health-insurance schemes do not cover infertility services. Yet infertility is a departure from normal functioning, even if some people never want to bear children. Controversy may remain about how much social obligation we have to correct this form of impaired opportunity, especially where the costs of some interventions, such as in vitro fertilization, are high and their effectiveness is modest. Different societies will judge this question differently, in part because they may place different values on the rearing of biologically related children or on the experience of child-bearing.

Hard cases involve non-reproductive technologies as well. In the United States, for example, many insurers will cover growth hormone treatment only for children deficient in growth hormone, not for those who are equally short but without any pathology. Yet the children denied therapy will suffer just as much as those who are eligible. Similar difficulties are involved in drawing a line between covered and non-covered uses of mental health services (Sabin and Daniels, 1994). As in the cases of reproductive technologies, there is room for different societies to “construct” the concept of mental disorder somewhat differently, with resulting variation in decisions about insurance coverage.

### Rights and Limits on Effective Treatments

Even when some health-care service is reasonably effective at meeting a medical need, not all such needs are equally important. When a disease or disability has little impact on the range of opportunities open to someone, it is not as morally important to treat as other conditions that more seriously impair opportunity. The effect on opportunity thus gives us some guidance in thinking about resource allocation priorities.

Unfortunately, the impact on our range of opportunities gives only a crude and incomplete measure of the importance or priority we should give to a need or service. In making decisions about priorities for purposes of resource allocation in health care, we face difficult questions about distributive fairness that are not answered by this measure of

importance. For example, we must sometimes make a choice between investing in a technology that delivers a significant benefit to few people or one that delivers a more modest benefit to a larger number of people. Sometimes we must make a choice between investing in a service that helps the sickest, most impaired patients or one that helps those whose functioning is less impaired. Sometimes we must decide between the fairness of giving a scarce resource to those who derive the largest benefit or giving a broader range of people some chance at getting a benefit. In all of these cases, we lack clear principles for deciding how to make our choices, and the account of a right to health care we are discussing does not provide those principles either (Daniels, 1993). Some methodologies, like cost-effectiveness analysis, are intended to help us make appropriate resource allocation decisions in these kinds of cases. But these methodologies may themselves embody controversial moral assumptions about distributive fairness. This means they cannot serve as decision procedures for making these choices and can at best serve as aids to decision-makers who must be explicit about the moral reasoning that determines the distributive choices they make (Gold et al., 1996).

In any health-care system, then, some choices will have to be made by a fair, publicly accountable, decision-making process. Just what constitutes a fair decision-making procedure for resolving moral disputes about health care entitlements is itself a matter of controversy. It is a problem that has been addressed little in the literature. Our rights are not violated, however, if the choices that are made through fair decision-making procedures turn out to be ones that do not happen to meet our personal needs, but instead meet needs of others that are judged more important (Daniels and Sabin, 1997).

### How Equal Must Our Rights to Health Care Be?

How equal must our rights to health care be? Specifically, must everyone receive exactly the same kinds of health-care services and coverage, or is fairness in health care compatible with a “tiered” system? Around the world, even countries that offer universal health insurance differ in their answers to

this question. In Canada and Norway, for example, no supplementary insurance is permitted. Everyone is served solely by the national health-insurance schemes, though people who seek additional services or more rapid service may go elsewhere, as some Canadians do by crossing the border. In Britain, supplementary private insurance allows about 10 percent of the population to gain quicker access to services for which there is extensive queuing in the public system. Basing a right to health care on an obligation to protect equality of opportunity is compatible with the sort of tiering the British have, but it does not require it, and it imposes some constraints on the kind of tiering allowed.

The primary social obligation is to assure everyone access to a tier of services that effectively promotes normal functioning and thus protects equality of opportunity. Since health care is not the only important good, resources to be invested in the basic tier are appropriately and reasonably limited, for example, by democratic decisions about how much to invest in education or job training as opposed to health care. Because of their very high “opportunity costs,” there will be some beneficial medical services that it will be reasonable not to provide in the basic tier, or to provide only on a limited basis, for example, with queuing. To say that these services have “high opportunity costs” means that providing them consumes resources that would produce greater health benefits and protect opportunity more if used in other ways.

In a society that permits significant income and wealth inequalities, some people will want to buy coverage for these additional services. Why not let them? After all, we allow people to use their after-tax income and wealth as they see fit to pursue the “quality of life” and opportunities they prefer. The rich can buy special security systems for their homes. They can buy safer cars. They can buy private schooling for their children. Why not allow them to buy supplementary health care for their families?

One objection to allowing a supplementary tier is that its existence might undermine the basic tier either economically or politically. It might attract better-quality providers away from the basic tier, or raise costs in the basic tier, reducing the ability of

society to meet its social obligations. The supplementary tier might undermine political support for the basic tier, for example, by undercutting the social solidarity needed if people are to remain committed to protecting opportunity for all. These objections are serious, and where a supplementary tier undermines the basic tier in either way, economically or politically, priority must be given to protecting the basic tier. In principle, however, it seems possible to design a system in which the supplementary tier does not undermine the basic one. If that can be done, then a system that permits tiering avoids restricting liberty in ways that some find seriously objectionable.

A second objection is not to tiering itself but to the structure of inequality that results. Compare two scenarios. In one, most people are adequately served by the basic tier and only the best-off groups in society have the means and see the need to purchase supplementary insurance. That is the case in Great Britain. In the other, the basic tier serves only the poorest groups in society and most other people buy supplementary insurance. The Oregon plan to expand Medicaid eligibility partly through rationing the services it covers has aspects of this structure of inequality, since most people are covered by plans that avoid these restrictions (Daniels, 1991). The first scenario seems preferable to the second on grounds of fairness. In the second, the poorest groups can complain that they are left behind by others in society even in the protection of their health. In the first, the majority has less grounds for reasonable resentment or regret.

If the basic tier is not undermined by higher tiers, and if the structure of the inequality that results is not objectionable, then it is difficult to see why some tiering should not be allowed. There is a basic conflict here between concerns about equality and concerns about liberty, between wanting to make sure everyone is treated properly with regard to health care and wanting to give people the liberty to use their resources (after tax) to improve their lives as they see fit. In practice, the crucial constraint on the liberty we allow people seems to depend on the magnitude of the benefit available in the supplementary tier and unavailable in the basic tier. Highly visible forms of saving lives and

improving function would be difficult to exclude from the basic tier while we make them available in a supplementary tier. In principle, however, some forms of tiering will not be unfair even when they involve medical benefits not available to everyone.

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## The Right to a Decent Minimum of Health Care

ALLEN E. BUCHANAN

In this article Buchanan argues that the notion of a universal right to a decent minimum of health care cannot justify a mandatory decent minimum policy. But the combined weight of other arguments, he says, can establish that the state should provide certain individuals or groups with a decent minimum. The necessary arguments are from special rights, from the prevention of harm, from prudential considerations, and from enforced beneficence.

### The Assumption That There Is a Right to a Decent Minimum

A consensus that there is (at least) a right to a decent minimum of health care pervades recent policy debates and much of the philosophical literature on health care. Disagreement centers on two issues. Is there a more extensive right than the right to a decent minimum of health care? What is included in the decent minimum to which there is a right?

### Preliminary Clarification of the Concept

Different theories of distributive justice may yield different answers both to the question “Is there a right to a decent minimum?” and to the question “What comprises the decent minimum?” The justification a particular theory provides for the claim that there is a right to a decent minimum must at least cohere with the justifications it provides for other right-claims. Moreover, the character of this

justification will determine, at least in part, the way in which the decent minimum is specified, since it will include an account of the nature and significance of health-care needs. To the extent that the concept of a decent minimum is theory-dependent, then, it would be naive to assume that a mere analysis of the concept of a decent minimum would tell us whether there is such a right and what its content is. Nonetheless, before we proceed to an examination of various theoretical attempts to ground and specify a right to a decent minimum, a preliminary analysis will be helpful.

Sometimes the notion of a decent minimum is applied not to health care but to health itself, the claim being that everyone is entitled to some minimal level, or welfare floor, of health. I shall not explore this variant of the decent minimum idea because I think its implausibility is obvious. The main difficulty is that assuring any significant level of health for all is simply not within the domain of social control. If the alleged right is understood instead as the right to everything which can be done to achieve some significant level of

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health for all, then the claim that there is such a right becomes implausible simply because it ignores the fact that in circumstances of scarcity the total social expenditure on health must be constrained by the need to allocate resources for other goods.

Though the concept of a right is complex and controversial, for our purposes a partial sketch will do. To say that person A has a right to something, X, is first of all to say that A is entitled to X, that X is due to him or her. This is not equivalent to saying that if A were granted X it would be a good thing, even a morally good thing, or that X is desired by or desirable for A. Second, it is usually held that valid right-claims, at least in the case of basic rights, may be backed by sanctions, including coercion if necessary (unless doing so would produce extremely great disutility or grave moral evil), and that (except in such highly exceptional circumstances) failure of an appropriate authority to apply the needed sanctions is itself an injustice. Recent right-theorists have also emphasized a third feature of rights, or at least of basic rights or rights in the strict sense: valid right-claims “trump” appeals to what would maximize utility, whether it be the utility of the right-holder, or social utility. In other words, if A has a right to X, then the mere fact that infringing A’s right would maximize overall utility or even A’s utility is not itself a sufficient reason for infringing it.<sup>1</sup> Finally, a universal (or general) right is one which applies to all persons, not just to certain individuals or classes because of their involvement in special actions, relationships, or agreements.

The second feature—enforceability—is of crucial importance for those who assume or argue that there is a universal right to a decent minimum of health care. For, once it is granted that there is such a right and that such a right may be enforced (absent any extremely weighty reason against enforcement), the claim that there is a universal right provides the moral basis for using the coercive power of the state to assure a decent minimum for all. Indeed, the surprising absence of attempts to justify a coercively backed decent minimum policy by arguments that do *not* aim at establishing a universal right suggests the following hypothesis: advocates of a coercively based decent minimum have

operated on the assumption that such a policy must be based on a universal right to a decent minimum. The chief aim of this article is to show that this assumption is false.

I think it is fair to say that many who confidently assume there is a (universal) right to a decent minimum of health care have failed to appreciate the significance of the first feature of our sketch of the concept of a right. It is crucial to observe that the claim that there is a right to a decent minimum is much stronger than the claim that everyone *ought* to have access to such a minimum, or that if they did it would be a good thing, or that any society which is capable, without great sacrifice, of providing a decent minimum but fails to do so is deeply morally defective. None of the latter assertions implies the existence of a right, if this is understood as a moral entitlement which ought to be established by the coercive power of the state if necessary. . . .

### **The Attractions of the Idea of a Decent Minimum**

There are at least three features widely associated with the idea of a right to a decent minimum which, together with the facile consensus that vagueness promotes, help explain its popularity over competing conceptions of the right to health care. First, it is usually, and quite reasonably, assumed that the idea of a decent minimum is to be understood in a society-relative sense. Surely it is plausible to assume that, as with other rights to goods or services, the content of the right must depend upon the resources available in a given society and perhaps also upon a certain consensus of expectations among its members. So the first advantage of the idea of a decent minimum, as it is usually understood, is that it allows us to adjust the level of services to be provided as a matter of right to relevant social conditions and also allows for the possibility that as a society becomes more affluent the floor provided by the decent minimum should be raised.

Second, the idea of a decent minimum avoids the excesses of what has been called the strong equal access principle, while still acknowledging a substantive universal right. According to the strong equal access principle, everyone has an equal right to the best health-care services available. Aside

from the weakness of the justifications offered in support of it, the most implausible feature of the strong equal access principle is that it forces us to choose between two unpalatable alternatives. We can either set the publicly guaranteed level of health care lower than the level that is technically possible or we can set it as high as is technically possible. In the former case, we shall be committed to the uncomfortable conclusion that no matter how many resources have been expended to guarantee equal access to that level, individuals are forbidden to spend any of their resources for services not available to all. Granted that individuals are allowed to spend their after-tax incomes on more frivolous items, why shouldn't they be allowed to spend it on health? If the answer is that they should be so allowed, as long as this does not interfere with the provision of an adequate package of health-care services for everyone, then we have retreated from the strong equal access principle to something very like the principle of a decent minimum. If, on the other hand, we set the level of services guaranteed for all so high as to eliminate the problem of persons seeking extra care beyond this level, this would produce a huge drain on total resources, foreclosing opportunities for producing important goods other than health care.

So both the recognition that health care must compete with other goods and the conviction that beyond some less than maximal level of publicly guaranteed services individuals should be free to purchase additional services point toward a more limited right than the strong access principle asserts. Thus, the endorsement of a right to a decent minimum may be more of a recognition of the implausibility of the stronger right to equal access than a sign of any definite position on the content of the right to health care.

A third attraction of the idea of a decent minimum is that since the right to health care must be limited in scope (to avoid the consequences of a strong equal access right), it should be limited to the "most basic" services, those normally "adequate" for health, or for a "decent" or "tolerable" life. However, although this aspect of the idea of a decent minimum is useful because it calls attention to the fact that health-care needs are heterogeneous

and must be assigned some order of priority, it does not itself provide any basis for determining which are most important.

### **The Need for a Supporting Theory**

In spite of these attractions, the concept of a right to a decent minimum of health care is inadequate as a moral basis for a coercively backed decent minimum policy in the absence of a coherent and defensible theory of justice. Indeed, when taken together they do not even imply that there is a right to a decent minimum. Rather, they only support the weaker conditional claim that if there is a right to health care, then it is one that is more limited than a right of strong equal access, and is one whose content depends upon available resources and some scheme of priorities which shows certain health services to be more basic than others. . . .

My suggestion is that the combined weight of arguments from special (as opposed to universal) rights to health care, harm-prevention, prudential arguments of the sort used to justify public health measures, and two arguments that show that effective charity shares features of public goods (in the technical sense) is sufficient to do the work of an alleged universal right to a decent minimum of health care.

### **Arguments from Special Rights**

The right-claim we have been examining (and find unsupported) has been a *universal* right-claim: one that attributes the same right to all persons. *Special* right-claims, in contrast, restrict the right in question to certain individuals or groups.

There are at least three types of arguments that can be given for special rights to health care. First, there are arguments from the requirements of rectifying past or present institutional injustices. It can be argued, for example, that American blacks and native Americans are entitled to a certain core set of health-care services owing to their history of unjust treatment by government or other social institutions, on the grounds that these injustices have directly or indirectly had detrimental effects on the health of the groups in question. Second, there are arguments from the requirements of compensation to those who have suffered unjust harm or who have

been unjustly exposed to health risks by the assignable actions of private individuals or corporations—for instance, those who have suffered neurological damage from the effects of chemical pollutants.

Third, a strong moral case can be made for special rights to health care for those who have undergone exceptional sacrifices for the good of society as a whole—in particular those whose health has been adversely affected through military service. The most obvious candidates for such compensatory special rights are soldiers wounded in combat.

### **Arguments from the Prevention of Harm**

The content of the right to a decent minimum is typically understood as being more extensive than those traditional public health services that are usually justified on the grounds that they are required to protect the citizenry from certain harms arising from the interactions of persons living together in large numbers. Yet such services have been a major factor—if not *the* major factor—in reducing morbidity and mortality rates. Examples include sanitation and immunization. The moral justification of such measures, which constitute an important element in a decent minimum of health care, rests upon the widely accepted Harm (Prevention) Principle, not upon a right to health care.

The Harm Prevention argument for traditional public health services, however, may be elaborated in a way that brings them closer to arguments for a universal right to health care. With some plausibility one might contend that once the case has been made for expending public resources on public health measures, there is a moral (and perhaps Constitutional) obligation to achieve some standard of *equal protection* from the harms these measures are designed to prevent. Such an argument, if it could be made out, would imply that the availability of basic public health services should not vary greatly across different racial, ethnic, or geographic groups within the country.

### **Prudential Arguments**

Prudent arguments for health-care services typically emphasize benefits rather than the prevention of harm. It has often been argued, in particular, that

the availability of certain basic forms of health care make for a more productive labor force or improve the fitness of the citizenry for national defense. This type of argument, too, does not assume that individuals have moral rights (whether special or universal) to the services in question.

It seems very likely that the combined scope of the various special health-care rights discussed above, when taken together with harm prevention and prudential arguments for basic health services and an argument from equal protection through public health measures, would do a great deal toward satisfying the health-care needs which those who advocate a universal right to a decent minimum are most concerned about. In other words, once the strength of a more pluralistic approach is appreciated, we may come to question the popular dogma that policy initiatives designed to achieve a decent minimum of health care for all must be grounded in a universal moral right to a decent minimum. This suggestion is worth considering because it again brings home the importance of the methodological difficulty encountered earlier. Even if, for instance, there is wide consensus on the considered judgment that the lower health prospects of inner city blacks are not only morally unacceptable but an injustice, it does not follow that this injustice consists of the infringement of a universal right to a decent minimum of health care. Instead, the injustice might lie in the failure to rectify past injustices or in the failure to achieve public health arrangements that meet a reasonable standard of equal protection for all.

### **Two Arguments for Enforced Beneficence**

The pluralistic moral case for a legal entitlement to a decent minimum of health care (in the absence of a universal moral right) may be strengthened further by non-rights-based arguments from the principle of beneficence.<sup>2</sup> The possibility of making out such arguments depends upon the assumption that some principles may be justifiably enforced even if they are not principles specifying valid right-claims. There is at least one widely recognized class of such principles requiring contribution to the production of “public goods” in the technical sense (for example, tax laws requiring contribution to

national defense). It is characteristic of public goods that each individual has an incentive to withhold his contribution to the collective goal even though the net result is that the goal will not be achieved. Enforcement of a principle requiring all individuals to contribute to the goal is necessary to overcome the individual's incentive to withhold contribution by imposing penalties for his own failure to contribute and by assuring him that others will contribute. There is a special subclass of principles whose enforcement is justified not only by the need to overcome the individual's incentive to withhold compliance with the principle but also to ensure that individuals' efforts are appropriately *coordinated*. For example, enforcing the rule of the road to drive only on the right not only ensures a joint effort toward the goal of safe driving but also coordinates individuals' efforts so as to make the attainment of that goal possible. Indeed, in the case of the "rule of the road" a certain kind of coordinated joint effort is the public good whose attainment justifies enforcement. But regardless of whether the production of a public good requires the solution of a coordination problem or not, there may be no *right* that is the correlative of the coercively backed obligation specified by the principle. There are two arguments for enforced beneficence, and they each depend upon both the idea of coordination and on certain aspects of the concept of a public good.

Both arguments begin with an assumption reasonable libertarians accept: there is a basic moral obligation of charity or beneficence to those in need. In a society that has the resources and technical knowledge to improve health or at least to ameliorate important health defects, the application of this requirement of beneficence includes the provision of resources for at least certain forms of health care. If we are sincere, we will be concerned with the efficacy of our charitable or beneficent impulses. It is all well and good for the libertarian to say that voluntary giving *can* replace the existing array of government entitlement programs, but this *possibility* will be cold comfort to the needy if, for any of several reasons, voluntary giving falters.

Social critics on the left often argue that in a highly competitive acquisitive society such as ours it is naive to think that the sense of beneficence will

win out over the urgent promptings of self-interest. One need not argue, however, that voluntary giving fails from weakness of the will. Instead one can argue that even if each individual recognizes a moral duty to contribute to the aid of others and is motivationally capable of acting on that duty, some important forms of beneficence will not be forthcoming because each individual will rationally conclude that he should not contribute.

Many important forms of health care, especially those involving large-scale capital investment for technology, cannot be provided except through the contributions of large numbers of persons. This is also true of the most important forms of medical research. But if so, then the beneficent individual will not be able to act effectively, in isolation. What is needed is a coordinated joint effort.

*First argument.* There are many ways in which I might help others in need. Granted the importance of health, providing a decent minimum of health care for all, through large-scale collective efforts, will be a more important form of beneficence than the various charitable acts A, B, and C, which I might perform *independently*, that is, whose success does not depend upon the contributions of others. Nonetheless, if I am rationally beneficent I will reason as follows: either enough others will contribute to the decent minimum project to achieve this goal, even if I do not contribute to it; or not enough others will contribute to achieve a decent minimum, even if I do contribute. In either case, my contribution will be wasted. In other words, granted the scale of the investment required and the virtually negligible size of my own contribution, I can disregard the minute possibility that my contribution might make the difference between success and failure. But if so, then the rationally beneficent thing for me to do is not to waste my contribution on the project of ensuring a decent minimum but instead to undertake an independent act of beneficence; A, B, or C—where I know my efforts will be needed and efficacious. But if everyone, or even many people, reason in this way, then what we each recognize as the most effective form of beneficence will not come about. Enforcement of a principle requiring contributions to ensuring a decent minimum is needed.

The first argument is of the same form as standard public goods arguments for enforced contributions to national defense, energy conservation, and many other goods, with this exception. In standard public goods arguments, it is usually assumed that the individual's incentive for not contributing is self-interest and that it is in his interest not to contribute because he will be able to partake of the good, if it is produced, even if he does not contribute. In the case at hand, however, the individual's incentive for not contributing to the joint effort is not self-interest, but rather his desire to maximize the good he can do for others with a given amount of his resources. Thus if he contributes but the goal of achieving a decent minimum for all would have been achieved without his contribution, then he has still failed to use his resources in a maximally beneficent way relative to the options of either contributing or not to the joint project, even though the goal of achieving a decent minimum is attained. The rationally beneficent thing to do, then, is not to contribute, even though the result of everyone's acting in a rationally beneficent way will be a relatively ineffective patchwork of small-scale individual acts of beneficence rather than a large-scale, coordinated effort.

*Second argument.* I believe that ensuring a decent minimum of health care for all is more important than projects A, B, or C, and I am willing to contribute to the decent minimum project, but only if I have assurance that enough others will contribute to achieve the threshold of investment necessary for success. Unless I have this assurance, I will conclude that it is less than rational—and perhaps even morally irresponsible—to contribute my resources to the decent minimum project. For my contribution will be wasted if not enough others contribute. If I lack assurance of sufficient contributions by others, the rationally beneficent thing for me to do is to expend my "beneficence budget" on some less-than-optimal project A, B, or C, whose success does not depend on the contribution of others. But without enforcement, I cannot be assured that enough others will contribute, and if others reason as I do, then what we all believe to be the most effective form of beneficence will not be forthcoming. Others may fail to contribute either because the

promptings of self-interest overpower their sense of beneficence, or because they reason as I did in the First Argument, or for some other reason.

Both arguments conclude that an enforced decent minimum principle is needed to achieve coordinated joint effort. However, there is this difference. The Second Argument focuses on the *assurance problem*, while the first does not. In the Second Argument all that is needed is the assumption that rational beneficence requires assurance that enough others will contribute. In the First Argument the individual's reason for not contributing is not that he lacks assurance that enough others will contribute, but rather that it is better for him not to contribute regardless of whether others do or not.

Neither argument depends on an assumption of conflict between the individual's moral motivation of beneficence and his inclination of self-interest. Instead the difficulty is that in the absence of enforcement, individuals who strive to make their beneficence most effective will thereby fail to benefit the needy as much as they might.

A standard response to those paradoxes of rationality known as public goods problems is to introduce a coercive mechanism which attaches penalties to non-contribution and thereby provides each individual with the assurance that enough others will reciprocate so that his contribution will not be wasted and an effective incentive for him to contribute even if he has reason to believe that enough others will contribute to achieve the goal without his contribution. My suggestion is that the same type of argument that is widely accepted as a justification for enforced principles requiring contributions toward familiar public goods provides support for a coercively backed principle specifying a certain list of health programs for the needy and requiring those who possess the needed resources to contribute to the establishment of such programs, even if the needy have no *right* to the services those programs provide. Such an arrangement would serve a dual function: it would coordinate charitable efforts by focusing them on one set of services among the indefinitely large constellation of possible expressions of beneficence, and it would ensure that the decision to allocate resources to these services will become effective.

**NOTES**

1. Ronald Dworkin, *Taking Rights Seriously* (Cambridge, MA: Harvard University Press, 1977), pp. 184–205.
2. For an exploration of various arguments for a duty of beneficence and an examination of the relationship

between justice and beneficence, in general and in health care, see Allen E. Buchanan, “Philosophical Foundations of Beneficence,” *Beneficence and Health Care*, ed. Earl E. Shelp (Dordrecht, Holland: Reidel Publishing Co., 1982).

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## **Rights to Health Care, Social Justice, and Fairness in Health Care Allocations: Frustrations in the Face of Finitude**

H. TRISTRAM ENGELHARDT, JR.

Engelhardt asserts that “a basic human secular moral right to health care does not exist—not even to a ‘decent minimum of health care.’” He distinguishes between losses that people suffer because of bad fortune and those due to unfairness. The former do not establish a duty of aid to the unfortunate (there is no moral right to such aid), but the latter may constitute claims on others. Out of compassion or benevolence, society may freely consent to help those in need, but there is no forced obligation to do so.

The imposition of a single-tier, all-encompassing health care system is morally unjustifiable. It is a coercive act of totalitarian ideological zeal, which fails to recognize the diversity of moral visions that frame interests in health care, the secular moral limits of state authority, and the authority of individuals over themselves and their own property. It is an act of secular immorality.

A basic human secular moral right to health care does not exist—not even to a “decent minimum of health care.” Such rights must be created.

The difficulty with supposed right to health care, as well as with many claims regarding justice or fairness in access to health care, should be apparent. Since the secular moral authority for common action is derived from permission or consent, it is difficult (indeed, for a large-scale society, materially impossible) to gain moral legitimacy for the thoroughgoing imposition on health care of one among the many views of beneficence and justice. There

are, after all, as many accounts of beneficence, justice, and fairness as there are major religions.

Most significantly, there is a tension between the foundations of general secular morality and the various particular positive claims founded in particular visions of beneficence and justice. It is materially impossible both to respect the freedom of all and to achieve their long-range best interests. Loose talk about justice and fairness in health care is therefore morally misleading, because it suggests that there is a particular canonical vision of justice or fairness that all have grounds to endorse. . . .

Rights to health care constitute claims on services and goods. Unlike rights to forbearance, which require others to refrain from interfering, which show the unity of the authority to use others, rights to beneficence are rights grounded in particular theories or accounts of the good. For general authority, they require others to participate actively in a particular understanding of the good life or justice. Without an appeal to the principle of permission, to advance such rights is to claim that one may press others into labor or confiscate their property. Rights to health care, unless they are derived

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from special contractual agreements, depend on particular understandings of beneficence rather than on authorizing permission. They may therefore conflict with the decisions of individuals who may not wish to participate in, and may indeed be morally opposed to, realizing a particular system of health care. Individuals always have the secular moral authority to use their own resources in ways that collide with fashionable understandings of justice or the prevailing consensus regarding fairness.

### **Health Care Policy: The Ideology of Equal, Optimal Care**

It is fashionable to affirm an impossible commitment in health care delivery, as, for example, in the following four widely embraced health care policy goals, which are at loggerheads:

1. The best possible care is to be provided for all.
2. Equal care should be guaranteed.
3. Freedom of choice on the part of health care provider and consumer should be maintained.
4. Health care costs are to be contained.

One cannot provide the best possible health care for all and contain health care costs. One cannot provide equal health care for all and respect the freedom of individuals peaceably to pursue with others their own visions of health care or to use their own resources and energies as they decide. For that matter, one cannot maintain freedom in the choice of health care services while containing the costs of health care. One may also not be able to provide all with equal health care that is at the same time the very best care because of limits on the resources themselves. That few openly address these foundational moral tensions at the roots of contemporary health care policy suggests that the problems are shrouded in a collective illusion, a false consciousness, an established ideology within which certain facts are politically unacceptable.

These difficulties spring not only from a conflict between freedom and beneficence, but from a tension among competing views of what it means to pursue and achieve the good in health care (e.g., is it more important to provide equal care to all or the best possible health care to the least-well-off class?).

The pursuit of incompatible or incoherent health care is rooted in the failure to face the finitude of secular moral authority, the finitude of secular moral vision, the finitude of human powers in the face of death and suffering, the finitude of human life, and the finitude of human financial resources. A health care system that acknowledges the moral and financial limitations on the provision of health care would need to

1. endorse inequality in access to health care as morally unavoidable because of private resources and human freedom;
2. endorse setting a price on saving human life as a part of establishing a cost-effective health care system established through communal resources.

Even though all health care systems de facto enjoy inequalities and must to some extent ration the health care they provide through communal resources, this is not usually forthrightly acknowledged. There is an ideological bar to recognizing and coming to terms with the obvious.

Only a prevailing collective illusion can account for the assumption in U.S. policy that health care may be provided (1) while containing costs (2) without setting a price on saving lives and preventing suffering when using communal funds and at the same time (3) ignoring the morally unavoidable inequalities due to private resources and human freedom. This false consciousness shaped the deceptions central to the Clinton health care proposal, as it was introduced in 1994. It was advanced to support a health care system purportedly able to provide all with (1) the best of care and (2) equal care, while achieving (3) cost containment, and still (4) allowing those who wish the liberty to purchase fee-for-service health care.<sup>1</sup> While not acknowledging the presence of rationing, the proposal required silent rationing in order to contain costs by limiting access to high-cost, low-yield treatments that a National Health Board would exclude from the “guaranteed benefit package.”<sup>2</sup> In addition, it advanced mechanisms to slow technological innovation so as further to reduce the visibility of rationing choices.<sup>3</sup> One does not have to ration that which is not available. There has been a failure to acknowledge the

moral inevitability of inequalities in health care due to the limits of secular governmental authority, human freedom, and the existence of private property, however little that may be. There was also the failure to acknowledge the need to ration health care within communal programs if costs are to be contained. It has been ideologically unacceptable to recognize these circumstances. . . .

### **Justice, Freedom, and Inequality**

Interests in justice as beneficence are motivated in part by inequalities and in part by needs. That some have so little while others have so much properly evokes moral concerns of beneficence. Still, . . . the moral authority to use force to set such inequalities aside is limited. These limitations are in part due to the circumstance that the resources one could use to aid those in need are already owned by other people. One must establish whether and when inequalities and needs generate rights or claims against others.

### **The Natural and Social Lotteries**

“Natural lottery” is used to identify changes in fortune that result from natural forces, not directly from the actions of persons. The natural lottery shapes the distribution of both naturally and socially conditioned assets. The natural lottery contrasts with the social lottery, which is used to identify changes in fortune that are not the result of natural forces but the actions of persons. The social lottery shapes the distribution of social and natural assets. The natural and social lotteries, along with one’s own free decisions, determine the distribution of natural and social assets. The social lottery is termed a lottery, though it is the outcome of personal actions, because of the complex and unpredictable interplay of personal choices and because of the unpredictable character of the outcomes, which do not conform to an ideal pattern and because the outcomes are the results of social forces, not the immediate choices of those subject to them.

All individuals are exposed to the vicissitudes of nature. Some are born healthy and by luck remain so for a long life, free of disease and major suffering. Others are born with serious congenital or genetic diseases, others contract serious crippling fatal illnesses early in life, and yet others are injured and

maimed. Those who win the natural lottery will for most of their lives not be in need of medical care. They will live full lives and die painless and peaceful deaths. Those who lost the natural lottery will be in need of health care to blunt their sufferings and, where possible, to cure their diseases and to restore function. There will be a spectrum of losses, ranging from minor problems such as having teeth with cavities to major tragedies such as developing childhood leukemia, inheriting Huntington’s chorea, or developing amyotrophic lateral sclerosis.

These tragic outcomes are the deliverances of nature, for which no one, without some special view of accountability or responsibility, is responsible (unless, that is, one recognizes them as the results of the Fall or as divine chastisements). The circumstance that individuals are injured by hurricanes, storms, and earthquakes is often simply no one’s fault. When no one is to blame, no one may be charged with the responsibility of making whole those who lose the natural lottery on the ground of accountability for the harm. One will need an argument dependent on a particular sense of fairness to show that the readers of this volume should submit to the forcible redistribution of their resources to provide health care for those injured by nature. It may very well be unfeeling, unsympathetic, or uncharitable not to provide such help. One may face eternal hellfires for failing to provide aid.<sup>4</sup> But it is another thing to show in general secular moral terms that individuals owe others such help in a way that would morally authorize state force to redistribute their private resources and energies or to constrain their free choices with others. To be in dire need does not by itself create a secular moral right to be rescued from that need. The natural lottery creates inequalities and places individuals at disadvantage without creating a straightforward secular moral obligation on the part of others to aid those in need.

Individuals differ in their resources not simply because of outcomes of the natural lottery, but also due to the actions of others. Some deny themselves immediate pleasures in order to accumulate wealth or to leave inheritances; through a complex web of love, affection, and mutual interest, individuals convey resources, one to another, so that those who

are favored prosper and those who are ignored languish. Some as a consequence grow wealthy and others grow poor, not through anyone's malevolent actions or omissions, but simply because they were not favored by the love, friendship, collegiality, and associations through which fortunes develop and individuals prosper. In such cases there will be neither fairness nor unfairness, but simply good and bad fortune.

In addition, some will be advantaged or disadvantaged, made rich, poor, ill, diseased, deformed, or disabled because of the malevolent and blameworthy actions and omissions of others. Such will be unfair circumstances, which just and beneficent states should try to prevent and to rectify through legitimate police protection, forced restitution, and charitable programs. Insofar as an injured party has a claim against an injurer to be made whole, not against society, the outcome is unfortunate from the perspective of society's obligations and obligations of innocent citizens to make restitution. Restitution is owed by the injurer, not society or others. There will be outcomes of the social lottery that are on the one hand blameworthy in the sense of resulting from the culpable actions of others, though on the other hand a society has no obligation to rectify them. The social lottery includes the exposure to the immoral and unjust actions of others. Again, one will need an argument dependent on a particular sense of fairness to show that the readers of this volume should submit to the forcible redistribution of their resources to provide health care to those injured by others.

When individuals come to purchase health care, some who lose the natural lottery will be able at least in part to compensate for those losses through their winnings at the social lottery. They will be able to afford expensive health care needed to restore health and to regain function. On the other hand, those who lose in both the natural and the social lottery will be in need of health care, but without the resources to acquire it.

### **The Rich and the Poor: Differences in Entitlements**

If one owns property by virtue of just acquisition or just transfer, then one's title to that property will not be undercut by the tragedies and needs of

others. One will simply own one's property. On the other hand, if one owns property because such ownership is justified within a system that ensures a beneficent distribution of goods (e.g., the achievement of the greatest balance of benefits over harms for the greatest number or the greatest advantage for the least-well-off class), one's ownership will be affected by the needs of others. . . . Property is in part privately owned in a strong sense that cannot be undercut by the needs of others. In addition, all have a general right to the fruits of the earth, which constitutes the basis for a form of taxation as rent to provide fungible payments to individuals, whether or not they are in need. Finally, there are likely to be resources held in common by groups that may establish bases for their distribution to meet health care concerns. The first two forms of entitlement or ownership exist unconstrained by medical or other needs. The last form of entitlement or ownership, through the decision of a community, may be conditioned by need.

The existence of any amount of private resources can be the basis for inequalities that secular moral authority may not set aside. Insofar as people own things, they will have a right to them, even if others need them. Because the presence of permission is cardinal, the test of whether one must transfer one's goods to others will not be whether such a redistribution will not prove onerous or excessive for the person subjected to the distribution, but whether the resources belong to that individual. Consider that you may be reading this book next to a person in great need. The test of whether a third person may take resources from you to help that individual in need will not be whether you will suffer from the transfer, but rather whether you have consented—at least this is the case if the principle of permission functions in general secular morality. . . . The principle of permission is the source of authority when moral strangers collaborate, because they do not share a common understanding of fairness or of the good. As a consequence, goal-oriented approaches to the just distribution of resources must be restricted to commonly owned goods, where there is authority to create programs for their use.

Therefore, one must qualify the conclusions of the 1983 American President's Commission for the

Study of Ethical Problems that suggest that excessive burdens should determine the amount of tax persons should pay to sustain an adequate level of health care for those in need.<sup>5</sup> Further, one will have strong grounds for morally condemning systems that attempt to impose an all-encompassing health care plan that would require “equality of care [in the sense of avoiding] the creation of a tiered system [by] providing care based only on differences of need, not individual or group characteristics.”<sup>6</sup> Those who are rich are always at secular moral liberty to purchase more and better health care.

### **Drawing the Line Between the Unfortunate and the Unfair**

How one regards the moral significance of the natural and social lotteries and the moral force of private ownership will determine how one draws the line between circumstances that are simply unfortunate and those that are unfortunate and in addition unfair in the sense of constituting a claim on the resources of others.

Life in general, and health care in particular, reveal circumstances of enormous tragedy, suffering, and deprivation. The pains and sufferings of illness, disability, and disease, as well as the limitations of deformity, call on the sympathy of all to provide aid and give comfort. Injuries, disabilities, and diseases due to the forces of nature are unfortunate. Injuries, disabilities, and diseases due to the unconsented-to actions of others are unfair. Still, outcomes of the unfair actions of others are not necessarily society’s fault and are in this sense unfortunate. The horrible injuries that come every night to the emergency rooms of major hospitals may be someone’s fault, even if they are not the fault of society, much less that of uninvolved citizens. Such outcomes, though unfair with regard to the relationship of the injured with the injurer, may be simply unfortunate with respect to society and other citizens (and may licitly be financially exploited). One is thus faced with distinguishing the difficult line between acts of God, as well as immoral acts of individuals that do not constitute a basis for societal retribution on the one hand, and injuries that provide such a basis on the other.

A line must be created between those losses that will be made whole through public funds and those that will not. Such a line was drawn in 1980 by Patricia Harris, the then secretary of the Department of Health, Education, and Welfare, when she ruled that heart transplantations should be considered experimental and therefore not reimbursable through Medicare.<sup>7</sup> To be in need of a heart transplant and not have the funds available would be an unfortunate circumstance but not unfair. One was not eligible for a heart transplant even if another person had intentionally damaged one’s heart. From a moral point of view, things would have been different if the federal government had in some culpable fashion injured one’s heart. So, too, if promises of treatment had been made. For example, to suffer from appendicitis or pneumonia and not as a qualifying patient receive treatment guaranteed through a particular governmental or private insurance system would be unfair, not simply unfortunate.

Drawing the line between the unfair and the unfortunate is unavoidable because it is impossible in general secular moral terms to translate all needs into rights, into claims against the resources of others. One must with care decide where the line is to be drawn. To distinguish needs from mere desires, one must endorse one among the many competing visions of morality and human flourishing. One is forced to draw a line between those needs (or desires) that constitute claims on the aid of others and those that do not. The line distinguishing unfortunate from unfair circumstances justifies by default certain social and economic inequalities in the sense of determining who, if anyone, is obliged in general secular morality to remedy such circumstances or achieve equality. Is the request of an individual to have life extended through a heart transplant at great cost, and perhaps only for a few years, a desire for an inordinate extension of life? Or is it a need to be secure against a premature death? . . . Outside a particular view of the good life, needs do not create rights to the services or goods of others.<sup>8</sup> Indeed, outside of a particular moral vision there is no canonical means for distinguishing desires from needs.

There is a practical difficulty in regarding major losses at the natural and social lotteries as

generating claims to health care: attempts to restore health indefinitely can deplete societal resources in the pursuit of ever-more incremental extensions of life of marginal quality. A relatively limited amount of food and shelter is required to preserve the lives of individuals. But an indefinite amount of resources can in medicine be committed to the further preservation of human life, the marginal postponement of death, and the marginal alleviation of human suffering and disability. Losses at the natural lottery with regard to health can consume major resources with little return. Often one can only purchase a little relief, and that only at great costs. Still, more decisive than the problem of avoiding the possibly overwhelming costs involved in satisfying certain health care desires (e.g., postponing death for a while through the use of critical care) is the problem of selecting the correct contentfull account of justice in order canonically to distinguish between needs and desires and to translate needs into rights.

### **Beyond Equality: An Egalitarianism of Altruism Versus an Egalitarianism of Envy**

The equal distribution of health care is itself problematic, a circumstance recognized in *Securing Access to Health Care*, the 1983 report of the President's Commission.<sup>9</sup> The difficulties are multiple:

1. Although in theory, at least, one can envisage providing all with equal levels of decent shelter, one cannot restore all to or preserve all in an equal state of health. Many health needs cannot be satisfied in the same way one can address most needs for food and shelter.
2. If one provided all with the same amount of funds to purchase health care or the same amount of services, the amount provided would be far too much for some and much too little for others who could have benefited from more investment in treatment and research.
3. If one attempts to provide equal health care in the sense of allowing individuals to select health care only from a predetermined list of available therapies, or through some managed health care plan such as accountable

(to the government) health care plans or regional health alliances, which would be provided to all so as to prevent the rich from having access to better health care than the poor, one would have immorally confiscated private property and have restricted the freedom of individuals to join in voluntary relationships and associations.

That some are fortunate in having more resources is neither more nor less arbitrary or unfair than some having better health, better looks, or more talents. In any event, the translation of unfortunate circumstances into unfair circumstances, other than with regard to violations of the principle of permission, requires the imposition of a particular vision of beneficence or justice. . . .

### **Conflicting Models of Justice: From Content to Procedure**

John Rawls's *A Theory of Justice* and Robert Nozick's *Anarchy, State, and Utopia* offer contrasting understandings of what should count as justice or fairness. They sustain differing suggestions regarding the nature of justice in health care. They provide a contrast between justice as primarily structural, a pattern of distributions that is amenable to rational disclosure, versus justice as primarily procedural, a matter of fair negotiation.<sup>10</sup> In *A Theory of Justice* Rawls forwards an expository device of an ahistorical perspective from which to discover the proper pattern for the distribution of resources, and therefore presumably for the distribution of health care resources. In this understanding, it is assumed that societally based entitlements have moral priority. Nozick, in contrast, advances a historical account of just distributions within which justice depends on what individuals have agreed to do with and for each other. Nozick holds that individually based entitlements are morally prior to societally based entitlements. In contrast with Rawls, who argues that one can discover a proper pattern for the allocation of resources, Nozick argues that such a pattern cannot be discovered and that instead one can only identify the characteristics of a just process for fashioning rights to health care. . . .

The differences between Nozick of *Anarchy, State, and Utopia* and Rawls of *A Theory of Justice* express themselves in different accounts of entitlements and ownership, and in different understandings of nonprincipled fortune and misfortune. For Rawls, one has justifiable title to goods if such a title is part of a system that ensures the greatest benefit to the least advantaged, consistent with a just-savings principle, and with offices and positions open to all under conditions of fair equality and opportunity, and where each person has an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all. In contrast, for Nozick, one simply owns things: "Things come into the world already attached to people having entitlements over them."<sup>11</sup> If one really owns things, there will be freedom-based limitations on principles of distributive justice. One may not use people or their property without their permission or authorization. The needs of others will not erase one's property rights. The readers of this book should consider that they may be wearing wedding rings or other jewelry not essential to their lives, which could be sold to buy antibiotics to save identifiable lives in the third world. Those who keep such baubles may in part be acting in agreement with Nozick's account and claiming that "it is my right to keep my wedding ring for myself, even though the proceeds from its sale could save the lives of individuals in dire need."

Nozick's account requires a distinction between someone's secular moral rights and what is right, good, or proper to do. At times, selling some (perhaps all) of one's property to support the health care of those in need will be the right thing to do, even though one has a secular moral right to refuse to sell. This contrast derives from the distinction Nozick makes between *freedom as a side constraint*, as the very condition for the possibility of a secular moral community, and *freedom as one value among others*. This contrast can be understood as a distinction between those claims of justice based on the very possibility of a moral community, versus those claims of justice that turn on interests in particular goods and values, albeit interests recognized in the original position. For Nozick, one may not use innocent free persons without their consent, even if

that use will save lives by providing needed health care or securing equality of opportunity. Even if such would be a good thing to do (e.g., in this sense of saving lives), no one has a right to do it. Because for Nozick one needs the *actual* consent of *actual* persons in order to respect them as free persons, their rights can morally foreclose the pursuit of many morally worthy goals. In contrast, Rawls treats freedom or liberty as a value. As a consequence, in developing just institutions, Rawls does not require actual consent of those involved. As a result, Rawls would allow rights to self-determination to be limited in order to achieve important social goals....

This contrast between Rawls and Nozick can be appreciated more generally as a contrast between two quite different principles of justice, each of which has strikingly different implications for the allocation of health care resources.

1. Freedom- or permission-based justice is concerned with distributions of goods made in accord with the notion of the secular moral community as a peaceable social structure binding moral strangers, members of diverse concrete moral communities. Such justice will therefore require the consent of the individuals involved in a historical nexus of justice-regarding institutions understood in conformity with the principle of permission. The principle of beneficence may be pursued only within constraints set by the principle of permission.
2. Goals-based justice is concerned with the achievement of the good of individuals in society, where the pursuit of beneficence is not constrained by a strong principle of permission, but driven by some particular understanding of morality, justice, or fairness. Such justice will vary in substance as one attempts, for example, to (a) give each person an equal share; (b) give each person what that person needs; (c) give each person a distribution as a part of a system designed to achieve the greatest balance of benefits over harms for the greatest number of persons; (d) give each person a distribution as a part of a

system designed to maximize the advantage of the least-well-off class with conditions of equal liberty for all and of fair opportunity.

Allocations of health care in accord with freedom- or permission-based justice must occur within the constraint to respect the free choices of persons, including their exercise of their property rights. Allocations of health care in accord with goals-based justice will need to establish what it means to provide a just pattern of health care, and what constitutes true needs, not mere desires, and how to rank the various health goals among themselves and in comparison with nonhealth goals. Such approaches to justice in health care will require a way of ahistorically discovering the proper pattern for the distribution of resources.

Permission-based and goals-based approaches to justice in health care contrast because they offer competing interpretations of the maxim, "*Justitia est constans et perpetua voluntas jus suum cuique tribuens*" (Justice is the constant and perpetual to render everyone his due).<sup>12</sup> A permission-based approach holds that justice is first and foremost giving to each the right to be respected as a free individual as the source of secular moral authority, in the disposition of personal services and private goods; that which is due (*ius*) to individuals is respect of their authority over themselves and their possessions. In contrast, a goals-based approach holds that justice is receiving a share of the goods, which is fair by an appeal to a set of ahistorical criteria specifying what a fair share should be, that is, what share is due to each individual. Since there are various senses of a fair share (e.g., an equal share, a share in accordance with the system that maximizes the balance of benefits over harms, etc.), there will be various competing senses of justice in health care under the rubric of goals-based justice. . . .

### **The Moral Inevitability of a Multitier Health Care System**

. . . In the face of unavoidable tragedies and contrary moral intuitions, a multitiered system of health care is in many respects a compromise. On the one hand, it provides some amount of health care for all, while on the other hand allowing those

with resources to purchase additional or better services. It can endorse the use of communal resources for the provision of a decent minimal or basic amount of health care for all, while acknowledging the existence of private resources at the disposal of some individuals to purchase better basic as well as luxury care. While the propensity to seek more than equal treatment for oneself or loved ones is made into a vicious disposition in an egalitarian system, a multitier system allows for the expression of individual love and the pursuit of private advantage, though still supporting a general social sympathy for those in need. Whereas an egalitarian system must suppress the widespread human inclination to devote private resources to the purchase of the best care for those whom one loves, a multitier system can recognize a legitimate place for the expression of such inclinations. A multitier system (1) should support individual providers and consumers against attempts to interfere in their free association and their use of their own resources, though (2) it may allow positive rights to health care to be created for individuals who have not been advantaged by the social lottery.

The serious task is to decide how to define and provide a decent minimum or basic level of care as a floor of support for all members of society, while allowing money and free choice to fashion special tiers of services for the affluent. In addressing this general issue of defining what is to be meant by a decent minimum basic level or a minimum adequate amount of health care, the American President's Commission in 1983 suggested that in great measure content is to be created rather than discovered by democratic processes, as well as by the forces of the market. "In a democracy, the appropriate values to be assigned to the consequences of policies must ultimately be determined by people expressing their values through social and political processes as well as in the marketplace."<sup>13</sup> The Commission, however, also suggested that the concept of adequacy could in part be discovered by an appeal to that amount of care that would meet the standards of sound medical practice. "Adequacy does require that everyone receive care that meets standards of sound medical practice."<sup>14</sup> But what one means by "sound medical practice" is itself

dependent on particular understandings within particular cultures. Criteria for sound medical practice are as much created as discovered. The moral inevitability of multiple tiers of care brings with it multiple standards of proper or sound medical practice and undermines the moral plausibility of various *obiter dicta* concerning the centralized allocation of medical resources. . . .

#### NOTES

1. The White House Domestic Policy Council, *The President's Health Security Plan* (New York: Times Books, 1993).
2. The White House Domestic Policy Council, *The President's Health Security Plan*, p. 43.
3. Innovation would be discouraged as drug prices are subject to review as reasonable. The White House Domestic Policy Council, *The President's Health Security Plan*, p. 45.
4. In considering how to respond to the plight of the impetuous, one might consider the story Jesus tells of the rich man who fails to give alms to "a certain beggar named Lazarus, full of sores, who was laid at his gate, desiring to be fed with the crumbs which fell from the rich man's table" (Luke 16:20–21). The rich man, who was not forthcoming with alms, was condemned to a hell of excruciating torment.
5. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,
- Securing Access to Health Care (Washington, DC.: U.S. Government Printing Office, 1983), vol. 1, pp. 43–46.
6. The White House Domestic Policy Council, "Ethical Foundations of Health Reform," in *The President's Health Security Plan*, p. 11.
7. H. Newman, "Exclusion of Heart Transplantation Procedures from Medicare Coverage," *Federal Register* 45 (Aug. 6, 1980): 52296. See also H. Newman, "Medicare Program: Solicitation of Hospitals and Medical Centers to Participate in a Study of Heart Transplants," *Federal Register* 46 (Jan. 22, 1981): 7072–75.
8. The reader should understand that the author holds that almsgiving is one of the proper responses to human suffering (in addition to being an appropriate expression of remorse, an act of repentance to which surely the author is obligated). It is just that the author acknowledges the limited secular moral authority of the state to compel charity coercively.
9. President's Commission, *Securing Access to Health Care*, vol. 1, pp. 18–19.
10. John Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard University Press, 1971), and Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, 1974).
11. Nozick, *Anarchy, State, and Utopia*, p. 160.
12. Flavius Petrus Sabbatius Justinianus, *The Institutes of Justinian*, trans. Thomas C. Sandars (1922; repr. Westport, Conn.: Greenwood Press, 1970), 1.1, p. 5.
13. President's Commission, *Securing Access to Health Care*, vol. 1, p. 37.
14. Ibid.

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## Mirror, Mirror 2017: International Comparison Reflects Flaws and Opportunities for Better U.S. Health Care

ERIC C. SCHNEIDER, DANA O. SARNAK, DAVID SQUIRES, ARNAV SHAH, AND MICHELLE M. DOTY

This report compares health care system performance in the United States with that of ten other prosperous countries (Switzerland, France, Germany, Canada, Netherlands, and others). It concludes that although the United States spends more on health care than other countries, the nation overall experiences poorer health. Life expectancy is lower for many U.S. populations, and more people are living with serious health problems, while the U.S. system fails to reliably deliver health care services to those who need them.

## The United States Health System Falls Short

The United States spends far more on health care than other high-income countries, with spending levels that rose continuously over the past three decades. Yet the U.S. population has poorer health than other countries.<sup>1</sup> Life expectancy, after improving for several decades, worsened in recent years for some populations, aggravated by the opioid crisis.<sup>2</sup> In addition, as the baby boom population ages, more people in the U.S.—and all over the world—are living with age-related disabilities and chronic disease, placing pressure on health care systems to respond.

Timely and accessible health care could mitigate many of these challenges, but the U.S. health care system falls short, failing to deliver indicated services reliably to all who could benefit.<sup>3</sup> In particular, poor access to primary care has contributed to inadequate prevention and management of chronic diseases, delayed diagnoses, incomplete adherence to treatments, wasteful overuse of drugs and technologies, and coordination and safety problems.

This report uses recent data to compare health care system performance in the U.S. with that of 10 other high-income countries and considers the different approaches to health care organization and delivery that can contribute to top performance. We based our analysis on 72 indicators that measure performance in five domains important to policymakers, providers, patients, and the public: Care Process, Access, Administrative Efficiency, Equity, and Health Care Outcomes.

Our data come from a variety of sources. One is comparative survey research. Since 1998, The Commonwealth Fund, in collaboration with international partners, has supported surveys of patients and primary care physicians in advanced countries, collecting information for a standardized set of metrics on health system performance. Other comparative data are drawn from the most recent reports of the Organization for Economic Cooperation and Development (OECD), the

European Observatory on Health Systems and Policies, and the World Health Organization (WHO).

## Performance Varies Among Health Systems

The United States ranks last in health care system performance among the 11 countries included in this study. The U.S. ranks last in Access, Equity, and Health Care Outcomes, and next to last in Administrative Efficiency, as reported by patients and providers. Only in Care Process does the U.S. perform better, ranking fifth among the 11 countries. Other countries that rank near the bottom on overall performance include France (10th) and Canada (9th).

This analysis reveals striking variations in performance across the domains. No country ranks first consistently across all domains or measures, suggesting that all countries have room to improve. The U.S., France, and Canada score lower than the 11-country average across most of the five domains, but all three achieve above-average performance on at least one domain: France on Health Care Outcomes, Canada on Care Process and Administrative Efficiency, and the U.S. on Care Process.

## Top Performers

The top-ranked countries overall are the United Kingdom, Australia, and the Netherlands. In general, the U.K. achieves superior performance compared to other countries in all areas except Health Care Outcomes, where it ranks 10th despite experiencing the fastest reduction in deaths amenable to health care in the past decade. Australia ranks highest on Administrative Efficiency and Health Care Outcomes, is among the top-ranked countries on Care Process and Access, but ranks low on Equity. The Netherlands is among the top performers on Care Process, Access, and Equity; its performance on Administrative Efficiency stands out as an area for improvement.

New Zealand performs well on measures of Care Process and Administrative Efficiency, but below the 11-country average on other indicators. Norway and Sweden did better on Health Care Outcomes compared to the other countries, despite having relatively low rankings on Care Process. Switzerland performs well on measures of Equity and

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From Eric C. Schneider, Dana O. Sarnak, et al. "Mirror, Mirror 2017," The Commonwealth Fund, <http://interactives.commonwealthfund.org>.

### Health Care System Performance Rankings

	AUS	CAN	FRA	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
OVERALL RANKING	2	9	10	8	3	4	4	6	6	1	11
Care Process	2	6	9	8	4	3	10	11	7	1	5
Access	4	10	9	2	1	7	5	6	8	3	11
Administrative Efficiency	1	6	11	6	9	2	4	5	8	3	10
Equity	7	9	10	6	2	8	5	3	4	1	11
Health Care Outcomes	1	9	5	8	6	7	3	2	4	10	11

Health Care Outcomes, while Germany achieves a high rank only on measures of Access.

#### Care Process

The United Kingdom ranks first and Sweden last on Care Process based on the performance across the four subdomains of prevention, safe care, coordination, and patient engagement. The United States ranks in the middle on Care Process (5th), with stronger performance on the subdomains of prevention, safety, and engagement. The U.S. performs slightly below the 11-country average in the coordination subdomain.

The U.S. tends to excel on measures that involve the doctor-patient relationship, performing relatively better on wellness counseling related to healthy behaviors, shared decision-making with primary care and specialist providers, chronic disease management, and end-of-life discussions. The U.S. also performs above the 11-country average on preventive measures like mammography screening and older adult influenza immunization rates. However, the U.S. performs poorly on several coordination measures, including information flows between primary care providers and specialist and social service providers. The U.S. also lags other countries on avoidable hospital admissions.

The U.K., Australia, and New Zealand are the top performers in the Care Process domain. These three countries consistently perform above the 11-country average across all subdomains (except for Australia on coordinated care). The U.K. excels in safety, while Australia is the top performer in patient engagement. On the other end of the spectrum, Norway and Sweden's

performance is below average on each of the Care Process subdomains.

#### Access

Overall, the United States ranks last on Access. The U.S. has the poorest performance of all countries on the affordability subdomain, scoring much lower than even the second-to-last country, Switzerland. The U.S. ranks ninth on the subdomain of timeliness.

The Netherlands performs the best of the 11 countries on Access, ranking first on timeliness and in the middle on affordability. Germany ranks second on Access, and is among the top-ranked countries on both subdomains. The United Kingdom, Sweden, and Norway are the other top-ranked performers on affordability.

#### Administrative Efficiency

The United States ranks 10th on Administrative Efficiency. Compared to the other countries, more U.S. doctors reported problems related to coverage restrictions. Larger percentages of U.S. patients also reported Administrative Efficiency problems compared to those in other countries (except France). The top performers in this domain are Australia, New Zealand, the United Kingdom, and Norway. At the lower end of the range, respondents from France were most likely to report problems in this area among the surveyed countries.

#### Equity

The United Kingdom, the Netherlands, and Sweden rank highest on measures related to the equity of health systems with respect to access and

care process. In these three countries, there are relatively small differences between lower- and higher-income adults on the 11 measures related to timeliness, financial barriers to care, and patient-centered care.

In contrast, the United States, France, and Canada have larger disparities between lower- and higher-income adults. These were especially large on measures related to financial barriers, such as skipping needed doctor visits or dental care, forgoing treatments or tests, and not filling prescriptions because of the cost.

### **Health Care Outcomes**

The United States ranks last overall in Health Care Outcomes. However, the pattern of performance across different outcomes measures reveals nuances. Compared to the other countries, the U.S. performs relatively poorly on population health outcomes such as infant mortality and life expectancy at age 60. The U.S. has the highest rate of mortality amenable to health care and has experienced the smallest reduction in that measure during the past decade. In contrast, the U.S. appears to perform relatively well on 30-day in-hospital mortality after heart attack or stroke. The U.S. also performs as well as several top performers on breast cancer five-year relative survival rate and close to the 11-country average on colorectal cancer five-year relative survival rate.

Australia has the best Health Care Outcomes overall. Sweden and Norway rank second and third in the domain. While the United Kingdom ranks 10th in the health care outcomes domain overall, it had the largest reduction in mortality amenable to health care during the past decade.

### **Causes of Poor Performance**

Based on a broadly inclusive set of performance metrics, we find that U.S. health care system performance ranks last among 11 high-income countries. The country's performance shortcomings cross several domains of care including Access, Administrative Efficiency, Equity, and Health Care Outcomes. Only within the domain of Care Process is U.S. performance close to the 11-country average. These results are troubling because the U.S. has the highest

per capita health expenditures of any country and devotes a larger percentage of its GDP to health care than any other country.

The U.S. health care system is unique in several respects. Most striking: it is the only high-income country lacking universal health insurance coverage. The U.S. has taken an important step to expand coverage through the Affordable Care Act. As a 2017 Commonwealth Fund report showed, the ACA has catalyzed widespread and historic gains in access to care across the U.S.<sup>4</sup> More than 20 million Americans gained insurance coverage. Additional actions could extend insurance coverage to those who lack it. Furthermore, Americans with coverage often face far higher deductibles and out-of-pocket costs than citizens of other countries, whose systems offer more financial protection.<sup>5</sup> Incomplete and fragmented insurance coverage may account for the relatively poor performance of the U.S. on health care outcomes, affordability, administrative efficiency, and equity.

Several new U.S. federal initiatives—notably the Affordable Care Act—have promoted actions to improve U.S. health care system performance.<sup>6</sup> In addition to extending insurance coverage to millions of Americans, recent legislation includes initiatives to spur innovation in health care delivery by changing payment incentives for providers. But health systems can be slow to change. Additional legislative and policy reforms may be needed to close the performance gap between the U.S. and other countries.

The U.S. could learn important lessons from other high-income countries. For example, the U.S. performs poorly in administrative efficiency mainly because of doctors and patients reporting wasting time on billing and insurance claims. Other countries that rely on private health insurers, like the Netherlands, minimize some of these problems by standardizing basic benefit packages, which can both reduce administrative burden for providers and ensure that patients face predictable copayments.

The U.K. stands out as a top performer in most categories except for health care outcomes, where it ranks with the U.S. near the bottom. In contrast to

the U.S., over the past decade the U.K. saw a larger decline in mortality amenable to health care (i.e., a greater improvement in the measure) than the other countries studied. (The U.S. has had the smallest decline, or lowest level of improvement.) In the early 2000s, the U.K. made a major investment in its National Health Service, reforming primary care and cancer care in addition to increasing health care spending from 6.2 percent of GDP in 2000 to 9.9 percent of GDP in 2014.<sup>7</sup> The reforms and increased spending may have contributed to the rapid decline in mortality amenable to health care in the U.K.

There is a striking contrast between the U.S.'s poor performance on infant mortality, life expectancy, and amenable mortality and its relatively better performance on in-hospital mortality after heart attack or stroke. Researchers have noted that the only modest decline in the rate of amenable mortality in the U.S. may be attributable to better management, once diagnosed, of hypertension and cerebrovascular disease that lead to cardiovascular mortality.<sup>8</sup> These findings highlight the combined impact of a lack of universal insurance coverage and barriers to accessing primary care, and suggest that the U.S. could make gains by investing more in preventing chronic disease. The high level of inequity in the U.S. health care system intensifies the problem. For the first time in decades, midlife mortality for less-educated Americans is rapidly increasing.<sup>9</sup>

In conclusion, the performance of the U.S. health care system ranks last compared to other high-income countries. [The] U.S. health system is a substantial outlier when it comes to achieving value. Despite spending nearly twice as much as several other countries, the country's performance is lackluster. This report points to several areas that the U.S. could improve, building on recent health reforms, to achieve better performance. The success of U.S. initiatives to reduce readmissions and hospital-acquired conditions suggest the country's health care can be improved. To gain more than incremental improvement, however,

the U.S. may need to pursue different approaches to organizing and financing the delivery system. These could include strengthening primary care, supporting organizations that excel at care coordination and moving away from fee-for-service payment to other types of purchasing that create incentives to better coordinate care. These steps should ensure early diagnosis and treatment, improve the affordability of care, and ultimately improve the health of all Americans.

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## Public Health Ethics: Mapping the Terrain

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Childress et al. discuss the main concepts and issues in public health ethics, providing a working definition of the public health sphere, identifying the considerations that dominate moral deliberations, and outlining how moral conflicts arise. They also examine a central question in public health ethics: "When can paternalistic interventions [by the state or other authorities] . . . be ethically justified if they infringe general moral considerations such as respect for autonomy, including liberty of action?"

Public health ethics, like the field of public health it addresses, traditionally has focused more on practice and particular cases than on theory, with the result that some concepts, methods, and boundaries remain largely undefined. This paper attempts to provide a rough conceptual map of the terrain of public health ethics. We begin by briefly defining public health and identifying general features of the field that are particularly relevant for a discussion of public health ethics.

Public health is primarily concerned with the health of the entire population, rather than the health of individuals. Its features include an emphasis on the promotion of health and the prevention of disease and disability; the collection and use of epidemiological data, population surveillance, and other forms of empirical quantitative assessment; a recognition of the multidimensional nature of the determinants of health; and a focus on the complex interactions of many factors—biological, behavioral, social, and environmental—in developing effective interventions.

How can we distinguish public health from medicine? While medicine focuses on the treatment and cure of individual patients, public health aims to understand and ameliorate the causes of disease and disability in a population. In addition,

whereas the physician-patient relationship is at the center of medicine, public health involves interactions and relationships among many professionals and members of the community as well as agencies of government in the development, implementation, and assessment of interventions. From this starting point, we can suggest that public health systems consist of all the people and actions, including laws, policies, practices, and activities, that have the primary purpose of protecting and improving the health of the public.<sup>1</sup> While we need not assume that public health systems are tightly structured or centrally directed, we recognize that they include a wide range of governmental, private and non-profit organizations, as well as professionals from many disciplines, all of which (alone and together) have a stake in and an effect on a community's health. Government has a unique role in public health because of its responsibility, grounded in its police powers, to protect the public's health and welfare, because it alone can undertake certain interventions, such as regulation, taxation, and the expenditure of public funds, and because many, perhaps most, public health programs are public goods that cannot be optimally provided if left to individuals or small groups.

The Institute of Medicine's landmark 1988 definition of public health provides additional insight: "Public health is what we, as a society, do collectively to assure the conditions in which people can

be healthy.”<sup>2</sup> The words “what we, as a society, do collectively” suggest the need for cooperative behavior and relationships built on overlapping values and trust. The words “to assure the conditions in which people can be healthy” suggest a far-reaching agenda for public health that focuses attention not only on the medical needs of individuals, but on fundamental social conditions that affect population levels of morbidity and mortality. From an ethical standpoint, public health activities are generally understood to be teleological (end-oriented) and consequentialist—the health of the public is the primary end that is sought and the primary outcome for measuring success.<sup>3</sup> Defining and measuring “health” is not easy, as we will emphasize below, but, in addition, “public” is a complex concept with at least three dimensions that are important for our discussion of ethics.

First, public can be used to mean the “numerical public,” i.e., the target population. In view of public health’s goal of producing net health benefits for the population, this meaning of public is very important. In measurement and analysis, the “numerical public” reflects the utilitarian view that each individual counts as one and only one. In this context, ethical analysis focuses on issues in measurement, many of which raise considerations of justice. For example, how should we define a population, how should we compare gains in life expectancy with gains in health-related quality of life, and whose values should be used in making those judgments?

Second, public is what we collectively do through government and public agency—we can call this “political public.” Government provides much of the funding for a vast array of public health functions, and public health professionals in governmental roles are the focal point of much collective activity. In the United States, as Lawrence Gostin notes, government “is compelled by its role as the elected representative of the community to act affirmatively to promote the health of the people,” even though it “cannot unduly invade individuals’ rights in the name of the communal good.”<sup>4</sup> The government is a central player in public health because of the collective responsibility it must assume and implement. The state’s use of its police powers for public health raises important ethical questions,

particularly about the justification and limits of governmental coercion and about its duty to treat all citizens equally in exercising these powers. In a liberal, pluralistic democracy, the justification of coercive policies, as well as other policies, must rest on moral reasons that the public in whose name the policies are carried out could reasonably be expected to accept.<sup>5</sup>

Third, public, defined as what we do collectively in a broad sense, includes all forms of social and community action affecting public health—we can call this “communal public.” Ethical analysis on this level extends beyond the political public. People collectively, outside of government and with private funds, often have greater freedom to undertake public health interventions since they do not have to justify their actions to the political public. However, their actions are still subject to various moral requirements, including, for instance, respect for individual autonomy, liberty, privacy and confidentiality, and transparency in disclosure of conflicts of interest.

### **General Moral Considerations**

In providing a map of the terrain of public health ethics, we do not suggest that there is a consensus about the methods and content of public health ethics.<sup>6</sup> Controversies persist about theory and method in other areas of applied or practical ethics, and it should not be surprising that variety also prevails in public health ethics.<sup>7</sup> The terrain of public health ethics includes a loose set of general moral considerations—clusters of moral concepts and norms that are variously called values, principles, or rules—that are arguably relevant to public health. Public health ethics, in part, involves ongoing efforts to specify and to assign weights to these general moral considerations in the context of particular policies, practices, and actions, in order to provide concrete moral guidance.

Recognizing general moral considerations in public health ethics does not entail a commitment to any particular theory or method. What we describe and propose is compatible with several approaches. To take one major example, casuistical reasoning (examining the relevant similarities and differences between cases) is not only compatible

with but indispensable to our conception of public health ethics. Not only do—or should—public health agents examine new situations they confront in light of general moral considerations, but they should also focus on a new situation's relevant similarities to and differences from paradigm or precedent cases—cases that have gained a relatively settled moral consensus. Whether a relatively settled moral consensus is articulated first in a general moral consideration or in precedent cases does not constitute a fundamental issue—both are relevant. Furthermore, some of the precedents may concern how general moral considerations are interpreted, specified, and balanced in some public health activity, especially where conflicts emerge.

Conceptions of morality usually recognize a formal requirement of universalizability in addition to a substantive requirement of attention to human welfare. Whatever language is used, this formal feature requires that we treat similar cases in a similar way. This requirement undergirds casuistical reasoning in morality as well as in law. In public health ethics, for example, any recommendations for an HIV screening policy must take into account both past precedents in screening for other infectious diseases and the precedents the new policy will create for, say, screening for genetic conditions. Much of the moral argument will hinge on which similarities and differences between cases are morally relevant, and that argument will often, though not always, appeal to general moral considerations.<sup>8</sup> We can establish the relevance of a set of these considerations in part by looking at the kinds of moral appeals that public health agents make in deliberating about and justifying their actions as well as at debates about moral issues in public health. The relevant general moral considerations include:

- producing benefits;
- avoiding, preventing, and removing harms;
- producing the maximal balance of benefits over harms and other costs (often called utility);
- distributing benefits and burdens fairly (distributive justice) and ensuring public participation, including the participation of affected parties (procedural justice);

- respecting autonomous choices and actions, including liberty of action;
- protecting privacy and confidentiality;
- keeping promises and commitments;
- disclosing information as well as speaking honestly and truthfully (often grouped under transparency); and
- building and maintaining trust.

Several of these general moral considerations—especially benefiting others, preventing and removing harms, and utility—provide a *prima facie* warrant for many activities in pursuit of the goal of public health. It is sufficient for our purposes to note that public health activities have their grounding in general moral considerations, and that public health identifies one major broad benefit that societies and governments ought to pursue. The relation of public health to the whole set of general moral considerations is complex. Some general moral considerations support this pursuit; institutionalizing several others may be a condition for or means to public health (we address this point later when we discuss human rights and public health); and yet, in particular cases, some of the same general moral considerations may limit or constrain what may be done in pursuit of public health. Hence, conflicts may occur among these general moral considerations.

The content of these various general moral considerations can be divided and arranged in several ways—for instance, some theories may locate one or more of these concepts under others. But, whatever theory one embraces, the whole set of general moral considerations roughly captures the moral content of public health ethics. It then becomes necessary to address several practical questions. First, how can we make these general moral considerations more specific and concrete in order to guide action? Second, how can we resolve conflicts among them? Some of the conflicts will concern how much weight and significance to assign to the ends and effects of protecting and promoting public health relative to the other considerations that limit and constrain ways to pursue such outcomes. While each general moral consideration may limit and constrain public health activities in some circumstances, for our purposes, justice or

fairness, respect for autonomy and liberty, and privacy and confidentiality are particularly noteworthy in this regard.

### Specifying and Weighting General Moral Considerations

We do not present a universal public health ethic. Although arguably these general moral considerations find support in various societies and cultures, an analysis of the role of cultural context in public health ethics is beyond the scope of this paper. Instead, we focus here on public health ethics in the particular setting of the United States, with its traditions, practices, and legal and constitutional requirements, all of which set directions for and circumscribe public health ethics. (Below we will indicate how this conception of public health ethics relates to human rights.)

General moral considerations have two major dimensions. One is their meaning and range or scope; the other is their weight or strength. The first determines the extent of conflict among them—if their range or scope is interpreted in certain ways, conflicts may be increased or reduced. The second dimension determines when different considerations yield to others in cases of conflict.

Specifying the meaning and range or scope of general moral considerations—the first dimension—provides increasingly concrete guidance in public health ethics. A common example is specifying respect for autonomy by rules of voluntary, informed consent. However, it would be a mistake to suppose that respect for autonomy requires consent in all contexts of public health or to assume that consent alone sufficiently specifies the duty to respect autonomy in public health settings. Indeed, specifying the meaning and scope of general moral considerations entails difficult moral work. Nowhere is this more evident in public health ethics than with regard to considerations of justice. Explicating the demands of justice in allocating public health resources and in setting priorities for public health policies, or in determining whom they should target, remains among the most daunting challenges in public health ethics.

The various general moral considerations are not absolute. Each may conflict with another and

each may have to yield in some circumstances. At most, then, these general moral considerations identify features of actions, practices, and policies that make them *prima facie* or presumptively right or wrong, i.e., right or wrong, all other things being equal. But since any particular action, practice, or policy for the public's health may also have features that infringe one or more of these general moral considerations, it will be necessary to determine which of them has priority. Some argue for a lexical or serial ordering, in which one general moral consideration, while not generally absolute, has priority over another. For instance, one theory might hold that protecting or promoting public health always has priority over privacy, while another might hold that individual liberty always has priority over protecting or promoting public health. Neither of these priority rules is plausible, and any priority rule that is plausible will probably involve tight or narrow specifications of the relevant general moral considerations to reduce conflicts. From our standpoint, it is better to recognize the need to balance general moral considerations in particular circumstances when conflicts arise. We cannot determine their weights in advance, only in particular contexts that may affect their weights—for instance, promises may not have the same moral weights in different contexts.

### Resolving Conflicts Among General Moral Considerations

We do not believe it is possible to develop an algorithm to resolve all conflicts among general moral considerations. Such conflicts can arise in multiple ways. For example, it is common in public health practice and policy for conflicts to emerge between privacy and justice (for instance, the state collects and records private information in disease registries about individuals in order to allocate and provide access to resources for appropriate prevention and treatment services), or between different conceptions of justice (for instance, a government with a finite public health budget must decide whether to dedicate resources to vaccination or to treatment of conditions when they arise). In this paper, however, we focus on one particular permutation of conflicts among general

moral considerations that has received the most attention in commentary and in law. This is the conflict between the general moral considerations that are generally taken to instantiate the goal of public health—producing benefits, preventing harms, and maximizing utility—and those that express other moral commitments. For conflicts that assume this structure, we propose five “justificatory conditions”: effectiveness, proportionality, necessity, least infringement, and public justification. These conditions are intended to help determine whether promoting public health warrants overriding such values as individual liberty or justice in particular cases.

**Effectiveness.** It is essential to show that infringing one or more general moral considerations will probably protect public health. For instance, a policy that infringes one or more general moral considerations in the name of public health but has little chance of realizing its goal is ethically unjustified.

**Proportionality.** It is essential to show that the probable public health benefits outweigh the infringed general moral considerations—this condition is sometimes called proportionality. For instance, the policy may breach autonomy or privacy and have undesirable consequences. All of the positive features and benefits must be balanced against the negative features and effects.

**Necessity.** Not all effective and proportionate policies are necessary to realize the public health goal that is sought. The fact that a policy will infringe a general moral consideration provides a strong moral reason to seek an alternative strategy that is less morally troubling. This is the logic of a *prima facie* or presumptive general moral consideration. For instance, all other things being equal, a policy that provides incentives for persons with tuberculosis to complete their treatment until cured will have priority over a policy that forcibly detains such persons in order to ensure the completion of treatment. Proponents of the forcible strategy have the burden of moral proof. This means that the proponents must have a good faith belief, for which they can

give supportable reasons, that a coercive approach is necessary. In many contexts, this condition does not require that proponents provide empirical evidence by actually trying the alternative measures and demonstrating their failure.<sup>9</sup>

**Least Infringement.** Even when a proposed policy satisfies the first three justificatory conditions—that is, it is effective, proportionate, and essential in realizing the goal of public health—public health agents should seek to minimize the infringement of general moral considerations. For instance, when a policy infringes autonomy, public health agents should seek the least restrictive alternative; when it infringes privacy, they should seek the least intrusive alternative; and when it infringes confidentiality, they should disclose only the amount and kind of information needed, and only to those necessary, to realize the goal.<sup>10</sup> The justificatory condition of least infringement could plausibly be interpreted as a corollary of necessity—for instance, a proposed coercive measure must be necessary in degree as well as in kind.

**Public Justification.** When public health agents believe that one of their actions, practices, or policies infringes one or more general moral considerations, they also have a responsibility, in our judgment, to explain and justify that infringement, whenever possible, to the relevant parties, including those affected by the infringement. In the context of what we called “political public,” public health agents should offer public justification for policies in terms that fit the overall social contract in a liberal, pluralistic democracy. This transparency stems in part from the requirement to treat citizens as equals and with respect by offering moral reasons, which in principle they could find acceptable, for policies that infringe general moral considerations. Transparency is also essential to creating and maintaining public trust; and it is crucial to establishing accountability. (Below we elaborate a process-oriented approach to public accountability that goes beyond public justification to include, as an expression of justice and fairness, input from the relevant affected parties in the formulation of policy.)

### Screening Program Example

An extended example may illustrate how these moral justificatory conditions function in public health ethics. Let us suppose that public health agents are considering whether to implement a screening program for HIV infection, tuberculosis, another infectious or contagious disease, or a genetic condition (see Figure 1 for some morally relevant features of screening programs).

The relevant justificatory conditions will require public health agents to consider whether any proposed program will be likely to realize the public health goal that is sought (effectiveness), whether its probable benefits will outweigh the infringed general moral considerations (proportionality), whether the policy is essential to realize the end (necessity), whether it involves the least infringement possible consistent with realizing the goal that is sought (least infringement), and whether it can be publicly justified. These conditions will give priority to selective programs over universal ones if the selective programs will realize the goal (as we note below, questions may arise about universality within selected categories, such as pregnant women), and to voluntary programs over mandatory ones if the voluntary programs will realize the goal.<sup>11</sup>

Different screening programs may fail close scrutiny in light of one or more of these conditions. For instance, neither mandatory nor voluntary universal screening for HIV infection can meet these conditions in the society as a whole. Some voluntary and some mandatory selective screening programs for HIV infection can be justified, while others cannot. Mandatory screening of donated blood, organs, sperm, and ova is easily justified, and screening of individuals may also be justified in

some settings where they can expose others to bodily fluids and potential victims cannot protect themselves. The question of whether and under what conditions screening of pregnant women for HIV infection should be instituted has been particularly controversial. Even before the advent of effective treatment for HIV infection and the identification of zidovudine (AZT) as effective in reducing the rate of perinatal transmission, there were calls for mandatory screening of pregnant women, especially in “high risk” communities. These calls were defeated by sound arguments that such policies entailed unjustifiable violations of autonomy, privacy, and justice.<sup>12</sup> In effect, the recommended policies failed to satisfy any of the justificatory conditions we have proposed here.

However, once it was established that zidovudine could interrupt maternal-fetal transmission of HIV, the weight of the argument shifted in the direction of instituting screening programs of some type. The focus of the debate became the tensions between the public health interests in utility and efficiency, which argued for mandatory, selective screening in high-risk communities, and considerations of liberty, privacy, and justice, which argued for voluntary, universal screening.<sup>13</sup>

In many situations, the most defensible public health policy for screening and testing *expresses* community rather than *imposes* it. Imposing community involves mandating or compelling testing through coercive measures. By contrast, expressing community involves taking steps to express solidarity with individuals, to protect their interests, and to gain their trust. Expressing community may include, for example, providing communal support, disclosing adequate information, protecting privacy and confidentiality, and encouraging

Extent of Screening	Degree of Voluntariness	
	Voluntary	Mandatory
	Universal	Selective

**Figure 1 Features of Public Health Screening Programs**

certain choices. This approach seeks to make testing a reasonable, and perhaps moral, choice for individuals, especially by engendering public trust, rather than making it compulsory. Several diseases that might be subjected to screening for public health reasons involve stigma, and breaches of privacy and confidentiality may put individuals' employment and insurance at risk. Expressing community is often an appropriate strategy for public health, and, *ceteris paribus*, it has priority over imposing community through coercive policies.

### **Processes of Public Accountability**

Our discussion of the fifth justificatory condition—public justification—focused on providing public reasons for policies that infringe general moral considerations; this condition is particularly applicable in the political context. While public accountability includes public justification, it is broader—it is prospective as well as retrospective. It involves soliciting input from the relevant publics (the numerical, political, and communal publics) in the process of formulating public health policies, practices, and actions, as well as justifying to the relevant publics what is being undertaken. This is especially, but not only, important when one of the other *prima facie* general moral considerations is infringed, as with coercive protective measures to prevent epidemics. At a minimum, public accountability involves transparency in openly seeking information from those affected and in honestly disclosing relevant information to the public; it is indispensable for engendering and sustaining public trust, as well as for expressing justice.<sup>14</sup>

Public accountability regarding health promotion or priority-setting for public health funding additionally might involve a more developed fair process. Noting that in a pluralistic society we are likely to find disagreement about which principles should govern issues such as priority-setting in health care, Norman Daniels calls for a fair process that includes the following elements: transparency and publicity about the reasons for a decision; appeals to rationales and evidence that fair-minded parties would agree are relevant; and procedures for appealing and revising decisions in light of

challenges by various stakeholders. He explains why this process can facilitate social learning: "Since we may not be able to construct principles that yield fair decisions ahead of time, we need a process that allows us to develop those reasons over time as we face real cases."<sup>15</sup>

Public accountability also involves acknowledging the more complex relationship between public health and the public, one that addresses fundamental issues such as those involving characterization of risk and scientific uncertainty. Because public health depends for its success on the satisfaction of deeply personal health goals of individuals and groups in the population, concepts such as "health" and "risk" cannot be understood or acted upon on the basis of a priori, formal definitions or scientific analysis. Public accountability recognizes that the fundamental conceptualization of these terms is a critical part of the basic formulation of public health goals and problems to be addressed. This means that the public, along with scientific experts, plays an important role in the *analysis* of public health issues, as well as in the development and assessment of appropriate *strategies* for addressing them.

Risk characterization provides a helpful example. A National Research Council report, *Understanding Risk: Informing Decisions in a Democratic Society*, concluded that risk characterization is not properly understood if defined only as a summary of scientific information; rather, it is the outcome of a complex analytic-deliberative process—"a decision-driven activity, directed toward informing choices and solving problems."<sup>16</sup> The report explains that scientific analysis, which uses rigorous, replicable methods, brings new information into the process, and that deliberation helps to frame analysis by posing new questions and new ways of formulating problems, with the result that risk characterization is the output of a recursive process, not a linear one, and is a decision-driven activity.

Assessment of the health risks of dioxin illustrates this process. While scientific analysis provides information about the dose-response relationship between dioxin exposure and possible human health effects, public health focuses on the

placement of waste incinerators and community issues in which dioxin is only one of many hazardous chemicals involved and cancer only one of many outcomes of concern. The critical point is that good risk characterization results from a process that “not only gets the science right,” but also “gets the right science.”<sup>17</sup>

Public health accountability addresses the responsibility of public health agents to work with the public and scientific experts to identify, define, and understand at a fundamental level the threats to public health, and the risks and benefits of ways to address them. The appropriate level of public involvement in the analytic-deliberative process depends on the particular public health problem.

Public accountability requires an openness to public deliberation and imposes an obligation on decision-makers to provide honest information and justifications for their decisions. No ethical principle can eliminate the fact that individual interests must sometimes yield to collective needs. Public accountability, however, ensures that such trade-offs will be made openly, with an explicit acknowledgement that individuals’ fundamental well-being and values are at stake and that reasons, grounded in ethics, will be provided to those affected by the decisions.<sup>18</sup> It provides a basis for public trust, even when policies infringe or appear to infringe some general moral considerations.

### **Public Health Interventions vs. Paternalistic Interventions**

An important empirical, conceptual, and normative issue in public health ethics is the relationship between protecting and promoting the health of individuals and protecting and promoting public

health. Although public health is directed to the health of populations, the indices of population health, of course, include an aggregation of the health of individuals. But suppose the primary reason for some restrictions on the liberties of individuals is to prevent harm to those whose actions are substantially voluntary and do not affect others adversely. The ethical question then is, when can paternalistic interventions (defined as interventions designed to protect or benefit individuals themselves against their express wishes) be ethically justified if they infringe general moral considerations such as respect for autonomy, including liberty of action?

Consider the chart in Figure 2: An individual’s actions may be substantially voluntary (competent, adequately informed, and free of controlling influences) or non-voluntary (incompetent, inadequately informed, or subject to controlling influences). In addition, those actions may be self-regarding (the adverse effects of the actions fall primarily on the individual himself or herself) or other-regarding (the adverse effects of the actions fall primarily on others).

Paternalism in a morally interesting and problematic sense arises in the first quadrant (marked by the number “1” in Figure 2)—where the individual’s actions are both voluntary and self-regarding. According to John Stuart Mill, whose *On Liberty* has inspired this chart, other-regarding conduct not only affects others adversely, but also affects them directly and without “their free, voluntary, and undeceived consent and participation.”<sup>19</sup> If others, in the maturity of their faculties, consent to an agent’s imposition of risk, then the agent’s actions are not other-regarding in Mill’s sense.

<i>Voluntariness of Individuals’ Actions</i>	<i>Adverse Effects of Individuals’ Actions</i>	
	Self-regarding	Other-regarding
	Voluntary	
Non-voluntary		

**Figure 2 Types of Individual Action**

Whether an agent's other-regarding conduct is voluntary or non-voluntary, the society may justifiably intervene in various ways, including the use of coercion, to reduce or prevent the imposition of serious risk on others. Societal intervention in non-voluntary self-regarding conduct is considered weak (or soft) paternalism, if it is paternalistic at all, and it is easily justified. By contrast, societal interference in voluntary self-regarding conduct would be strong (or hard) paternalism. Coercive intervention in the name of strong paternalism would be insulting and disrespectful to individuals because it would override their voluntary actions for their own benefit, even though their actions do not harm others. Such interventions are thus very difficult to justify in a liberal, pluralistic democracy.

Because of this difficulty, proponents of public health sometimes contend that the first quadrant is really a small class of cases because individuals' risky actions are, in most cases, other-regarding or non-voluntary, or both. Thus, they insist, even if we assume that strong or hard paternalism cannot be ethically justified, the real question is whether most public health interventions in personal life plans and risk budgets are paternalistic at all, at least in the morally problematic sense.

To a great extent, the question is where we draw the boundaries of the self and its actions; that is, whether various influences on agents so determine their actions that they are not voluntary, and whether the adverse effects of those actions extend beyond the agents themselves. Such boundary drawing involves empirical, conceptual, and normative questions that demand attention in public health ethics. On the one hand, it is not sufficient to show that social-cultural factors influence an individual's actions; it is necessary to show that those influences render that individual's actions substantially non-voluntary and warrant societal interventions to protect him or her. Controversies about the strong influence of food marketing on diet and weight (and, as a result, on the risk of disease and death) illustrate the debates about this condition.

On the other hand, it is not sufficient to show that an individual's actions have some adverse effects on others; it is necessary to show that those adverse effects on others are significant enough to

warrant overriding the individual's liberty. Controversies about whether the state should require motorcyclists to wear helmets illustrate the debates about this condition. These controversies also show how the inclusion of the financial costs to society and the emotional costs to, say, observers and rescue squads can appear to make virtually any intervention non-paternalistic. But even if these adverse financial and emotional effects on others are morally relevant as a matter of social utility, it would still be necessary to show that they are significant enough to justify the intervention.

Either kind of attempt to reduce the sphere of autonomous, self-regarding actions, in order to warrant interventions in the name of public health, or, more broadly, social utility, can sometimes be justified, but either attempt must be subjected to careful scrutiny. Sometimes both may represent rationalization and bad faith as public health agents seek to evade the stringent demands of the general moral consideration of respect for autonomy. Requiring consistency across an array of cases may provide a safeguard against rationalization and bad faith, particularly when motives for intervention may be mixed.

Much of this debate reflects different views about whether and when strong paternalistic interventions can be ethically justified. In view of the justificatory conditions identified earlier, relevant factors will include the nature of the intervention, the degree to which it infringes an individual's fundamental values, the magnitude of the risk to the individual apart from the intervention (either in terms of harm or lost benefit), and so forth. For example, even though the authors of this paper would disagree about some cases, we agree that strong paternalistic interventions that do not threaten individuals' core values and that will probably protect them against serious risks are more easily justifiable than strong paternalistic interventions that threaten individuals' core values and that will reduce only minor risks. Of course, evaluating actual and proposed policies that infringe general moral considerations becomes very complicated when both paternalistic and public health reasons exist for, and are intertwined in, those policies.

### Social Justice, Human Rights, and Health

We have noted potential and actual conflicts between promoting the good of public health and other general moral considerations. But it is important not to exaggerate these conflicts. Indeed, the societal institutionalization of other general moral considerations in legal rights and social-cultural practices generally contributes to public health. Social injustices expressed in poverty, racism, and sexism have long been implicated in conditions of poor health. In recent years, some evidence suggests that societies that embody more egalitarian conceptions of socioeconomic justice have higher levels of health than ones that do not.<sup>20</sup> Public health activity has traditionally encompassed much more than medicine and health care. Indeed, historically much of the focus of public health has been on the poor and on the impact of squalor and sanitation on health. The focus today on the social determinants of health is in keeping with this tradition. The data about social determinants are impressive even though not wholly uncontroversial. At any rate, they are strong enough to warrant close attention to the ways conditions of social justice contribute to the public's health.

Apart from social justice, some in public health argue that embodying several other general moral considerations, especially as articulated in human rights, is consistent with and may even contribute to public health. For example, Jonathan Mann contended that public health officials now have two fundamental responsibilities—protecting and promoting public health and protecting and promoting human rights. Sometimes public health programs burden human rights, but human rights violations “have adverse effects on physical, mental, and social well-being” and “promoting and protecting human rights is inextricably linked with promoting and protecting health.”<sup>21</sup> Mann noted, and we concur, that, ultimately, “ethics and human rights derive from a set of quite similar, if not identical, core values,” several of which we believe are captured in our loose set of general moral considerations.<sup>22</sup> Often, as we have suggested, the most effective ways to protect public health respect general moral considerations rather than violate them, employ voluntary measures rather

than coercive ones, protect privacy and confidentiality, and, more generally, express rather than impose community. Recognizing that promoting health and respecting other general moral considerations or human rights may be mutually supportive can enable us to create policies that avoid or at least reduce conflicts.

While more often than not public health and human rights—or general moral considerations not expressed in human rights—do not conflict and may even be synergistic, conflicts do sometimes arise and require resolution.<sup>23</sup> Sometimes, in particular cases, a society cannot simultaneously realize its commitments to public health and to certain other general moral considerations, such as liberty, privacy, and confidentiality. We have tried to provide elements of a framework for thinking through and resolving such conflicts. This process needs to be transparent in order to engender and sustain public trust.

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6. For some other approaches, see P. Nieburg, R. Gaare-Bernheim, and R. Bonnie, “Ethics and the Practice of Public Health,” in R. A. Goodman et al., eds., *Law in Public Health Practice* (New York: Oxford University Press, in press), and N. E. Kass, “An Ethics Framework for Public Health,” *American Journal of Public Health*, 91 (2001): 1776–82.
  7. We do not explore here the overlaps among public health ethics, medical ethics, research ethics, and public policy ethics, although some areas of overlap and difference will be evident throughout the discussion. Further work is needed to address some public health activities that fall within overlapping areas—for instance, surveillance, outbreak investigations, and community-based interventions may sometimes raise issues in the ethics of research involving human subjects.
  8. Recognizing universalizability by attending to past precedents and possible future precedents does not preclude a variety of experiments, for instance, to determine the best ways to protect the public’s health. Thus, it is not inappropriate for different states, in our federalist system, to try different approaches, as long as each of them is morally acceptable.
  9. This justificatory condition is probably the most controversial. Some of the authors of this paper believe that the language of “necessity” is too strong. Whatever language is used, the point is to avoid a purely utilitarian strategy that accepts only the first two conditions of effectiveness and proportionality and to ensure that the non-utilitarian general moral considerations set some *prima facie* limits and constraints and establish moral priorities, *ceteris paribus*.
  10. For another version of these justificatory conditions, see T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001): at 19–21. We observe that some of these justificatory conditions are quite similar to the justificatory conditions that must be met in U.S. constitutional law when there is strict scrutiny because, for instance, a fundamental liberty is at stake. In such cases, the government must demonstrate that it has a “compelling interest,” that its methods are strictly necessary to achieve its objectives, and that it has adopted the “least restrictive alternative.” See Gostin, *supra* note 4, at 80–81.
  11. Of course, this chart is oversimplified, particularly in identifying only voluntary and mandatory options. For a fuller discussion, see R. Faden, M. Powers, and N. Kass, “Warrants for Screening Programs: Public Health, Legal and Ethical Frameworks,” in R. Faden, G. Geller, and M. Powers, eds., *AIDS, Women and the Next Generation* (New York: Oxford University Press, 1991): 3–26.
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  13. See Faden, Geller, and Powers, *supra* note 11; Gostin, *supra* note 4, at 199–201.
  14. In rare cases, it may be ethically justifiable to limit the disclosure of some information for a period of time (for example, when there are serious concerns about national security; about the interpretation, certainty, or reliability of public health data; or about the potential negative effects of disclosing the information, such as with suicide clusters).
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  21. J. M. Mann, “Medicine and Public Health, Ethics and Human Rights,” *The Hastings Center Report*, 27 (May–June 1997): 6–13, at 11–12. Contrast Gostin, *supra* note 4, at 21. For a fuller analysis and assessment of Mann’s work, see L. O. Gostin, “Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann,” S. P. Marks, “Jonathan Mann’s Legacy to the 21st Century: The Human Rights Imperative for Public Health,” and L. O. Gostin, “A Vision of Health and Human Rights for the 21st Century: A Continuing Discussion with Stephen P. Marks,” *Journal of Law, Medicine, and Ethics*, 29, no. 2 (2001): 121–40.
  22. Mann, *supra* note 21, at 10. Mann thought that the language of ethics could guide individual behavior, while the language of human rights could best guide societal-level analysis and response. See Mann, *supra* note 21, at 8; Marks, *supra* note 21, at 131–38. We disagree with this separation and instead note the overlap of ethics and human rights, but we endorse the essence of Mann’s position on human rights.
  23. See Gostin, *supra* note 4, at 21.

## Human Rights Approach to Public Health Policy

D. TARANTOLA AND S. GRUSKIN

Tarantola and Gruskin, both scholars in public health issues, argue for a human rights approach in public health. They contend that we can produce just distributions of health and health care by ensuring that human rights in general are respected. Respecting human rights contributes to well-being and health, and these contributions to health depend on respect for human rights.

### Introduction

The origin and justification for human rights, whether anchored in natural law, positive law, or other theories and approaches laid out by various authors, as well as their cultural specificity and actual value as international legal commitments, remains subject to ongoing lively debate. Theoretical and rhetorical discourses continue to challenge and enrich current understanding of the relevance of human rights for policy and governance. Nonetheless, human rights have found their way into public health and play today an increasing role in the shaping of health policies, programs, and practice.

Health and human rights are not distinct but intertwined aspirations. Viewed as a universal aspiration, the notion of health as the attainment of physical, mental, and social well-being implies its dependency on and contribution to the realization of all human rights. From the same perspective, the enjoyment by everyone of the highest attainable standard of physical and mental health is in itself a recognized human right. From a global normative perspective, health and human rights are closely intertwined in many international treaties and declarations supported by mechanisms of monitoring and accountability (even as their effectiveness can be questioned) that draw from both fields.

With respect to health specifically, it is arguably viewed as an important prerequisite for and desirable outcome of human development and progress. Health is

... directly constitutive of the person's well-being and it enables a person to function as an agent—that is, to pursue the various goals and projects in life that she has reason to value. (Anand, 2004: 17–18)

Health is also the most extensively measured component of well-being; it benefits from dedicated services and is commonly seen as a *sine-qua-non* for the fulfillment of all other aspirations. It may also be . . . “a marker, a way of keeping score of how well the society is doing in delivering well-being” (Marmot, 2004: 37).

Health and human rights individually occupy privileged places in the public discourse, political debates, public policy, and the media, and both are at the top of human aspirations. There is hardly a proposed political agenda that does not refer to health in its own right, as well as justice, security, housing, education, and employment opportunities—all with relevance to health. These aspirations are often not framed as human rights but the fact that they are contained in human rights treaties and often translated into national constitutions and legislations provides legal support for efforts in these areas.

Incorporating human rights in public health policy therefore responds to the demands of people, policy makers, and political leaders for outcomes that meet public aspirations. It also creates opportunities for helping decipher how all human rights and other determinants of well-being and social progress interact. It allows progress toward these goals to be measured and shapes policy directions and agendas for action.

This article highlights the evolution that has brought human rights and health together in

mutually reinforcing ways. It draws from the experience gained in the global response to HIV/AIDS, summarizes key dimensions of public health and of human rights and suggests a manner in which these dimensions intersect that may be used as a framework for health policy analysis, development, and evaluation.

### **Human Rights as Governmental Obligations**

Human rights constitute a set of normative principles and standards which as a philosophical concept can be traced back to antiquity, with mounting interest among intellectuals and political leaders since the seventeenth century (Tomuschat, 2003). The atrocities perpetrated during World War II gave rise, in 1948, to the Universal Declaration of Human Rights (United Nations, 1948) and later to a series of treaties and conventions that extended the aspirational nature of the UDHR into instruments that would be binding on states under international human rights law. Among these are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR), both of which came into force in 1976.

Human rights are legal claims that persons have on governments simply on the basis of their being human. They are “what governments can do to you, cannot do to you and should do for you” (Gruskin, 2004). Even though people hold their human rights throughout their lives, they are nonetheless often constrained in their ability to fully realize them. Those who are most vulnerable to violations or neglect of their rights are also often those who lack sufficient power to claim the impact of the lack of enjoyment of their rights on their well-being, including their state of personal health. Human rights are intended to be inalienable (individuals cannot lose these rights any more than they can cease being human beings); they are indivisible (individuals cannot be denied a right because it is deemed less important or nonessential); they are interdependent (all human rights are part of a complementary framework, one right impacting on and being impacted by all others) (United Nations, 1993). They bring into focus the

relationship between the State—the first-line provider and protector of human rights—and individuals who hold their human rights simply for being human. In this regard, governments have three sets of obligations toward their people (Eide, 1995):

- They have the obligation to respect human rights, which requires governments to refrain from interfering directly or indirectly with the enjoyment of human rights. In practice, no health policy, practice, program, or legal measure should violate human rights. Policies should ensure the provision of health services to all population groups on the basis of equality and freedom from discrimination, paying particular attention to vulnerable and marginalized groups.
- They have the obligation to protect human rights, which requires governments to take measures that prevent non-state actors from interfering with human rights, and to provide legal means of redress that people know about and can access. This relates to such important non-state actors as private health-care providers, pharmaceutical companies, health insurance companies and, more generally, the health-related industry, but also national and multinational enterprises whose actions can impact significantly on lifestyle, labor, and the environment such as oil and other energy-producing companies, car manufacturers, agriculture, food industry, and labor-intensive garment factories.
- They have the obligation to fulfill human rights, which requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional, and other measures toward the full realization of human rights, including putting into place appropriate health and health-related policies that ensure human rights promotion and protection. In practice, governments should be supported in their efforts to develop and apply these measures and monitor their impact, with an immediate focus on vulnerable and marginalized groups.

Government responsibility for health exists in several ways. The right to the highest attainable standard of health appears in one form or another in most international and regional human rights documents, and equally importantly, nearly every article of every document can be understood to have clear implications for health.

### The Right to Health

The right to the highest attainable standard of health builds on, but is by no means limited to, Article 12 of the ICESCR (Table 1). Rights relating to autonomy, information, education, food and nutrition, association, equality, participation, and non-discrimination are integral and indivisible parts of the achievement of the highest attainable standard of health, just as the enjoyment of the right to health

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**Table I The right to highest attainable standard of health, Article 12 of the International Covenant on Economic, Social and Cultural Rights**

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1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health
  2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
    - a. The provision for the reduction of the still-birth rate and of infant mortality and for the healthy development of the child
    - b. The improvement of all aspects of environmental and industrial hygiene
    - c. The prevention, treatment, and control of epidemic, endemic, occupational and other diseases
    - d. The creation of conditions which would assure to all medical service and medical attention in the event of sickness
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From United Nations (1966a) *Article 2, International Covenant on Economic, Social and Cultural Rights*. United Nations General Assembly Resolution 2200A [XXI], 16/12/1966, entered into force 03/01/1976 in accordance with Art 17. New York: United Nations.

is inseparable from all other rights, whether they are categorized as civil and political, economic, social, or cultural.

This recognition is based on empirical observation and on a growing body of evidence that establishes the impact that lack of fulfillment of any and all of these rights has on people's health status: Education, nondiscrimination, food and nutrition epitomizing this relationship (Gruskin and Tarantola, 2001). Conversely, ill-health constrains the fulfillment of all rights as the capacity of individuals to claim and enjoy all their human rights depends on their physical, mental, and social well-being.

The right to health does not mean the right to be healthy as such, but the obligation on the part of the government to create the conditions necessary for individuals to achieve their optimal health status. In addition to the ICESCR, the right to health is further elaborated in CERD (Convention on the Elimination of all forms of Racial Discrimination, 1965); in CEDAW (Convention on the Elimination of all forms of Discrimination against Women, 1979); and CRC (Convention on the Rights of the Child art 24, 1989) and in a range of regional human rights documents.

In May 2000, the United Nations Committee on Economic, Social, and Cultural Rights adopted a General Comment further clarifying the substance of government obligations relating to the right to health (UN Committee on Economic, Social and Cultural Rights, 2000). In addition to clarifying governmental responsibility for policies, programs and practices impacting the underlying conditions necessary for health, it sets out requirements related to the delivery of health services including their availability, acceptability, accessibility, and quality. It lays out directions for the practical application of Article 12 and proposes a monitoring framework. Reflecting the mounting interest in determining international policy focused on the right to health, the UN Commission on Human Rights appointed in 2002 a Special Rapporteur whose mandate concerns the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The Special Rapporteur's role is to undertake country visits, transmit

communications to states on alleged violations of the right to health, and submit annual reports to the Commission and the UN General Assembly. Accordingly, through publication review and country visits, the Special Rapporteur has explored policies and programs related to such issues as maternal mortality, neglected medicines, and reproductive health as they connect to human rights (Hunt, 2007).

All international human rights treaties and conventions contain provisions relevant to health as defined in the preamble of the Constitution of the World Health Organization (WHO), repeated in many subsequent documents and currently adopted by the 191 WHO Member States: Health is a “state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.” The Constitution further stipulates that “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, political belief, economic or social condition.” The Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States (World Health Organization, 1946), and entered into force on 7 April 1948. Amendments adopted by the Twenty-sixth, Twenty-ninth, Thirty-ninth and Fifty-first World Health Assemblies (resolutions WHA26.37, WHA29.38, WHA39.6 and WHA51.23) came into force on 3 February 1977, 20 January 1984, 11 July 1994 and 15 September 2005, respectively, and are incorporated in the present text....

### **HIV and Genesis of the Integration of Human Rights into Health Practice**

Cognizant of the need to engage HIV-affected communities in the response to the fast-spreading epidemics in order to achieve their public health goals, human rights were understood as valuable by policy makers not for their moral or legal value but to open access to prevention and care for those who needed these services most, away from fear, discrimination and other forms of human rights violations, and as a way to ensure communities that needed to be reached did not go underground. The

deprivation of such entitlements as access to health and social services, employment, or housing imposed on people living with HIV was understood to constrain their capacity to become active subjects rather than the objects of HIV programs, and this was recognized as unsound from a public health perspective.

The evolution of thinking about HIV/AIDS moved from the initial recognition of negative effects of human rights violations among people living with HIV to principles that guided the formulation of a global strategy on HIV/AIDS and, beyond, to the application of these principles to other health issues. In the decade that followed the emergence of AIDS, tremendous efforts were made to induce behavior change through policies that supported intensified, targeted prevention efforts. Everywhere, the initial approaches to HIV had been focused on the reduction of risk of acquiring HIV infection through policies that supported the creation of protective barriers: The use of condoms, early diagnosis and treatment of sexually transmitted infections, and reduction in the number of sexual partners. Some of these efforts were successful on a small scale, in particular where communities were educated and cohesive, as was the case for communities of gay men on the East and West Coasts of the United States, Western Europe, and Australia. Less immediately successful were interventions in communities under immediate social or economic stress and those hampered in their ability to confront HIV/AIDS as a result of strong cultural and other barriers. In sub-Saharan African countries, for example, early interventions related to condoms and other prevention methods, even when supported by national-level policy, were confronted with denial and rejection. Gender-related discrimination was often at the core of resistance to change. Stigma and discrimination directed toward people living with HIV or people whose behaviors were associated with a risk of acquiring and transmitting infection (sex workers, injecting drug users, as well as people defined by their racial or ethnic characteristics) also created obstacles to reaching those who, even perhaps more than others, needed open access to prevention and care. For these reasons, the protection of human rights and combating

discrimination became important underlying principles of the first Global Strategy on HIV/AIDS formulated by WHO in 1987 (World Health Organization, 1987).

The risk-reduction strategies of the late 1980s confronted several obstacles in implementation. One was the practical difficulty of scaling up successful approaches to national or international levels. Another was the poor results achieved from applying models proven successful in some settings to different social and cultural environments: Clearly, one size did not fit all. Empirical evidence showed that even as the capacity of individuals to minimize or modulate their risk of exposure to HIV was closely related to specific behaviors or situations, these were in turn influenced by a variety of other factors. In 1992, a risk-vulnerability analysis and reduction model was put forward, positing that in order to successfully impact on risk-taking behaviors, it was necessary to recognize and act on factors that determined the likelihood of individuals engaging in such behaviors (Mann and Tarantola, 1992). A broader perspective suggesting the need for an expanded response to HIV began to emerge, bridging risk, as measured by the occurrence of HIV infection, to risk-taking behaviors, and to their vulnerability determinants. Vulnerability factors could be categorized for simpler analysis as individual (linked to personal history and status, agency, knowledge, or skills); societal (linked to social, economic, and cultural characteristics of the community within which people lived or had lived, including the policy and legal environment); and program-related (dependent on the capacity and approach of programs—health and social in particular) and the extent to which they responded appropriately to people's needs and expectations and assured their participation (Mann and Tarantola, 1996).

While the linkages between health outcomes and health determinants were already very present in the public health discourse, the mounting HIV epidemic made clear the need for policy to simultaneously address a wide and complex assembly of health outcome and determinants touching many facets of society. Simply listing these determinants born out of the established and empirical evidence

was overwhelming. There was a need to categorize these determinants in a logical fashion and in a way that would allow them to be taken up by different sectors engaged in human development. The human rights framework was very well suited to this purpose in that it allowed vulnerability factors to be categorized as civil, political, social, economic, or cultural, and each of these factors, recognized through research or empirical evidence, could be easily linked to one or more specific human rights. This expanded approach helped clarify the related responsibilities of different sectors, thereby expanding the scope of public policy change and possible interventions. Importantly, these interventions could build on commitments already expressed, and obligations subscribed to, by governments under international human rights law. From an initial focus on nondiscrimination toward people known or assumed to live with HIV/AIDS, human rights was now helping guide the analysis of the roots, manifestations, and impacts of the HIV epidemics. Stemming from an instrumental approach rather than moral or legal principles, the response to HIV had exposed the congruence between sound public health policy and the upholding of human rights norms and standards (Mann et al., 1994).

The analytical and action-oriented risk and vulnerability framework that linked HIV to the neglect or violations of human rights and the call for needed structural and societal changes grounded in solid policy were important features of the 1994 Paris Summit Declaration on HIV/AIDS (UNAIDS, 1999) and later served as one of the founding principles of the 1996 UNAIDS global strategy and its subsequent revisions (UNAIDS, 1996). These ideas are also apparent in the Declaration of Commitment which emerged from the 2001 United Nations General Assembly.

International activism and a series of international political conferences that took place in this period facilitated similar changes in the approach taken to a wide range of diseases and health conditions, in particular with respect to reproductive and sexual health issues (Freedman, 1997). The 1994 Cairo International Conference on Population and Development was a watershed in recognizing the responsibility of governments worldwide to

translate their international-level commitments into national laws, policies, programs, and practices that promote and do not hinder sexual and reproductive health among their populations. National laws and policies were thus open to scrutiny to determine both the positive and negative influences they could have on sexual and reproductive health programming, information, services, and choices. Human rights concerns, including legal, policy, and practice barriers that impact on the delivery and use of sexual and reproductive health services thereafter became a valid target for international attention.

### **Human Rights and Health Policy in the New Millennium: Key Concepts**

As, from a theoretical perspective, the interaction between health and human rights was drawing increased attention from policy makers in an expanding array of health-related domains, two issues were and continue to be cited as creating obstacles to the translation of theory into practice. The first is that the realization of the right to health cannot be made real in view of the structures, services, and resources it requires. The second, often cited by those concerned with communicable disease control, is that the protection of human rights should not be the prime concern of policy makers when and where such public health threats as emerging epidemics call for the restriction of certain individual rights. As these two obstacles are often used and misused to question the validity of the health and human rights framework, they are discussed briefly below.

#### **Progressive Realization of Health-Related Human Rights**

In all countries, resource and other constraints can make it impossible for a government to fulfill all rights immediately and completely. The principle of progressive realization is fundamental to the achievement of human rights as they apply to health (United Nations, 1966a), and applies equally to resource-poor countries as to wealthier countries whose responsibilities extend not only to what they do within their own borders, but also their engagement in international assistance and cooperation (United Nations, 1966b).

Given that progress in health necessitates infrastructure and human and financial resources that may not match existing or future needs in any country, the principle of progressive realization takes into account the inability of governments to meet their obligations overnight. Yet, it creates an obligation on governments to set their own benchmarks, within the maximum of the resources available to them, and to show how and to what extent, through their policies and practices, they are achieving progress toward the health goals they have agreed to in international forums such as the World Health Assembly, as well as those they have set for themselves. In theory, States account for progress in health (or lack thereof) through a variety of mechanisms that include global monitoring mechanisms, as well as national State of the Health of the Nation reports or similar forms of domestic public reporting.

#### **Human Rights Limitations in the Interest of Public Health**

There remains a deeply rooted concern of many in the health community that application of a health and human rights approach to health policy will deprive the State from applying such measures as isolation or quarantine or travel restrictions when public health is at stake. Public health and care practitioners alike, acting on behalf of the State, are used to applying restrictions to individual freedom in cases where the enjoyment of these rights creates a real or perceived threat to the population at large. Recently, the SARS and Avian flu epidemics have demonstrated that such restrictions can also be applied globally under the revised International Health Regulations (IHR), the only binding agreement thus far under the auspices of WHO (World Health Organization, 2005). They stipulate that WHO can make recommendations on an ad hoc, time-limited, risk-specific basis, as a result of a public health emergency of international concern, and that implementation of these Regulations "shall be with full respect for the dignity, human rights and fundamental freedoms of persons." The human rights framework recognizes that these are situations where there can be legitimate and valid restriction of rights, and this under several

circumstances relevant to the creation of health policies: Public emergencies and public health imperatives. Public emergencies stipulate that in time of a public emergency that threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, color, sex, language, religion, or social origin (Art 49, ICCPR). Public health imperatives give governments the right to take the steps they deem necessary for the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases (Art 16, ICCPR).

Public health may therefore justify the limitation of certain rights under certain circumstances. Policies that interfere with freedom of movement when instituting quarantine or isolation for a serious communicable disease—for example, Ebola fever, syphilis, typhoid, or untreated tuberculosis, more recently SARS and pandemic influenza—are examples of limitation of rights that may be necessary for the public good and therefore may be considered legitimate under international human rights law. Yet arbitrary restrictive measures taken or planned by public health authorities that fail to consider other valid alternatives may be found to be both abusive of human rights principles and in contradiction with public health best practice. The limitation of most rights in the interest of public health remains an option under both international human rights law and public health laws, but the decision to impose such limitations must be achieved through a structured and accountable process. Increasingly, such consultative processes are put in place by national authorities to debate over the approach taken to public health issues as they arise, such as in the case of immunization, disability, mental health, HIV, smoking, and more recently pandemic influenza preparedness.

Limitations on rights are considered a serious issue under international human rights law—as noted in specific provisions within international

human treaties—regardless of the apparent importance of the public good involved. When a government limits the exercise or enjoyment of a right, this action must be taken only as a last resort and will only be considered legitimate if the following criteria are met:

1. The restriction is provided for and carried out in accordance with the law.
2. The restriction is in the interest of a legitimate objective of general interest.
3. The restriction is strictly necessary in a democratic society to achieve the objective.
4. There are no less intrusive and restrictive means available to reach the same goal.
5. The restriction is not imposed arbitrarily, i.e., in an unreasonable or otherwise discriminatory manner (United Nations, 1984).

The restriction of rights, if legitimate, is therefore consistent with human rights principles. Both principles of progressive realization and legitimate limitations of rights are directly relevant to public health policy as they can inform decisions on how to achieve the optimal balance between protecting the rights of the individual and the best interest of the community. Examples of the impact of human rights violations and protection on public health are set out below. Discrimination—a frequent, severe, and persistent issue confronted both in society and in the health-care setting—has been chosen to illustrate how public health can be hampered by the neglect of human rights and enhanced by their incorporation in public health policy.

### **Public Health Policy and Nondiscrimination**

Discrimination can impact directly on the ways that morbidity, mortality, and disability—the burden of disease—are both measured and acted upon. In fact, the burden of disease itself discriminates: Disease, disability, and death are not distributed randomly or equally within populations, nor are their devastating effects within communities. Tuberculosis, for example, is exploding in disenfranchised communities, in particular among prison inmates and people already affected by HIV and subjected to dual discrimination both in their communities and in the health-care setting.

Far from uncommon, discrimination in health systems, including health centers, hospitals, or mental institutions, may further contribute to exacerbating disparities in health. A few examples of myriads that could be cited are named here. Undocumented migrant workers receive poor or no treatment for fear of having to justify their civil status. Documented migrant workers, refugees, and asylum seekers and their families may not avail themselves of services that have not been designed to suit their culture and respond to their specific needs. People with hemophilia have been given unsafe blood products on the premise that this adds only a marginal risk to their lives. People with physical or mental disabilities receive substandard care; they are unable to complain or if they do, they fare poorly in legal action (Moss et al., 2007). Discrimination in health systems concerns not only diseases that are already stigmatized, such as AIDS, hepatitis B and C, tuberculosis, and cancer, but also others, such as diabetes and cardiovascular diseases, which could be alleviated if equal treatment within societies and within health-care settings became the norm. A health and human rights approach to policy development concerning health systems requires that state authorities refrain from enacting discriminatory policies and provide information, education, training, and support to their staff toward eliminating discrimination in public health practice and within the workforce.

Discrimination can also be at the root of unsound human development policies and programs that may impact directly or indirectly on health. For example, an infrastructure development project may require the displacement of entire populations and fail to pay sufficient attention to the new environment to which these populations will have to adjust. In the developing world, when the health impact of large-scale development programs at the local level is considered, it is often from the perspective of the possible further spread of such infectious diseases as malaria and other waterborne diseases. The psychological capacity of displaced communities to relocate and rebuild new lives or the long-term physical and social consequences of such displacement are seldom factored into the equation.

The ongoing international movement toward poverty alleviation has emphasized the critical importance of health in the fight against poverty. The eight Millennium Development Goals (MDGs)—which set targets for 2015 to halve extreme poverty, halt the spread of HIV/AIDS, and improve health and education—have been agreed to by all the world's countries and all the world's leading development institutions (United Nations, 2005). Arguably, all MDGs have a linkage to health either by their direct bearing on health outcomes and the needed services (e.g., through efforts to reduce child and maternal mortality, HIV, malaria, and other diseases) or by underscoring principles central to public health policy (e.g., gender equality) or else by calling for the creation of policies addressing the underlying conditions for progress in health (e.g., education, environmental sustainability, and global partnerships).

### **Public Health Policy and the Value of Health and Human Rights**

Human rights and public health policy intersect in a number of ways, which, for practical purposes, can be regrouped into three broad categories: The national and international context within which policy is developed; the outcome of public policy; and the process through which it is developed, applied, and monitored.

#### **Context**

A distinction exists between public policy affecting health (most of them do) and public health policy (often emerging from public health governmental authorities or on their initiative). Policies affecting health—for example, those related to gender, trade, intellectual property, the environment, migration, education, housing, or labor—are contingent upon national laws and international treaties or agreements which often overlook—by omission or commission—their potential health consequences. As the Health Impact Assessment of development and social policies gained credence in the 1990s, the development of a human rights assessment for the formulation and evaluation of public health policies emerged (Gostin and Mann, 1999). Health Impact Assessment (HIA), applying different methods, has

become more frequently practiced to guide policy options both nationally and internationally. While the aim of such exercises is to forecast the health impact of a single or alternative policies or programs (including those related to infrastructure, financing, service delivery, transportation, or production and many others), the impact of such policies and programs on both health and human rights remains to be adequately tested. Much work is currently ongoing toward the development of a Health and Human Rights Impact Assessment for which assessment methods and health and human rights indicators are required.

An example where such an impact assessment might have been useful was when a number of countries—industrialized and developing alike—applied for membership of the World Trade Organization when such a membership implied for the signatory country to become party to the Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS). The constraints imposed by TRIPS on developing countries with regards to intellectual protection of pharmaceuticals in particular only became evident in the late 1990s as new, proven therapies for HIV-AIDS were reaching the international market. Civil society movements and some international organizations embarked on an active campaign to overcome the constraints set by TRIPS to the production or importation of generic medicines by developing countries needing them most. It was not until 2002, however, that WHO and WTO jointly produced a document on WTO agreements and public health (World Health Organization and World Trade Organization, 2002). In most developing countries, Ministries of Health had not been consulted, been equipped to assess, or had underestimated, the possible health impacts of the new trade and intellectual property agreement they were signing on to as new members of the WTO. This was and continues to be a painful reminder of the oversight or deliberate neglect of the possible health consequences of public policy guided by other agendas, international trade in this case.

Public health policy should seek the optimal synergy between health and human rights, building on the premise that the optimal quality of a public health

policy is attained when the highest possible health outcome and the fullest realization of human rights are both attained. This requires a close interaction between public health professionals, human rights practitioners and representatives of affected communities. The response to HIV has been shaped by such an interaction with significant positive impact—at least in the short term—in such countries as Australia, Sweden, Thailand, Brazil, or Uganda. Where misconceptions about either sound public health or human rights have distorted HIV policies and programs, the epidemic has continued to strive, as illustrated by the situation in South Africa or China.

As it is generally formulated and monitored by the State, public health policy should operate in the context of the obligations the State has subscribed to under international human rights treaties and national law. Central to these obligations are those to respect, protect, and fulfill all human rights, including the rights to participate in public affairs and policy making, equality, nondiscrimination, and dignity.

### **Outcome and Impact**

Both public health policy and human rights emphasize the importance of outcome and impact, crudely measured in public health terms by the reduction of mortality, morbidity and disability, and the improvement of quality of life, along with economic measurement enabling an assessment of the value for money of particular policies or programs that can guide priority setting. The extent to which outcome includes the fulfillment of human rights is seldom factored in. For example, one would like to see the value of policies that promote sex education in school measured not only in terms of reduction of teenage pregnancy or the incidence of sexually transmitted diseases, but how the right of the child to information is fulfilled in this way and how it impacts on further demands for other health-related, life-saving information. Likewise, when assessing the outcome and impact of policies that prioritize childhood immunization programs, one would want to know not only how immunization makes people healthier, both early and later in their childhood, but also how such public health policies will advance the right of the child to growth and

development and her right to education by improving her attendance to and performance at school.

Measuring the outcome and impact of health and health-related policies from a combined health and human rights perspective implies measurement indicators that are neither fully developed nor tested. One of the constraints is that measuring health and human rights on the national, aggregate level is not sensitive to disparities that may exist within the nation, for example, as a result of discrimination.

### **Process**

The human rights to information, assembly, and participation in public affairs—including policy making—imply, among other practical steps, the engagement of communities in decisions affecting their health. As highlighted earlier, the history of health and human rights has amply established that community representation in decision-making bodies increases the quality and impact of public health measures. An important issue is to determine who can legitimately speak on behalf of concerned communities. In the last two decades, stimulated by the response to HIV in particular, nongovernmental organizations, and more broadly civil society, have played key roles in drawing attention to policies that were or could be detrimental to health (e.g., restrictions in access to medicines, denial of sex education of young people, access to harm reduction methods among substance users, promotion of tobacco products in young people, marginalized communities and low-income countries, environmental degradation, marketing of unhealthy foods). While state machineries are increasingly cognizant of the growing need for transparency in policy development, civil society is likely to sustain its contribution to such a process, and this through active monitoring by national-level NGOs and such international groups as Amnesty International, Human Rights Watch, or Physicians for Social Responsibility.

### **In Conclusion**

This article has attempted to lay out the principles underlying the application of health and human rights principles to public health policy, and it has

done so by recalling the historical emergence of these concepts and the opportunities they provide for new approaches to policy development.

Health and human rights, together and independently from each other, have achieved today a degree of prominence in the political and public discourse never witnessed before. The fields of health and rights are illuminated today by their commonalities, no longer by their differences. Both are obligations of governments toward their people; and each supports and requires the fulfillment of the other.

Overall, health and human rights provide a framework for all aspects of policy and program development. In practice, human rights considerations are often built into public health policy through the application of what are today called rights-based approaches. The practical application of these principles is a subject of active and rich debates. Rights-based approaches to health are but some of the attempts currently being made to offer practical guidance to health policy makers and other stakeholders in health and human rights toward translating these principles into health policies, programs, and interventions. Through further reflection, practice and research, public health and human rights practitioners can further establish how and to what extent the promotion and protection of health and human rights interact. In the search for a world where the attainment of the highest standard of physical, mental, and social well-being necessitates, and reinforces, the dignity, autonomy, and progress of every human being, the broad goals of health and human rights are universal and eternal. They give us direction for our understanding of humanity and practical tools for use in our daily work.

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## Pandemic Ethics

The COVID-19 pandemic has been both a worldwide human tragedy and a moral catastrophe. As of this writing, globally it has infected over 166 million people and killed more than 3.4 million. In the United States there have been over 32 million cases and nearly 600,000 deaths with many more likely before the virus is subdued. The moral upheaval comes from the life-and-death decisions that this plague has forced upon us, decisions that have arisen on several levels at once and that have often left us at a loss to deal with them. This pandemic, like all pandemics, has demanded technical and empirical answers from medicine, science, government, and public health officials—and their responses are weighted with moral implications at every turn. The pandemic has also forced us to decide what we as individuals should do about it—and our choices are moral as well as practical. The tough questions keep coming:

- When the pandemic is raging and essential resources like ventilators, ICU beds, and vaccines are scarce, how should we allocate these? What rules of **triage**—the sorting and allocation of treatments to patients in an emergency to maximize the number of survivors in medical emergencies—should apply? Which patients get ventilators? Who gets to stay in ICU beds? What does justice require? In the most dire cases, these questions have often boiled down to who should live and who should die.
- Health care workers are at risk when they treat infected patients, and their families can also be at risk. Many facilities have been understaffed, and caregivers have had to work without personal protective equipment (PPE). Thousands of them have already died. What then are their moral obligations to their patients? And what are our obligations to them? What should we do to help promote their safety and health, both mental and physical? What support do they deserve for their service to society?
- Racial and ethnic minorities generally experience lower health status than others, and they have therefore been at a much higher risk of being infected with and dying from COVID-19. Risk of hospitalization, for example, is almost three times higher for African Americans than for white, non-Hispanic persons; risk of death is almost twice as high.<sup>1</sup> Research shows that these health inequities are due mostly to systemic social inequalities—that is, to persistent disadvantages in access to good health care, insurance, housing, education, income, employment, and working conditions. Society has a standing obligation to try to remedy these inequalities, but what specifically in this pandemic should be done to overcome inequalities in treatment and prevention? What does justice demand? (This issue is discussed in depth in the next chapter.)
- In the pandemic, each of us has had to decide whether to wear a mask, practice social distancing, and get vaccinated, and these decisions have affected not only ourselves but others. For example, many people have refused to wear masks, even though the practice has been proven to greatly reduce their chances of transmitting

the virus to others and can provide them with some protection as well. Many who refused masks claimed a right of personal freedom, or autonomy. But this principle can conflict with the principle of justice, which refers to people getting what is fair or what is their due. Some have argued that in a seriously threatening pandemic, because those who refuse to wear masks are putting others at risk, they are treating people unfairly. Another relevant principle is respect for persons. By going without a mask when it's necessary, we expose others to the risk of contracting a deadly disease—an act that can be characterized as a most grievous form of disrespect. What are we morally obligated to do? What moral principle or theory should guide us? What do we owe each other?

- Misinformation about COVID-19 (or any other pandemic) can have tragic consequences. We therefore have a moral duty to speak responsibly about it, especially online where lies, falsehoods, and propaganda can zip around the world in seconds and be believed by millions. Posts on social media hype fake or unsafe treatments, claim the pandemic is a hoax, and allege that vaccines can kill you. We can assign the most moral blame to the deliberate deceivers, but how much blame should fall on true believers, those who unknowingly spread dangerous nonsense? How culpable are those who don't care whether what they say is true or false—and someone then ends up in an ICU bed as a result?
- Is it morally permissible to cut corners in the scientific quest for coronavirus cures or vaccines? The health care ethicist Meredith Celene Schwartz reminds us that “providing patients with drugs that have not been fully tested is a dangerous practice. We conduct research precisely when we do not know whether a drug,

vaccine, or treatment will be safe and effective in humans, and there are countless examples of trials in which initially promising treatments turned out to be dangerous.” Speeding up research can be risky, but delays in the development or use of effective treatments can also cost lives. What is the morally right balance?

- In attempts to limit the spread of infection, public health officials have used contact tracing—the practice of trying to identify all the individuals who have been in close contact with an infected person. Tracking apps using GPS and Bluetooth make it possible to pinpoint someone's location and identify contacts. Many countries have employed them to decrease infection rates—and simultaneously raised serious concerns about privacy and government intrusion. We are already part of the surveillance economy, in which vast quantities of personal data are being extracted from our mobile phones. Is contact tracing any worse? We all have a right to privacy, and we all would like to be secure from serious illness. But can we have both? Does our right to privacy preclude contact tracing; if contact tracing is necessary to fight a pandemic, must we relinquish privacy? Is there a morally acceptable compromise?

## PANDEMIC FACTS

When a disease occurs in larger numbers than expected in a particular population and geographic area, we call it an **epidemic**. When an epidemic goes worldwide, we call it a **pandemic**. Both phenomena cause widespread illness (morbidity) and death (mortality), and scientists use these terms to indicate the impact of the disease. Epidemiologists (scientists who study disease in populations) describe the seriousness of epidemics and pandemics with *rates*—typically expressed as a measure of the frequency with

which a disease occurs in a specified population and time period. For example, in the United States, the rate of COVID-19 occurrence was 9,361 people per population of 100,000, among the highest rates in the world.<sup>3</sup>

Scientific facts alone cannot tell us what our moral obligations are when we are threatened by a pandemic, but our moral judgments must take the facts into account. To ignore the scientific evidence, to misunderstand it, or to fall for misinformation or half-truths is to risk bad moral choices and unsafe decisions.

Coronaviruses are viruses that cause respiratory illness in humans, illnesses such as SARS (severe acute respiratory syndrome), MERS (Middle East respiratory syndrome), and the common cold. COVID-19 is a disease caused by a coronavirus that hasn't been seen in humans before, known as SARS-CoV-2. It causes mild symptoms in most people but severe illness and death in others. It provokes more serious illness than the flu and spreads faster. In many cases, serious health problems caused by the virus can linger for months. Those most likely to have dire symptoms are older people and people with existing medical conditions like cancer, chronic kidney disease, diabetes, and sickle cell disease, but young people have been hit hard, too.<sup>4</sup>

The virus is transmitted very easily from one person to another, mainly through respiratory droplets produced by people with COVID-19 when they cough, sneeze, talk, sing, or breathe. The infected person need not be showing any symptoms to spread the virus. Anyone can get COVID-19, and anyone can spread it.

One person can spread the virus to another just by talking or laughing while standing within six feet of them. This unsettling fact—and several others—led the CDC (the Centers for Disease Control and Prevention) to issue guidelines for slowing the spread of the virus: wear a mask, stay six feet from others who don't live with you, and avoid crowds.

Vaccines are available that have been proven safe and highly effective in preventing COVID-19.

Their benefits, however, go beyond prevention of infection. The CDC says:

- Based on what we know about vaccines for other diseases and early data from clinical trials, experts believe that getting a COVID-19 vaccine may also help keep you from getting seriously ill even if you do get COVID-19.
- Getting vaccinated yourself may also protect people around you, particularly people at increased risk for severe illness from COVID-19....
- COVID-19 can have serious, life-threatening complications, and there is no way to know how COVID-19 will affect you. And if you get sick, you could spread the disease to friends, family, and others around you....
- Wearing masks and social distancing help reduce your chance of being exposed to the virus or spreading it to others, but these measures are not enough. Vaccines will work with your immune system so it will be ready to fight the virus if you are exposed.<sup>5</sup>

## WHEN RESOURCES ARE SCARCE

Many moral questions about COVID-19 appear when health care workers try to decide how to allocate scarce medical resources—ventilators, ICU hospital beds, medical personnel, masks, PPE, medications, and vaccines. The decisions that must be made involve balancing principles such as justice, equity, autonomy, respect for persons, and utility. And they are far from academic, for lives weigh in the balance, and often every choice, whether right or wrong, brings anguish, dread, uncertainty, or grief.

Imagine a hospital that is overwhelmed by seriously ill COVID-19 patients (a scenario that has played out countless times in reality). Without proper treatment, many of them will die. Ventilators (life-saving machines that act as

bellows to move air in and out of the lungs), ICU beds, and PPE are in short supply. The hospital is understaffed, and the workers are stressed, many of them near exhaustion. Some of the patients are young adults, some are over 70, some were healthy before getting the virus, some have underlying medical conditions, some can afford any level of care, and many are poor. In situations like this when resources are extremely limited, and any allocation decision is likely to result in lives saved as well as lost, how do you decide how those resources should be used? What moral considerations apply?

Ethicists agree that some approaches should *not* be used. A person's wealth should not figure into decisions about who lives or dies. Wealthy, famous, or politically powerful people should not get priority over first responders and medical staff. When deciding who gets treatment, a first-come, first-served rule should not be followed. Such a procedure would give unfair preference to patients living closer to the hospital, and it would unjustly exclude patients who become ill later because they were conscientious (because they wore masks, maintained social distancing, and adhered to other safety guidelines). And society's perception of a person's moral worth should not be a factor.

A common difficulty in making the tough moral choices is that even when we know what moral principles are relevant to a decision, they may conflict. We can see this opposition, say ethicists, in appeals to the principles of utility and equity:

"Utility" would be understood as trying to maximise the number of lives saved, while "equity" refers to the idea that every patient should get an equal chance of receiving the life-saving care that they require. However, there is an important tension between honouring these two values: in order to maximise utility one would be led to discriminate against those who have, for instance, pre-existing medical conditions, or those who are simply of old age, in virtue of the fact that these people have

lower chances of recovery. Meanwhile, considerations of equity would condemn such discrimination and, instead, require that everyone, regardless of demographic features or pre-existing conditions, is given equal consideration.<sup>6</sup>

Some believe that many triage protocols lean far too heavily on utility at the expense of equity, resulting in bias in favor of people who are privileged and against those who are not. The bioethicist Angela Ballantyne takes this view:

Of course those justifying prioritization of utility don't endorse discrimination. But in reality, an ethical approach aimed at maximizing lives saved results in prioritizing certain social groups. The easy lives to save will be those of people who already enjoy social privilege. As a population, younger, white, wealthy people will be more likely to derive benefit from the ICU resources and survive because they enjoy, on average, higher baseline health status. . . .

Where there is uncertainty, we should err on the side of broader rather than stricter clinical criteria; meaning a wider range of patients get a shot at ICU, even where this is likely to be less efficient overall. Screening measures that include Quality Adjusted Life Years (QALYs) must be avoided as these are inherently biased against persons with disabilities.<sup>7</sup>

There is substantial agreement among ethicists about the relevant principles to be applied in medical allocations, even if opinions sometimes diverge on how to weight the values. And experts have tried to provide some guidance in how to adapt the principles to challenging circumstances. Ezekiel J. Emanuel and his colleagues, for example, have identified four fundamental values that should govern decisions: maximizing the benefits produced by scarce resources, treating people equally, promoting and rewarding instrumental value, and giving priority to the worst off. These four principles, they say, yield six specific recommendations:

**Recommendation 1:** In the context of a pandemic, the value of maximizing benefits is most

important. This value reflects the importance of responsible stewardship of resources: it is difficult to justify asking health care workers and the public to take risks and make sacrifices if the promise that their efforts will save and lengthen lives is illusory. Priority for limited resources should aim both at saving the most lives and at maximizing improvements in individuals' post-treatment length of life. Saving more lives and more years of life is a consensus value across expert reports. . . .

Operationalizing the value of maximizing benefits means that people who are sick but could recover if treated are given priority over those who are unlikely to recover even if treated and those who are likely to recover without treatment. Because young, severely ill patients will often comprise many of those who are sick but could recover with treatment, this operationalization also has the effect of giving priority to those who are worst off in the sense of being at risk of dying young and not having a full life.

Because maximizing benefits is paramount in a pandemic, we believe that removing a patient from a ventilator or an ICU bed to provide it to others in need is also justifiable and that patients should be made aware of this possibility at admission. . . .

**Recommendation 2:** Critical Covid-19 interventions—testing, PPE, ICU beds, ventilators, therapeutics, and vaccines—should go first to front-line health care workers and others who care for ill patients and who keep critical infrastructure operating, particularly workers who face a high risk of infection and whose training makes them difficult to replace. These workers should be given priority not because they are somehow more worthy, but because of their instrumental value: they are essential to pandemic response. . . .

**Recommendation 3:** For patients with similar prognoses, equality should be invoked and operationalized through random allocation, such as a lottery, rather than a first-come, first-served allocation process. . . .

**Recommendation 4:** Prioritization guidelines should differ by intervention and should respond

to changing scientific evidence. For instance, younger patients should not be prioritized for Covid-19 vaccines, which prevent disease rather than cure it, or for experimental post- or pre-exposure prophylaxis. Covid-19 outcomes have been significantly worse in older persons and those with chronic conditions. Invoking the value of maximizing saving lives justifies giving older persons priority for vaccines immediately after health care workers and first responders. . . .

**Recommendation 5:** People who participate in research to prove the safety and effectiveness of vaccines and therapeutics should receive some priority for Covid-19 interventions. Their assumption of risk during their participation in research helps future patients, and they should be rewarded for that contribution. . . .

**Recommendation 6:** There should be no difference in allocating scarce resources between patients with Covid-19 and those with other medical conditions. If the Covid-19 pandemic leads to absolute scarcity, that scarcity will affect all patients, including those with heart failure, cancer, and other serious and life-threatening conditions requiring prompt medical attention.<sup>8</sup>

Some ethicists worry that in allocating pandemic resources, even reasonable, carefully articulated moral guidelines can be undone by the unreasonable assumptions behind them. A case in point is triage involving people with disabilities, where dubious assumptions about their health status, their quality of life, and their “social utility” can engender prejudice against them and endanger their lives. Bioethicist Jackie Leach Scully explains how this can happen:

A key factor is a person’s *background health status*, because some underlying conditions are already known to significantly decrease the chance of recovery from the severe form of COVID-19—including hypertension, cardiovascular disease, chronic obstructive pulmonary disease, and cancer. But disability by itself, however, often has no impact on health. People with visual and hearing impairments for example, or

intellectual disability, can be just as healthy and therefore as likely to recover with treatment as anyone else. In other words, disability shouldn't automatically be used as a proxy for compromised health. . . .

The second set of assumptions concern predicted longer-term *quality of life*. . . . [U]sing predicted quality of life to make allocation decisions in a broadly *disablist* society generates a profound bias against people with disabilities. We know from abundant empirical evidence that people without disabilities tend to take it as a given that disability inescapably leads to life being worse, while disabled people on the whole rate their own quality of life as at least as good as anyone else's. . . . Triage guidance that, even implicitly, draws on assumptions about the quality of the saved life is in danger of codifying an unarticulated belief that "they can't actually enjoy life like that." . . .

Major ethical tensions arise when decision makers start to reach beyond the likelihood of benefit to the individual and towards some idea of "*social utility*," in other words how valuable that person, if saved, will be to society. Triaging by social utility is the shift that should probably concern us the most: it's also the one most likely to be resisted by patients and families, and to cause moral distress in healthcare professionals. . . . In situations of massive social collapse, there will be arguments for prioritizing people who can offer [vital social services]. . . . But the SARS-CoV-2 pandemic is *not* social collapse; and there is no ethical justification for making critical care decisions on the basis of factors like profession, or personal circumstances, or assumptions about the productivity or value to society of a disabled person.<sup>9</sup>

## PERSONAL CHOICES

Governments and public health officials throughout the world have responded to the COVID-19 pandemic by requiring or urging people to practice social distancing, wear face masks, and get vaccinated—or, in riskier

circumstances, to go into quarantine or self-isolate. (In **quarantine**, people who have been exposed are separated from others; in **self-isolation**, people who are sick or have symptoms are asked to stay home and go out only in an emergency.) The science behind these practices is not in dispute; each one is backed by solid evidence showing that they are among the most effective strategies we have for stopping the virus.<sup>10</sup> But although millions of people have embraced these measures, millions of others—including large numbers of Americans—have been unwilling to adopt them. Why?

There are both moral and nonmoral reasons. Some who have resisted mask-wearing or vaccines are simply misinformed: they believe that COVID-19 presents little or no risk, that COVID-19 vaccines are dangerous, that anti-vaxxer conspiracy theories are true, that wearing a mask will make them sick, that a home remedy can cure the disease, and so on.

Some people have hesitated or refused to be vaccinated for prudential reasons. Surprisingly, many health care workers are in this group. Consider this report from February 2021:

As vaccines began to roll out weeks ago, some hospitals around the country reported that 40 percent or more of their health care workers who could have gotten a Covid-19 vaccine by January had not immediately signed up for it. . . .

A December survey by the Kaiser Family Foundation found health care workers overall were about as likely to be hesitant about getting the vaccine as the general population (29 percent and 27 percent, respectively), with these respondents saying they would probably not or definitely not get the vaccine.

And even those who say they plan to get the vaccine might not actually do so right away. . . .

The experts we spoke with noted that most of the health care workers who are reluctant to get the Covid-19 vaccine immediately are not necessarily refusing it indefinitely. Many nurses . . . "are in a wait-and-see mode: 'I wouldn't mind if a few more million people got it before I did.'"

Despite robust safety and efficacy data, they want to see more real-world proof first.<sup>11</sup>

Many people hesitate to follow the guidance of health officials and medical professionals because they have a deep-down mistrust of intellectuals and experts, especially scientists—a mistrust that has been heightened by political polarization.

People of color have their own reasons for mistrust, as explained by the National Academy of Medicine in an op-ed published in the *New York Times*:

Our country is facing a public health crisis on a level not experienced for more than 100 years. It should be reasonable to expect that all citizens can rely on their government and health institutions to protect them. But for many Black Americans, trust in the government does not come easily.

Far too often, our health has been ignored and even abused in the name of science. It is no surprise that polls indicate Black Americans are far less likely than other groups to intend to get vaccinated against Covid-19.

We are among 60 Black members of the National Academy of Medicine, the premier health science organization in the United States. Together we are scientists, doctors, nurses, other health care professionals and public health experts. We feel compelled to make the case that all Black Americans should get vaccinated to protect themselves from a pandemic that has disproportionately killed them at a rate 1.5 times as high as white Americans in cases in which race is known—a rate that is most likely very conservative.<sup>12</sup>

A large proportion of people have flouted public health restrictions simply because they don't like being told what to do, not by the government or by anyone else. According to the bioethicist Barron H. Lerner:

One of the most surprising aspects of the Covid-19 pandemic for those of us who teach the history of public health is how unwilling many Americans have been to adopt health measures to protect others. Over the Thanksgiving holiday, tens of

millions of Americans traveled, despite the fact that the Centers for Disease Control and Prevention urged them to stay home and the overall death rate from the coronavirus is approaching 300,000 . . .

Despite the dangers presented by serious infectious diseases, many people—regardless of their social class—don't like restrictions, whether for their own good or the good of others. Two other facts support this conclusion. First, the U.S. has always had a strong tradition of individualism and libertarianism. And second, nonadherence to medical recommendations is extremely common, regardless of patients' health insurance or medical literacy.<sup>13</sup>

For many, resistance to public health restrictions is a political act. Refusing to wear a mask, for example, has become a way to reject the values of an opposing group or to show solidarity with a favored political tribe.

But not all resistance to public health recommendations is prudential, idiosyncratic, or political. Many resistors have offered moral arguments—most notably, libertarian appeals to individual freedom, which rest on the principle of autonomy, a person's right to direct their own life and choose for themselves. As one commentator noted:

There have been objections to lockdowns on the libertarian basis that they infringe on rights. Critiques are appearing saying that politicians haven't proven that such drastic measures are necessary. Before the coronavirus, the U.S. suffered a measles epidemic as the result of anti-vaccination activism, a libertarian cause that put parents' right to choose not to vaccinate their children above the state's attempt to defend other parents' right to expect that their own children wouldn't have to mix with unvaccinated peers. . . .

In public spaces around the world, libertarians are in conflict with the state. Social media is full of images of big social gatherings, often in luxurious social settings. "If I get corona, I get corona," as the 22-year-old said on video in Florida. "At the end of the day, I'm not gonna let it stop me from

partying.” Oklahoma’s governor even felt the need to tweet that he was at a packed restaurant. . . .

In these conditions, individual choices become freighted with moral significance. How, for example, will society eventually judge behavior like that of Kentucky Senator Rand Paul? Arguably the most prominent libertarian in the U.S., he continued to socialize as normal for a week after being told that he had had contact with someone who tested positive for the coronavirus. He had no symptoms. Recall that there are many elderly members of the Senate. Last weekend, after a workout in the Senate gym, he discovered that he had himself tested positive.<sup>14</sup>

A common response to the libertarian view is the communitarian argument that what matters most is not individual liberty but the common good, what’s best for the community as a whole.

### IN DEPTH

#### THE PRIVILEGE OF SOCIAL DISTANCING

Many assume COVID-19 has been thoroughly democratic, threatening every class and every race equally and granting to all an equal opportunity to fight it. But this is a deadly myth, argues Charles M. Blow:

We must dispense with the callous message that the best defense we have against the disease is something that each of us can control: We can all just stay home and keep social distance.

As a report last month by the Economic Policy Institute pointed out, “less than one in five black workers and roughly one in six Hispanic workers are able to work from home.”

As the report pointed out, “Only 9.2 percent of workers in the lowest quartile of the wage distribution can telework, compared with 61.5 percent of workers in the highest quartile.”

We should wear masks, practice social distancing, and get vaccinated to avoid spreading the virus to others. The Harvard philosopher Michael Sandel advocates a communitarian perspective and argues that in this pandemic we should ask what we owe each other:

Our ethical obligations are, first of all, to minimize the possibility that our behavior will expose others to the risk of contracting the virus. This means wearing masks and social distancing. Beyond this, those of us who are fortunate enough to work from the safety of our homes have a responsibility to support those who take risks on our behalf—not only doctors, nurses, and hospital workers, but delivery workers, grocery-store clerks, maintenance workers, child-care workers, home health care workers. This support should take the form of public appreciation for such

If you touch people for a living, in elder care or child care, if you cut or fix their hair, if you clean their spaces or cook their food, if you drive their cars or build their houses, you can’t do that from home.

Staying at home is a privilege. Social distancing is a privilege.

The people who can’t must make terrible choices: Stay home and risk starvation or go to work and risk contagion. . . .

If they go to work, they must often use crowded mass transportation, because low-wage workers can’t necessarily afford to own a car or call a cab.

Such is the life of the working poor, or those slightly above poverty, but still struggling. Our entire discussion around this virus is stained with economic elitism. In social media commentary about images of packed buses and crowds of delivery workers outside restaurants, people chastise black and brown people for not always being inside, but many of those doing the chastising do so from comfortable homes with sufficient money and food.<sup>17</sup>

workers, but also tangible, material support, such as health care, paid sick leave, and wage support.<sup>15</sup>

Other ethicists concur. One of them is Laurie Zoloth at the University of Chicago:

Social solidarity is the most precious tenet of our democracy. It begins with the notion that you should care about others, even strangers. And the idea that you should love your neighbor as profoundly as you love yourself—even placing their concerns and needs ahead of your own—is the great moral lesson and the core of justice in many religions. . . .

Freedom should not come at the expense of justice. In America, we once had a vision of freedom in which sacrifice was inherent: People sacrificed their very lives for the freedom of others. We've let that vision devolve into one of mere personal preference.<sup>16</sup>

Recall that justice refers to people getting what is fair or what is their due. It has been argued that in a seriously threatening pandemic, because those who refuse to wear masks are putting others at risk, they are treating them unjustly. Persons are entitled to freedom, but not if exercising that freedom constitutes an injustice.

## COVID FALSEHOODS

A distressing fact about COVID-19 is that as it spread throughout the world, so did misinformation about it. The virus itself has killed millions, but it has been abetted in the slaughter by viral falsehoods that tore through social media and online platforms at the speed of a keystroke. Politicians have promoted unproven treatments for the virus and declared that it is “just a flu”; an armchair epidemiologist offered bogus proof that the danger has been hyped by the mainstream media; social media posts urged people not to seek treatment; and a church touted a cure that consisted of toxic chemicals used to clean swimming pools. Fake news and social media influencers asserted that avoiding exposure to or use of 5G networks can prevent infection, drinking

alcohol and eating garlic protects you from the virus, hospitals are purposely diagnosing cases of COVID-19, face masks don’t work and can make you sick, and vaccines can alter people’s DNA and infect them with the virus.

Such assaults on the truth matter because, as scientific analyses and trustworthy news accounts keep reminding us, COVID misinformation can kill people. Here’s one of the many warnings issued by trustworthy sources:

The confluence of misinformation and infectious disease isn’t unique to COVID-19. Misinformation contributed to the spread of the Ebola epidemic in West Africa, and it plagues efforts to educate the public on the importance of vaccinating against measles. But when it comes to COVID-19, the pandemic has come to be defined by a tsunami of persistent misinformation to the public on everything from the utility of masks and the efficacy of school closures, to the wisdom behind social distancing, and even the promise of untested remedies. According to a study published by the National Bureau of Economic Research, areas of the country exposed to television programming that downplayed the severity of the pandemic saw greater numbers of cases and deaths—because people didn’t follow public health precautions.

In the United States, misinformation spread by elements of the media, by public leaders and by individuals with large social media platforms has contributed to a disproportionately large share of COVID-19 burden: we house 4 percent of the global population but account for 22 percent of global COVID-19 deaths.<sup>18</sup>

If this is the case—if pandemic falsehoods are hurting people—what moral responsibility do those who disseminate the falsehoods bear? If what we say, what we believe, and what we say we believe can alter the magnitude of the COVID-19 tragedy, are we then morally blame-worthy? In the age of social distancing, we are wirelessly huddled together closer than ever, nudging each other by our words toward higher or lower risk, safety or peril, comfort or terror. Our moral obligations to one another to speak

responsibly do not disappear just because we communicate digitally and impersonally. Under pressure from the pandemic, our duties seem to have become weightier than ever.

*Misinformation* is a falsehood, a statement that is factually incorrect. *Disinformation* is a deliberate falsehood, a statement that is factually incorrect *on purpose*—that is, a lie. What's wrong with lying? Ethicists argue that lying is morally wrong because it undermines personal autonomy—it interferes with a person's rational capacity to make personal choices. (Recall the discussion of informed consent in Chapters 1 and 5.) Either type of message—merely false or deliberately false—can have tragic consequences, and when it does, we might rightly judge the messengers as having acted not just rashly or recklessly but immorally. We can assign to them varying degrees of blame depending on their motives, awareness of their actions, and the degree of harm done.

The worst offenders are the *deliberate deceivers*, those who knowingly traffic in pandemic lies to score partisan points, show support for their tribe, troll the opposition, exact revenge, or make a buck. They are morally akin to the knave who knows the village's drinking water has been poisoned but still declares the water to be perfectly safe—or hawks snake oil to those seeking protection from the poison. People may die, but that's none of his concern.

Next on the scale of culpability are the *self-deceivers*. Philosophers define self-deceivers as people who are motivated to hold false beliefs despite contrary evidence and who may betray through their behavior some awareness of the truth. The obvious examples of the self-deceived are partisans who denied the severity of the COVID-19 threat because it made their favorite political leader look clueless, or decreased their party's electoral chances, or conflicted with the party line.

Can self-deceivers be held morally responsible for their own deception and for pushing the resulting falsehoods? The question comes down to whether self-deceivers have some control over

acquiring and sustaining their self-deceptive beliefs. On most philosophical accounts, self-deceivers can indeed possess the requisite control, either because they intended to acquire the false beliefs in the first place or because they can recognize and resist the desires and emotions that distort their thinking. If this is the case, then the self-deceiving commentators and social media stars who urged people to forgo face masks and social distancing because COVID-19 “was no more serious than the flu” will bear some moral responsibility for the catastrophe that likely followed. They are like the town crier who suspects the drinking water may be poisoned but tells no one because the news would put his boss, the mayor, in a bad light.

It can often be difficult to tell whether someone is deliberately deceiving or is self-deceived, whether the offender is a verbal mugger or an informational drunk driver. Either way, people can be harmed, and when they are, someone is to blame.

Mixed in with the deceivers and self-deceivers are many others whose statements are too often thought to be harmless. These are what the philosopher Harry G. Frankfurter called *bullshitters*—people who don't care whether what they say is true or false but who intend to deceive their audience about their motives.<sup>19</sup> They might blather to put themselves in a flattering light or to present themselves as something they are not. When they hold forth on the pandemic, they can do as much damage as the deliberate deceivers.

Because of their frequent fabrications, their disregard for evidence and accuracy, and their self-contradictions, many politicians and pundits have been accused of being supreme bullshitters and to have often spouted pandemic falsehoods.

But there seems to be plenty of blame to go around. Aren't people playing the same game when they forgo critical thinking and thoughtlessly share pandemic fake news, propaganda, partisan rants, viral rumors, and conspiracy theories? Aren't they at least partly responsible when they help spread misinformation that sends someone down a path that ends in a hospital bed?

## IN DEPTH AGAINST PANDEMIC FALSEHOODS

Research has shown that many of today's students—those who were practically born texting friends and surfing the net—lack the skills to understand media messages, use critical thinking to evaluate their truth, and check the credibility of their sources. In the age of COVID-19, this lack can be dangerous. Fortunately, critical thinking is an effective defense against online misinformation and disinformation.

The prerequisite for effective critical thinking is an attitude of *reasonable skepticism*. This attitude entails that we give up the habit of automatically accepting claims in the media, that we reject the questionable assumption that most of what's said online is true, that we stop taking the word of online sources on faith. Above all, reasonable skepticism means that we *do not believe a claim unless there are legitimate reasons for doing so*. Legitimate reasons are those that increase the likelihood of a claim being true. Such reasons come from reliable evidence, trustworthy sources, and critical reasoning. The problem is that we too often reach for illegitimate reasons, those that are *irrelevant* to the truth of a claim. Here are some illegitimate reasons for accepting or rejecting claims from a media source:

- This source contradicts my beliefs. (If I disagree with it, it must be fake news.)
- This source reinforces what I'd like to believe. (So I will believe it without question.)
- I reject any claim that comes from sources I don't like. (Because nothing they say can be right.)
- I feel strongly that the claims made by this source are true; therefore, they are true. (Because my feelings alone can certify claims.)
- Believing this claim or source makes me feel good. (And feeling good is what matters.)

So in evaluating online sources, cultivating a reasonable skepticism is essential. Fortunately even in the Wild West of the infosphere, there are also helpful strategies we can employ to discern what's real, what's fake, and what's worth our time.

### READ LATERALLY

Extensive research conducted by the Stanford History Education Group revealed that when professional fact-checkers want to know whether a website is a reliable source of information, they read *laterally*—they leave the site after a quick look and see what other sources have to say about the person or organization behind the site.<sup>20</sup> They don't just read *vertically*—they don't stay within the site and let themselves be distracted by features that are not sure indicators of reliability (such as the site's layout, design, and authoritative-sounding name). Thus, good fact-checkers are more likely than others to reach accurate conclusions about a site's reliability and to do so more quickly.

### READ CRITICALLY

Ultimately, the credibility of websites, social media, and other sources of information comes down to the truth of the claims. Critical thinking tells us that it is reasonable to

- (1) accept claims that are supported independently by reliable authorities, evidence, or other claims that you know to be true;
- (2) accept claims that are adequately supported by the source itself through citations to other credible sources (experts, research, reports, etc.) or through references to supporting facts;
- (3) reject claims when there is good reason for believing them false; and
- (4) suspend judgment on claims that you are unsure of, for it is unreasonable to accept a claim without good reasons, and the only cure for uncertainty about a source's claims is further research and reflection.

### USE TRUSTWORTHY FACT-CHECKERS

Fact-checking websites rate the reliability of sources and the truth of claims, but who rates the trustworthiness of the fact-checkers? Fortunately, the best, most reliable fact-checker organizations share certain characteristics that we can readily identify: (1) They are nonpartisan, and their funding is fully disclosed, (2) they explain their fact-checking methodology and disclose their sources, (3) they use nonpartisan and primary sources whenever possible and are appropriately skeptical of strongly biased information, (4) they employ neutral wording and minimize appeals to emotions, stereotypes, and logical fallacies, (5) they avoid partisan considerations in selecting topics to cover, (6) they promptly correct errors after publication, and (7) they have a solid track record in accurate reporting.

Here are four top sites that meet all or almost all of these criteria.\*

**Snopes.com**—One of the oldest and possibly the most trusted of fact-checking sites. For years it has been rendering definitive verdicts on urban legends, rumors, myths, and fake news, and—more recently—pandemic misinformation. Factual accuracy: high.

**PolitiFact.com**—The best site for checking the accuracy of political claims. Won the Pulitzer Prize. Factual accuracy: high.

**FactCheck.org**—Like Politifact, this site strives to decrease deception and misinformation in American politics. Checks the accuracy of political statements in speeches, TV ads, news releases, interviews, and more. Factual accuracy: very high.

**TruthOrFiction.com**—Similar to Snopes, this site fact-checks urban legends, myths, internet rumors, and other questionable claims but typically focuses on recurring stories rather than on those arising from current events. Factual accuracy: very high.\*

\*The source for these judgments is MediaBias-FactCheck.com, the authoritative rater of bias and accuracy in traditional and online news sources. MediaBiasFactCheck.com itself meets all seven criteria noted here. Some recommended fact-checkers such as Snopes.com and FactCheck.org are also signatories to the International Fact-Checking Network (IFCN) code of principles (<https://www.poynter.org/ifcn-fact-checkers-code-of-principles/>).

### KEY TERMS

epidemic  
pandemic  
quarantine  
self-isolation  
triage

### SUMMARY

The COVID-19 pandemic has been both a public health and moral challenge on a vast scale. It has forced moral choices on health care workers and on millions of others worldwide.

Science tells us that the pandemic is real, that it threatens multitudes, and that it can

be—and has been—deadly. These facts alone cannot tell us what our moral obligations are when we are confronted by this plague, but our moral judgments must take the facts into account. To ignore the scientific evidence, to misunderstand it, or to fall for misinformation or half-truths is to risk bad moral choices and unsafe decisions.

Many moral questions about COVID-19 appear when health care workers try to decide how to allocate scarce medical resources—ventilators, ICU hospital beds, personnel, masks, PPE, medications, and vaccines. The decisions that must be made involve balancing moral

principles, but a common difficulty is that even when we know what moral principles are relevant to a decision, they may conflict. For example, the principle of utility (maximize the number of lives saved) often conflicts with the principle of equity (every patient should get an equal chance to receive life-saving care). Ezekiel J. Emanuel and his colleagues have offered a strategy for reconciling the conflicts. They have identified four fundamental values that should govern decisions: maximizing the benefits produced by scarce resources, treating people equally, promoting and rewarding instrumental value, and giving priority to the worst off.

Even though science has identified the specific practices that can help defeat COVID-19, many people have been unwilling to adopt them. Some of the resistors are simply misinformed, some have prudential reasons, some have a deep distrust of experts, some hate being told what to do, and some have political motivations. Many people of color mistrust the government and health care institutions because of past discrimination and mistreatment. But many people offer moral arguments against compliance, most especially libertarian appeals to individual freedom. A common response to the libertarian view is the communitarian argument that what matters most is not individual liberty but the common good.

Scientific analyses and news accounts remind us that COVID-19 misinformation and disinformation can seriously harm people. Misinformation is a falsehood, a statement that is factually incorrect; disinformation is a deliberate falsehood, a lie. Either type of message—merely false or deliberately false—can have tragic consequences, and when it does, we might rightly judge the messengers as having acted not just rashly or recklessly but immorally. We can assign to them varying degrees of blame depending on their motives, awareness of their actions, and the degree of harm done.

## Cases for Evaluation

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### CASE I

#### Withdrawing Ventilators from COVID Patients

(*The New England Journal of Medicine*)—Although shortages of other goods and services may lead to deaths, in most cases it will be the combined effects of a variety of shortages that will result in worse outcomes. Mechanical ventilation is different. When patients' breathing deteriorates to the point that they need a ventilator, there is typically only a limited window during which they can be saved. And when the machine is withdrawn from patients who are fully ventilator-dependent, they will usually die within minutes. Unlike decisions regarding other forms of life-sustaining treatment, the decision about initiating or terminating mechanical ventilation is often truly a life-or-death choice.

Many states have developed strategies for rationing during pandemics. The New York Guidelines target saving the most lives, as defined by the patient's short-term likelihood of surviving the acute medical episode. Rationing is performed by a triage officer or a triage committee composed of people who have no clinical responsibilities for the care of the patient....

Anticipating the need to allocate ventilators to the patients who are most likely to benefit, clinicians should proactively engage in discussions with patients and families regarding do-not-intubate orders for high-risk subgroups of patients before their health deteriorates. Once patients have already been placed on mechanical ventilation, decisions to withdraw it are especially fraught. Less than 50 years ago, physicians argued that withdrawing a ventilator was an act of killing, prohibited by both law and ethics. Today, withdrawal of ventilatory support is the most common proximate cause of death in ICU patients, and withdrawal of this support at the request of a patient or surrogate is considered an ethical and legal obligation.

Withdrawal of a ventilator against the wishes of the patient or surrogate, however, is primarily done only in states and hospitals that permit physicians to unilaterally withdraw life support when treatment is determined to be futile.

Decisions to withdraw ventilators during a pandemic in order to make the resource available to another patient cannot be justified in either of these ways: it is not being done at the request of the patient or surrogate, nor can it be claimed that the treatment is futile. Even though the chances of survival may be low, in the absence of the pandemic the treatment would be continued. Whereas this type of rationing may not be unusual in countries that tragically have a chronic shortage of essential ICU care, it is unprecedented for most physicians who practice in well-resourced countries. Reports from Italy describe physicians “weeping in the hospital hallways because of the choices they were going to have to make.”\*

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*In decisions to withdraw ventilators from patients, what moral principles apply? Can withdrawing a ventilator to make it available to another patient be morally justified? If so, how and in what circumstances? If not, why not? Is withdrawing a ventilator against the wishes of the patient or surrogate ever morally justified? Why or why not?*

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\*“The Toughest Triage—Allocating Ventilators in a Pandemic,” *New England Journal of Medicine*, 2020; 382:1973–1975.

## CASE 2

### Refusing to Wear Face Masks

(*Los Angeles Times*)—When an employee told a group of 20-somethings they needed face masks to enter his fast-food restaurant, one woman fired off a stream of expletives. “Isn’t this Orange County?” snapped another member of the group. “We don’t have to wear masks!”

The responses came as a shock—but not really a surprise—to Nilu Patel, a certified registered nurse anesthetist at nearby UC Irvine Medical Center,

who observed the conflict while waiting for take-out. Healthcare workers suffer these angry encounters daily as they move between treacherous hospital settings and their communities, where mixed messaging from politicians has muddied common-sense public health precautions.

“Healthcare workers are scared, but we show up to work every single day,” Patel said. Wearing masks, she said, “is a very small thing to ask.”

Patel administers anesthesia to patients in the operating room, and her husband is a healthcare worker as well. They’ve suffered sleepless nights worrying about how to keep their two young children safe and schooled at home. The small but vocal chorus of people who view face coverings as a violation of their rights makes it all worse, she said. . . .

“Our leaders have not been pushing that this is something really serious,” said Jewell Harris Jordan, a 47-year-old registered nurse at the Kaiser Permanente Oakland Medical Center. She’s distraught that some Americans see mandates for face coverings as an infringement upon their rights instead of a show of solidarity with healthcare workers.

“If you come into the hospital and you’re sick, I’m going to take care of you,” Jordan said. “But damn, you would think you would want to try to protect the people that are trying to keep you safe.”\*

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*What is the argument that these health care workers are making about face masks? Do you agree with them? Explain.*

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\*Anna Almendrala, “A Nurse’s Plea: ‘Please Tell Me My Life Is Worth a LITTLE of Your Discomfort?’” *Los Angeles Times*, July 8, 2020, <https://www.latimes.com/science/story/2020-07-08/nurses-beg-public-to-wear-masks>.

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## CASE 3

### Just a Joke?

(*BBC.com*)—Prankster created a screenshot of a fake government text that claimed the recipient had been fined for leaving the house too many times. He thought it would be funny to scare people breaking lockdown rules.

After encouraging his followers to share it on Instagram, it found its way to local Facebook groups, where it was posted by worried residents, some of whom took it seriously.

"I don't really want to cause panic," says the prankster, who wouldn't give us his real name. "But if they believe a screenshot on social media, they really need to sort of re-evaluate the way they consume information on the internet."\*

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*Does the prankster bear any responsibility for frightening residents? Did he do anything wrong? Or should the residents be blamed for being gullible about social media messages? Explain.*

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## READINGS

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### **Why Some Americans Refuse to Social Distance and Wear Masks**

MICHAEL SANDEL WITH COLLEEN WALSH

In this interview published in the *Harvard Gazette*, the philosopher Michael Sandel says that many people refuse to wear masks because they think mask mandates are a violation of individual liberty and because they resent government officials who base their recommendations on the authority of science. He thinks our response to the crisis should instead be communitarian. "Our ethical obligations are, first of all, to minimize the possibility that our behavior will expose others to the risk of contracting the virus." What's missing in society now, he says, is a sense of social trust and solidarity.

Wearing a mask and social distancing are two important barriers to COVID-19 infection, public health experts and government officials say. But adoption of the seemingly simple precautions has become a cultural battleground in a country where individual rights have long been considered part of the nation's founding ethos. And yet, what do we owe our fellow citizens in the age of a deadly virus with no vaccine that has already taken close to

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Colleen Walsh, Interview with Michael Sandel, "Why Some Americans Refuse to Social Distance and Wear Masks," *The Harvard Gazette*, August 28, 2020.

170,000 lives, and will likely take thousands, and potentially hundreds of thousands, more? In his popular course "Justice," Michael Sandel, Harvard's Anne T. and Robert M. Bass Professor of Government, regularly asks his students to take on such thorny ethical questions. He will do so again this fall with his new class, "Justice: Ethics in an Age of Pandemic and Racial Reckoning." The Gazette recently asked Sandel for his thoughts on the subject.

GAZETTE: So many people have chosen not to wear masks or to keep their distance from others, despite the data that those simple measures help save lives. Why is there such resistance?

**SANDEL:** The wearing of masks has become a flashpoint of partisan disagreement, a new front in the culture wars. On one level, this seems puzzling. Why doesn't everyone simply wear a mask for the sake of public health? For two reasons: First, many Americans consider mask mandates a violation of individual liberty. They don't want the government to force them to wear a mask. Second, many Americans resent governing elites who claim to derive their authority from Science. Here, the debate over masks is similar to the partisan disagreement on climate change. Many supporters of President Trump share his resentment of elites and experts. They don't trust experts who tell them they should wear a mask to reduce the spread of the coronavirus any more than they trust experts who say they should pay a carbon tax to alleviate climate change. The resistance to wearing a mask is not about public health; it's about politics.

**GAZETTE:** What are our ethical obligations in the middle of a pandemic?

**SANDEL:** Our ethical obligations are, first of all, to minimize the possibility that our behavior will expose others to the risk of contracting the virus. This means wearing masks and social distancing. Beyond this, those of us who are fortunate enough to work from the safety of our homes have a responsibility to support those who take risks on our behalf—not only doctors, nurses, and hospital workers, but delivery workers, grocery-store clerks, maintenance workers, child-care workers, home health care workers. This support should take the form of public appreciation for such workers, but also tangible, material support, such as health care, paid sick leave, and wage support.

**GAZETTE:** There are periods in American history—like World War II—when nearly

everyone spent years voluntarily sacrificing in Service to a national cause. Why isn't that happening now? What has changed?

**SANDEL:** The question reminds me of an internet meme early in the pandemic: "Your grandparents were called to war. You are called to sit on your couch. You can do this." Even as the pandemic highlights our mutual dependence, it is striking how little solidarity and shared sacrifice it has called forth. Why do we seem incapable of solidarity at the time we need it most? The answer goes back to the social unraveling that preceded this crisis. The pandemic caught us unprepared—logistically and medically, but also morally unprepared. It arrived at a time of deep polarization and partisan rancor. Four decades of deepening inequality have driven us apart. Resentment of the elites whose policies produced these inequalities led to a populist backlash. The pandemic arrived at just the wrong moment—amid toxic politics, incompetent leadership, and fraying social bonds.

**GAZETTE:** How might Americans be the same or different from people in other societies in taking these types of individual steps to help society as a whole? Are there examples from COVID that you can point to?

**SANDEL:** Sadly, the U.S. has handled the COVID crisis worse than most affluent countries. We've had more than 4½ times the number of deaths per capita as Germany, 60 times the number in Japan, and more than 80 times as many as South Korea. Our poor performance is due partly to failed leadership at the federal level and the lack of an adequate public health system. But I think you are right to suggest that social habits and cultural factors come into play. Our ardent individualism is a strength in some settings but not in contending with a pandemic. In Japan, the ready acceptance

of face masks seems to have reduced the spread of the virus. In Germany, the electorate supported far greater investment in wage replacement and public health spending than the U.S. government could muster. In South Korea, a single-payer health system made testing easier and more widespread. In addition, a social movement among landlords to reduce or freeze rents helped keep small businesses afloat.

**GAZETTE:** What role do leaders have in supporting this social contract?

**SANDEL:** Trust matters in a pandemic—not only trust in the scientific information and medical advice the government provides, but trust among citizens. Perhaps the single greatest responsibility of leaders in times of crisis is to inspire such trust. Angela Merkel in Germany and Jacinda Ardern in New Zealand are examples of leaders who have led their countries through the crisis effectively, in part by fostering trust. In this country, by contrast, we've seen how evading responsibility and sowing discord undermines the trust and solidarity we need to contend with the pandemic.

**GAZETTE:** What does this say, when we are all so culturally siloed, about the future of shared American values and what we owe to each other?

**SANDEL:** From the outset of this crisis, we've heard the slogan, "We are all in this together." We hear it from politicians, advertisers, and celebrities. It evokes our mutual dependence and vulnerability in the face of COVID-19. It points to an inspiring ideal. But it rings hollow, because we know it doesn't describe the facts on the ground. Some of us work from home and hold meetings on Zoom. Others

have little choice but to risk their health and lives serving the public and delivering things to our doorsteps, enabling us to avoid risk. The people we now celebrate as "essential workers" are not the best-paid or most-honored workers in our society. This is a moment to ask how to reconfigure the economy to bring the rewards of such workers into better alignment with the importance of the work they do. This moment makes vivid the need for a broader public debate about the inequality this crisis has highlighted and a reconsideration of what we owe one another as citizens.

**GAZETTE:** What are some of the ethical questions you plan to take up in your fall semester, University-wide course "Justice: Ethics in an Age of Pandemic and Racial Reckoning"?

**SANDEL:** The course is an updated version of the "Justice" course I've taught over the years. The moral urgency of the pandemic and of this moment of racial reckoning prompted me to offer the course again, updated to include the ethical questions that confront us today. For example: Who should be first in line to get a coronavirus vaccine when one becomes available? Should we use cellphone tracking data to enforce stay-at-home orders? In deciding how to balance public health with reopening the economy, should we place a monetary value on human life? We will also take up current debates about racial injustice, including the question of reparations for slavery and racism. The course invites students to think through the fundamental moral and civic questions the crises of our day make unavoidable—about the meaning of a just society and our obligations to one another.

## Fair Allocation of Scarce Medical Resources in the Time of Covid-19

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MICHAEL PARKER, AARON GLICKMAN, CATHY ZHANG, CONNOR BOYLE,  
MAXWELL SMITH, AND JAMES P. PHILLIPS

A critical task in any pandemic is deciding how to distribute medical resources when there aren't enough to meet the needs of all patients—a job laden with moral questions and mortal implications. Emanuel and his colleagues address these difficulties and identify four fundamental moral values they think should guide judgments in dealing with the COVID-19 pandemic: "maximizing the benefits produced by scarce resources, treating people equally, promoting and rewarding instrumental value, and giving priority to the worst off." They argue that applying these principles consistently and thoughtfully yields six specific recommendations for allocation.

### Introduction

Covid-19 is officially a pandemic. It is a novel infection with serious clinical manifestations, including death, and it has reached at least 124 countries and territories. Although the ultimate course and impact of Covid-19 are uncertain, it is not merely possible but likely that the disease will produce enough severe illness to overwhelm health care infrastructure. Emerging viral pandemics "can place extraordinary and sustained demands on public health and health systems and on providers of essential community services."<sup>1</sup> Such demands will create the need to ration medical equipment and interventions.

Rationing is already here. In the United States, perhaps the earliest example was the near-immediate recognition that there were not enough high-filtration N-95 masks for health care workers, prompting contingency guidance on how to reuse masks designed for single use.<sup>2</sup> Physicians in Italy have proposed directing crucial resources such as intensive care beds and ventilators to patients who can benefit most from treatment.<sup>3,4</sup> Daegu, South Korea—home to most of that country's Covid-19

cases—faced a hospital bed shortage, with some patients dying at home while awaiting admission.<sup>5</sup> In the United Kingdom, protective gear requirements for health workers have been downgraded, causing condemnation among providers.<sup>6</sup> The rapidly growing imbalance between supply and demand for medical resources in many countries presents an inherently normative question: How can medical resources be allocated fairly during a Covid-19 pandemic?

### Health Impacts of Moderate-to-Severe Pandemics

In 2005, the U.S. Department of Health and Human Services (HHS) developed a Pandemic Influenza Plan that modeled the potential health care impact of moderate and severe influenza pandemics. The plan was updated after the 2009 H1N1 outbreak and most recently in 2017.<sup>1</sup> It suggests that a moderate pandemic will infect about 64 million Americans, with about 800,000 (1.25%) requiring hospitalization and 160,000 (0.25%) requiring beds in the intensive care unit (ICU). A severe pandemic would dramatically increase these demands.

Modeling the Covid-19 pandemic is challenging. But there are data that can be used to project resource demands. Estimates of the reproductive

number (R) of SARS-CoV-2 show that at the beginning of the epidemic, each infected person spreads the virus to at least two others, on average.<sup>10</sup> A conservatively low estimate is that 5% of the population could become infected within 3 months. Preliminary data from China and Italy regarding the distribution of case severity and fatality vary widely.<sup>7,8</sup> A recent large-scale analysis from China suggests that 80% of those infected either are asymptomatic or have mild symptoms, a finding that implies that demand for advanced medical services might apply to only 20% of the total infected. Of patients infected with Covid-19, about 15% have severe illness and 5% have critical illness.<sup>8</sup> Overall mortality ranges from 0.25% to as high as 3.0%.<sup>11</sup> Case fatality rates are much higher for vulnerable populations, such as persons over the age of 80 years (>14%) and those with coexisting conditions (10% for those with cardiovascular disease and 7% for those with diabetes).<sup>8</sup> Overall, Covid-19 is substantially deadlier than seasonal influenza, which has mortality of roughly 0.1%.

The exact number of cases will depend on a number of factors that are unknowable at this time, including the effect of social distancing and other interventions. However, the estimate given above—that 5% of the population is infected—is low; new data are only likely to increase estimates of sickness and demand for health care infrastructure.

### **Health System Capacity**

Even a conservative estimate shows that the health needs created by the coronavirus pandemic go well beyond the capacity of U.S. hospitals.<sup>9</sup> According to the American Hospital Association, there were 5198 community hospitals and 209 federal hospitals in the United States in 2018. In the community hospitals, there were 792,417 beds, with 3532 emergency departments and 96,500 ICU beds, of which 23,000 were neonatal and 5100 pediatric, leaving just under 68,400 ICU beds of all types for the adult population.<sup>12</sup> Other estimates of ICU bed capacity, which try to account for purported undercounting in the American Hospital Association data, show a total of 85,000 adult ICU beds of all types.<sup>13</sup>

There are approximately 62,000 full-featured ventilators (the type needed to adequately treat the most severe complications of Covid-19) available in the United States.<sup>14</sup> Approximately 10,000 to 20,000 more are estimated to be on call in our Strategic National Stockpile,<sup>15</sup> and 98,000 ventilators that are not full-featured but can provide basic function in an emergency during crisis standards of care also exist.<sup>14</sup> Supply limitations constrain the rapid production of more ventilators; manufacturers are unsure of how many they can make in the next year.<sup>16</sup> However, in the Covid-19 pandemic, the limiting factor for ventilator use will most likely not be ventilators but healthy respiratory therapists and trained critical care staff to operate them safely over three shifts every day. In 2018, community hospitals employed about 76,000 full-time respiratory therapists,<sup>12</sup> and there are about 512,000 critical care nurses—of which ICU nurses are a subset.<sup>17</sup> California law requires one respiratory therapist for every four ventilated patients; thus, this number of respiratory therapists could care for a maximum of 100,000 patients daily (25,000 respiratory therapists per shift).

Given these numbers—and unless the epidemic curve of infected individuals is flattened over a very long period of time—the Covid-19 pandemic is likely to cause a shortage of hospital beds, ICU beds, and ventilators. It is also likely to affect the availability of the medical workforce, since doctors and nurses are already becoming ill or quarantined.<sup>18</sup> Even in a moderate pandemic, hospital beds and ventilators are likely to be scarce in geographic areas with large outbreaks, such as Seattle, or in rural and smaller hospitals that have much less space, staff, and supplies than large academic medical centers.

Diagnostic, therapeutic, and preventive interventions will also be scarce. Pharmaceuticals like chloroquine, remdesivir, and favipiravir are currently undergoing clinical trials, and other experimental treatments are at earlier stages of study.<sup>19–21</sup> Even if one of them proves effective, scaling up supply will take time.<sup>22</sup> The use of convalescent serum, blood products from persons whose immune system has defeated Covid-19, is being contemplated as a possible treatment and preventive intervention.<sup>19</sup>

Likewise, if an effective vaccine is developed, it will take time to produce, distribute, and administer. Other critical medical supplies and equipment, such as personal protective equipment (PPE), are already scarce, presenting the danger that medical staff time will itself become scarce as physicians and nurses become infected.<sup>2</sup> Technical and governmental failures in the United States have led to a persistent scarcity of tests.<sup>23</sup> As more countries have been affected by Covid-19, worldwide demand for tests has begun to outstrip production, creating the need to prioritize patients.

Public health measures known to reduce viral spread, such as social distancing, cough etiquette, and hand hygiene, finally seem to be a U.S. national priority and may make resource shortages less severe by narrowing the gap between medical need and the available supply of treatments. But public health mitigation efforts do not obviate the need to adequately prepare for the allocation of scarce resources before it becomes necessary.

The choice to set limits on access to treatment is not a discretionary decision, but a necessary response to the overwhelming effects of a pandemic. The question is not whether to set priorities, but how to do so ethically and consistently rather than basing decisions on individual institutions' approaches or a clinician's intuition in the heat of the moment.

### **Ethical Values for Rationing Health Resources in a Pandemic**

Previous proposals for allocation of resources in pandemics and other settings of absolute scarcity, including our own prior research and analysis, converge on four fundamental values: maximizing the benefits produced by scarce resources, treating people equally, promoting and rewarding instrumental value, and giving priority to the worst off.<sup>24-29</sup> Consensus exists that an individual person's wealth should not determine who lives or dies.<sup>24-33</sup> Although medical treatment in the United States outside pandemic contexts is often restricted to those able to pay, no proposal endorses ability-to-pay allocation in a pandemic.<sup>24-33</sup>

Each of these four values can be operationalized in various ways. Maximization of benefits can be understood as saving the most individual lives or as

saving the most life-years by giving priority to patients likely to survive longest after treatment.<sup>24,26,28,29</sup> Treating people equally could be attempted by random selection, such as a lottery, or by a first-come, first-served allocation.<sup>24,28</sup> Instrumental value could be promoted by giving priority to those who can save others, or rewarded by giving priority to those who have saved others in the past.<sup>24,29</sup> And priority to the worst off could be understood as giving priority either to the sickest or to younger people who will have lived the shortest lives if they die untreated.<sup>24,28,30</sup>

The proposals for allocation discussed above also recognize that all these ethical values and ways to operationalize them are compelling. No single value is sufficient alone to determine which patients should receive scarce resources.<sup>24,33</sup> Hence, fair allocation requires a multivalue ethical framework that can be adapted, depending on the resource and context in question.<sup>24-33</sup>

### **Who Gets Health Resources in a Covid-19 Pandemic?**

These ethical values—maximizing benefits, treating equally, promoting and rewarding instrumental value, and giving priority to the worst off—yield six specific recommendations for allocating medical resources in the Covid-19 pandemic: maximize benefits; prioritize health workers; do not allocate on a first-come, first-served basis; be responsive to evidence; recognize research participation; and apply the same principles to all Covid-19 and non-Covid-19 patients.

**Recommendation 1:** In the context of a pandemic, the value of maximizing benefits is most important.<sup>3,26,28,29,31-33</sup> This value reflects the importance of responsible stewardship of resources: it is difficult to justify asking health care workers and the public to take risks and make sacrifices if the promise that their efforts will save and lengthen lives is illusory.<sup>29</sup> Priority for limited resources should aim both at saving the most lives and at maximizing improvements in individuals' post-treatment length of life. Saving more lives and more years of life is a consensus value across expert reports.<sup>26,28,29</sup> It is consistent both with utilitarian ethical perspectives that emphasize population

outcomes and with nonutilitarian views that emphasize the paramount value of each human life.<sup>34</sup> There are many reasonable ways of balancing saving more lives against saving more years of life<sup>30</sup>; whatever balance between lives and life-years is chosen must be applied consistently.

Limited time and information in a Covid-19 pandemic make it justifiable to give priority to maximizing the number of patients that survive treatment with a reasonable life expectancy and to regard maximizing improvements in length of life as a subordinate aim. The latter becomes relevant only in comparing patients whose likelihood of survival is similar. Limited time and information during an emergency also counsel against incorporating patients' future quality of life, and quality-adjusted life-years, into benefit maximization. Doing so would require time-consuming collection of information and would present ethical and legal problems.<sup>28,34</sup> However, encouraging all patients, especially those facing the prospect of intensive care, to document in an advance care directive what future quality of life they would regard as acceptable and when they would refuse ventilators or other life-sustaining interventions can be appropriate.

Operationalizing the value of maximizing benefits means that people who are sick but could recover if treated are given priority over those who are unlikely to recover even if treated and those who are likely to recover without treatment. Because young, severely ill patients will often comprise many of those who are sick but could recover with treatment, this operationalization also has the effect of giving priority to those who are worst off in the sense of being at risk of dying young and not having a full life.<sup>25,29,30</sup>

Because maximizing benefits is paramount in a pandemic, we believe that removing a patient from a ventilator or an ICU bed to provide it to others in need is also justifiable and that patients should be made aware of this possibility at admission.<sup>3,28,29,33,35</sup> Undoubtedly, withdrawing ventilators or ICU support from patients who arrived earlier to save those with better prognosis will be extremely psychologically traumatic for clinicians—and some clinicians might refuse to do so. However, many guidelines agree that the decision to withdraw a scarce

resource to save others is not an act of killing and does not require the patient's consent.<sup>26,28,29,33,35</sup> We agree with these guidelines that it is the ethical thing to do.<sup>26</sup> Initially allocating beds and ventilators according to the value of maximizing benefits could help reduce the need for withdrawal.

**Recommendation 2:** Critical Covid-19 interventions—testing, PPE, ICU beds, ventilators, therapeutics, and vaccines—should go first to front-line health care workers and others who care for ill patients and who keep critical infrastructure operating, particularly workers who face a high risk of infection and whose training makes them difficult to replace.<sup>27</sup> These workers should be given priority not because they are somehow more worthy, but because of their instrumental value: they are essential to pandemic response.<sup>27,28</sup> If physicians and nurses are incapacitated, all patients—not just those with Covid-19—will suffer greater mortality and years of life lost. Whether health workers who need ventilators will be able to return to work is uncertain, but giving them priority for ventilators recognizes their assumption of the high-risk work of saving others, and it may also discourage absenteeism.<sup>28,36</sup> Priority for critical workers must not be abused by prioritizing wealthy or famous persons or the politically powerful above first responders and medical staff—as has already happened for testing.<sup>37</sup> Such abuses will undermine trust in the allocation framework.

**Recommendation 3:** For patients with similar prognoses, equality should be invoked and operationalized through random allocation, such as a lottery, rather than a first-come, first-served allocation process. First-come, first-served is used for such resources as transplantable kidneys, where scarcity is long-standing and patients can survive without the scarce resource. Conversely, treatments for coronavirus address urgent need, meaning that a first-come, first-served approach would unfairly benefit patients living nearer to health facilities. And first-come, first-served medication or vaccine distribution would encourage crowding and even violence during a period when social distancing is paramount. Finally, first-come, first-served approaches mean that people who happen to get sick later on, perhaps because of their strict adherence to

recommended public health measures, are excluded from treatment, worsening outcomes without improving fairness.<sup>33</sup> In the face of time pressure and limited information, random selection is also preferable to trying to make finer-grained prognostic judgments within a group of roughly similar patients.

**Recommendation 4:** Prioritization guidelines should differ by intervention and should respond to changing scientific evidence. For instance, younger patients should not be prioritized for Covid-19 vaccines, which prevent disease rather than cure it, or for experimental post- or pre-exposure prophylaxis. Covid-19 outcomes have been significantly worse in older persons and those with chronic conditions.<sup>8</sup> Invoking the value of maximizing saving lives justifies giving older persons priority for vaccines immediately after health care workers and first responders. If the vaccine supply is insufficient for patients in the highest risk categories—those over 60 years of age or with coexisting conditions—then equality supports using random selection, such as a lottery, for vaccine allocation.<sup>24,28</sup> Invoking instrumental value justifies prioritizing younger patients for vaccines only if epidemiologic modeling shows that this would be the best way to reduce viral spread and the risk to others.

Epidemiologic modeling is even more relevant in setting priorities for coronavirus testing. Federal guidance currently gives priority to health care workers and older patients,<sup>38</sup> but reserving some tests for public health surveillance (as some States are doing) could improve knowledge about Covid-19 transmission and help researchers target other treatments to maximize benefits.<sup>39</sup>

Conversely, ICU beds and ventilators are curative rather than preventive. Patients who need them face life-threatening conditions. Maximizing benefits requires consideration of prognosis—how long the patient is likely to live if treated—which may mean giving priority to younger patients and those with fewer coexisting conditions. This is consistent with the Italian guidelines that potentially assign a higher priority for intensive care access to younger patients with severe illness than to elderly patients.<sup>34</sup> Determining the benefit-maximizing allocation of antivirals and other experimental treatments, which are likely to be most effective in

patients who are seriously but not critically ill, will depend on scientific evidence. These treatments may produce the most benefit if preferentially allocated to patients who would fare badly on ventilation.

**Recommendation 5:** People who participate in research to prove the safety and effectiveness of vaccines and therapeutics should receive some priority for Covid-19 interventions. Their assumption of risk during their participation in research helps future patients, and they should be rewarded for that contribution. These rewards will also encourage other patients to participate in clinical trials. Research participation, however, should serve only as a tie-breaker among patients with similar prognoses.

**Recommendation 6:** There should be no difference in allocating scarce resources between patients with Covid-19 and those with other medical conditions. If the Covid-19 pandemic leads to absolute scarcity, that scarcity will affect all patients, including those with heart failure, cancer, and other serious and life-threatening conditions requiring prompt medical attention. Fair allocation of resources that prioritizes the value of maximizing benefits applies across all patients who need resources. For example, a doctor with an allergy who goes into anaphylactic shock and needs life-saving intubation and ventilator support should receive priority over Covid-19 patients who are not front-line health care workers.

### Implementing Rationing Policies

The need to balance multiple ethical values for various interventions and in different circumstances is likely to lead to differing judgments about how much weight to give each value in particular cases. This highlights the need for fair and consistent allocation procedures that include the affected parties: clinicians, patients, public officials, and others. These procedures must be transparent to ensure public trust in their fairness.

The outcome of these fair allocation procedures, informed by the ethical values and recommendations delineated here, should be the development of prioritization guidelines that ensure that individual physicians are not faced with the terrible task of improvising decisions about whom to treat or making

these decisions in isolation. Placing such burdens on individual physicians could exact an acute and life-long emotional toll. However, even well-designed guidelines can present challenging problems in real-time decision making and implementation. To help clinicians navigate these challenges, institutions may employ triage officers, physicians in roles outside direct patient care, or committees of experienced physicians and ethicists, to help apply guidelines, to assist with rationing decisions, or to make and implement choices outright—relieving the individual front-line clinicians of that burden.<sup>26</sup> Institutions may also include appeals processes, but appeals should be limited to concerns about procedural mistakes, given time and resource constraints.<sup>29</sup>

## Conclusions

Governments and policy makers must do all they can to prevent the scarcity of medical resources. However, if resources do become scarce, we believe the six recommendations we delineate should be used to develop guidelines that can be applied fairly and consistently across cases. Such guidelines can ensure that individual doctors are never tasked with deciding unaided which patients receive life-saving care and which do not. Instead, we believe guidelines should be provided at a higher level of authority, both to alleviate physician burden and to ensure equal treatment. The described recommendations could shape the development of these guidelines.

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## ICU Triage: How Many Lives or Whose Lives?

ANGELA BALLANTYNE

Ballantyne argues that in the COVID-19 pandemic, triage protocols (schemes for allocating medical resources) can rely too heavily on the principle of utility at the expense of equity, procedures that work to the advantage of those who are privileged and against those who are not. Where there is uncertainty, she says, we should err on the side of broader rather than stricter clinical criteria so that a wider range of patients get a shot at ICU, even when this is likely to be less efficient overall.

Bioethicists around the world have been asked to advise on the goals and methods of triage protocols. Estimates suggest 5% of COVID19 cases will require ICU care. The key ethical tension is between utility and equity. There are other relevant principles of fair allocation such as reciprocity for frontline workers who have taken extraordinary risks; and a “fair innings” to prioritize those who are younger on the grounds that they have lived a shorter proportion of their natural life span. I leave these aside for now, because the major tension is between utility and equity.

The World Health Organization defines health equity as preventing remediable differences among groups of people, whether those groups are defined socially, economically, demographically. We cannot simultaneously prioritize utility (saving the most lives) and equity (avoiding unjust discrimination).

These values are direct trade-offs. We can save more lives or we save a more diverse group of lives. There is no perfect algorithm but we need to identify an acceptable balance.

Several influential bioethicists have argued that is it simply obvious that the “many” matters more than the “who”:

- “in a situation where resources are overwhelmed, and choices cannot be avoided, the ethical balance must shift to emphasising

benefit . . . this will mean prioritising intensive care for those patients who have the highest chance of surviving.”

- “Priority for limited resources should aim both at saving the most lives and at maximizing improvements in individuals’ post-treatment length of life. Saving more lives and more years of life is a consensus value across expert reports.”
- “As a basic rule, we try to act in such a way that the largest number of people survive, because that is in the public interest.”

According to these positions, the value of saving lives is a substantially more weighty ethical consideration than the value of equal outcomes. It is unsurprising that guidelines based on utility have already elicited legal challenge on the grounds of disability discrimination. Implicit cognitive biases will likely lead clinical decision-makers to unconsciously and unfairly discriminate against older persons or persons with disability. Some of the proposed triage tools add explicit barriers. Jackie Leach Scully argues that current triage guidelines are an “. . . indicator of our ongoing inability as a society to consider people with disabilities as equal members of the community, with equal human and civil rights, equal claims to citizenship, and equal moral agency.”

In this blog I consider the impact of a utility-focused triage approach on social and ethnic health disparities and question why equity has been so quickly de-prioritized. ICU triage tools cannot be expected to fix the problems of longstanding health

disparities. But that doesn't mean we should uncritically accept the mantra of utility.

There will be a point at which the prospect of a patient's survival in ICU will be so low that admittance would amount to a failure to responsibly steward public resources. But there is significant ground between maximizing ICU survival and senselessly throwing away resources. This middle ground should include at least some space for de prioritising utility in favor of giving a wider range of people a shot at ICU. Contrary to the dominant position described above, I argue that equity and justice are critical public interests that must be protected.

Of course those justifying prioritization of utility don't endorse discrimination. But in reality, an ethical approach aimed at maximizing lives saved results in prioritizing certain social groups. The easy lives to save will be those of people who already enjoy social privilege. As a population, younger, white, wealthy people will be more likely to derive benefit from the ICU resources and survive because they enjoy, on average, higher baseline health status.

Comorbidities are not evenly distributed amongst the population. Underlying health status correlates with privilege based ethnicity and wealth. Current evidence suggests that people with hypertension, cardiovascular disease, chronic obstructive pulmonary disease (COPD), and cancer are more likely to die from severe COVID19. In New Zealand for example prevalence of multimorbidity (two or more conditions) is higher for Māori (13.4%) and Pacific ethnic groups (13.8%) than for NZ Europeans (7.6% prevalence). Multimorbidity is also more common for people in areas of higher socio-economic deprivation. Māori aged 45 and over have a COPD hospitalisation rate over 3.5 times that of non-Māori. When you plug the clinical status of individuals into an ICU triage tool aimed at maximising population survival rates you will get results that reflect these social and ethnic divisions.

Exposure to coronavirus may also vary by socio-economic status. The ability to socially isolate is a luxury. According to US cell phone data, high income demographic groups have reduced their geographic scope of movement more significantly than lower income groups.

Prior epidemics in New Zealand have had disproportionate impact on Māori and Pacific peoples. This wasn't as a result of differential access to ICU, but probably does reflect vulnerabilities relating to underlying health status and access to medical care. The first ICUs were established in the late 1950s so access to ICU was not a relevant factor in the 1918 pandemic; and ICU access was not triaged during the 2009 pandemic in New Zealand. During the 1918 influenza pandemic, Māori in New Zealand died at eight times the rate of Europeans. During the 2009 H1N1 pandemic the mortality rate was 2.6 times higher for Māori and 5.8 times higher for Pacific peoples than European New Zealanders.

Maximising the number of lives saved is a function of (1) prognosis (chance of survival) and (2) length of time to benefit (how long each patient is likely to need ICU care). A key problem for utilitarianism has always been the accuracy of predictions. Standard scoring systems for ICU mortality are designed to predict capacity to benefit from ICU care. These include APACHE-II, sequential organ failure assessment (SOFA), and Simplified Acute Physiology Score. SOFA for example assesses the severity of the patient's clinical state based on function/dysfunction of six major organ systems. But how reliable are these scoring systems in predicting survival of severe COVID19 patients in ICU?

In China, the overall case-fatality rate (CFR) was 2.3%; but the CFR was higher for patients with pre-existing comorbid conditions—10.5% for cardiovascular disease, 7.3% for diabetes, 6.3% for chronic respiratory disease, 6.0% for hypertension, and 5.6% for cancer. The CFR was 49% among critical cases, but detailed information about critically ill COVID19 patients is scarce.

Analysis of emerging UK data published a week ago found that 7 COVID19 patients with severe comorbidities survived ICU (41.2%) whereas 10 died (58.8%). Is this data sufficient, either in quality or differential outcome, to suggest that those with even severe comorbidities should be denied access to ICU? If we are going to deny specific patient's access to ICU on the grounds of population utility we need a high degree of confidence in the clinical evidence.

Given this uncertainty, what can we do? I am not a health provider and not in a position to interpret the emerging clinical evidence or speak to the reliability of different ICU scoring systems. But as bioethicists are invited to consult on these triage tools we need to be asking hard questions about the reliability of the screening measures used to exclude certain patients.

Where there is uncertainty, we should err on the side of broader rather than stricter clinical criteria; meaning a wider range of patients get a shot at ICU, even where this is likely to be less efficient overall. Screening measures that include Quality Adjusted Life Years (QALYs) must be avoided as these are inherently biased against persons with disabilities. When resources are limited we need to allow time constrained ICU trials, and generate protocols for withdrawing ICU care. These are important mechanisms to give more people access to ICU. The following approach goes some way towards limiting the impact of comorbidities on access criteria:

“To address concerns about compounding injustices associated with systematic disadvantage and the arbitrariness of comorbidities, and unlike other approaches that have been proposed for ICU triage in a disaster, the scoring system described here affects patients whose comorbidities are so serious that they are expected to live no more than 12 months even with successful ICU treatment.”

Regardless of the specific number of patients who survive severe COVID19, we will need to tell a story about the values that guided us as a community in a time of crisis. The narratives that emerge during this pandemic will have a lasting legacy in bioethics. Public interest requires the responsive use of resources. But this does not exclusively entail maximizing utility. There is public interest in re-affirming human rights, the value of diversity, promoting fairness, and resisting entrenched privilege.

# Race, Racial Bias, and Health Care

In the twenty-first century, we want to believe that racial bias could not and does not infect modern science-based health care. But it can and it does. Research shows that the health of minority persons is generally worse than that of whites (often *much* worse)—and that the differences are not due primarily to racial or genetic inferiority or to personal or social preferences. To a very large extent, the differences derive from racial bias and inequities built into the very structures and institutions of society. We want to believe that people of color have the same access to health care as everyone else and that the care provided is as good as that provided to whites. But extensive evidence shows that this is not the case. We would like to think that racial profiling—which is so objectionable in law enforcement and schooling—does not exist in the clinic or hospital or doctor’s office. But despite the competence and compassion of well-meaning health care workers, it does.

To make moral sense of all this, we must first understand what race and racism are, and we must examine what recent scientific studies of racial bias in health and medicine have revealed.

## RACE AND RACISM

The basic presupposition of racism is that there are in fact such things as races—the notion that there are discrete groups of people who share certain essential, inherent characteristics. The traditional idea is that race is a matter of heritable *biological* features common to all members of a racial group and that these features explain the psychological and cultural traits of those

members. Race scholar Lawrence Blum points out that the popular idea of race generally omits the biological element but keeps the idea of *inherency*—the notion that “certain traits of mind, character, and temperament are inescapably part of a racial group’s ‘nature’ and hence define its racial fate.”<sup>1</sup> A group’s nature is supposed to be permanent and unchanging. On this conception of race, Whites are just naturally that way; Blacks are naturally this way; Jews have these inherent traits; Asians have these inherent characteristics; Native Americans have this inherent disposition. Racism, then, presupposes the idea that distinct races exist and that important, inherent differences among them can be distinguished. This presupposition alone, however, does not constitute racism. **Racism** is the additional belief that some races are inferior in these important ways or are otherwise deserving of dislike or hostility.

The two essential elements in this definition are what Blum calls *inferiorization* and *antipathy*. All forms of racism, he says, can be identified by reference to one or both of these concepts:

Inferiorization is linked to historical racist doctrine and racist social systems. Slavery, segregation, imperialism, apartheid, and Nazism all treated certain groups as inferior to other groups . . .

Though race-based antipathy is less related to the original concept of “racism,” today the term unequivocally encompasses racial bigotry, hostility, and hatred. Indeed, the racial bigot is many people’s paradigm image of a “racist.” . . .

Historical systems of racism did of course inevitably involve racial antipathy as well as

inferiorization. Hatred of Jews was central to Nazi philosophy; and it is impossible to understand American racism without seeing hostility to blacks and Native Americans as integral to the nexus of attitudes and emotions that shored up slavery and segregation.<sup>2</sup>

Racism is morally wrong, and shortly we'll examine exactly why that is. But racism is also *empirically* wrong—it is based on assumptions about the world that science has shown to be unfounded. The consensus among scientists and scholars is that the traditional view of races—that there are distinct groups of people sharing significant biological characteristics—is false. Race, in other words, has no physical scientific basis. Sociologist Tanya Maria Golash-Boza explains:

Race is a social construction, an idea we endow with meaning through daily interactions. It has no biological basis. This might seem odd to read, as the physical differences between a Kenyan, a Swede, and a Han Chinese, for example, are obvious. However, these physical differences do not necessarily mean that the world can be divided into discrete racial groups. If you were to walk from Kenya to Sweden to China, you would note incremental gradations in physical differences between people across space, and it would be difficult to decide where to draw the line between Africa and Europe and between Europe and Asia. There may be genetic differences between Kenyans and Swedes, but the genetic variations within the Kenyan population are actually greater than those between Swedes and Kenyans. Although race is a social, as opposed to a biological, construction, it has a wide range of consequences in our society, especially when used as a sorting and stratifying mechanism.<sup>3</sup>

Philosopher Naomi Zack, editor of *The Oxford Handbook of Philosophy and Race*, sums up the science like this:

There are no general genes for race, such that, once identified, their presence could be used to predict more specific, or secondary, racial

characteristics. None of the physical differences associated with racial difference in society is correlated with any important difference in human talent, function, or skill. . . .

To conclude, there is no foundation in science for racial difference, either on the basis of physical traits that in American society are believed to indicate biological racial membership, or on the basis of any traits that may be presumed to determine mental and psychological capabilities.<sup>4</sup>

If races don't exist in any biological sense—if there is no physical basis for sorting people into recognizable racial categories—then the central assumption underlying the traditional form of racism collapses.

Many people assume that the idea of race has been around since the dawn of history, but this assumption is incorrect. Historically, the idea that people can be divided into discrete groups based on their common biological and cultural traits is relatively new. In the ancient world, people did not think to categorize humanity into exclusive racial groups. They recognized that cultures might differ in various ways—in skin color, for example—but they did not lump all persons of a particular skin tone into a single social classification. The idea of race arose in different forms over time beginning only around the sixteenth century. Historians and sociologists maintain that as Europeans subjugated and enslaved Africans and native peoples in the Americas, the idea of inferior and superior races developed and was used to rationalize the unequal status and ill treatment of whole cultures.

In the nineteenth and early twentieth centuries, scientifically minded thinkers sought to prove that there were indeed separate races, that race could explain the basic differences among people, that some races were superior to others, and that the White European race was superior to all. These endeavors came to be known as *scientific racism*, and they have been largely discredited by modern science. Starting from dubious assumptions and drawing from data such as skull and brain measurements and

“intelligence” tests, these early investigators argued that European men were biologically more advanced and more intelligent than any other racial group and that these advantages explained their dominance in the world. Scientific research in later decades, however, debunked these conclusions by showing that they were based on obvious biases, faulty assumptions, methodological errors, and motivated reasoning.

So if race is a social construction, should we discard the concept of race altogether? Many who have studied this question are reluctant to do that. The political scientist Michael James, for example, says,

Race constructivists accept the skeptics’ dismissal of biological race but argue that the term still meaningfully refers to the widespread grouping of individuals into certain categories by society, indeed often by the very members of such racial ascriptions. Normatively, race constructivists argue that since society labels people according to racial categories, and since such labeling often leads to race-based differences in resources, opportunities, and well-being, the concept of race must be conserved, in order to facilitate race-based social movements or policies, such as affirmative action, that compensate for socially constructed but socially relevant racial differences.<sup>5</sup>

Even though races in the biological sense don’t exist, “racialized groups”—groups that people *believe* are discrete races and treat as such—do. Scholars contend that despite the nonexistence of biological race, giving up entirely our ability to talk and think about racialized groups and racial realities would have disastrous effects—which is why so many observers condemn the notion of racial color blindness. As Blum says,

Jettisoning race in the two ways I’ve mentioned (racial language and racial thinking) would have important moral costs as well. Many would be misled into thinking that if there are no races,

there can be no racism, no groups to be its target. But to be a target of racism requires only that a group is racialized, not that it is actually a race.

More fundamentally, race is part of our history and our current social arrangements. Groups defined by race are continuing targets of discrimination, inferiorizing, and stigmatizing. These groups, especially blacks, Native Americans, and some Latino/Hispanic groups, also live with accumulated deficits from even more horrendous injustices in the past. Whites possess a range of unearned advantages in virtually every major domain of social existence—education, jobs, health care, and political power; and often they harbor subtle assumptions that they are “all right” while other groups are defective in some way. If we give up race entirely, we abandon the ability to name these racial wrongs. . . . Color blindness has assumed the status of an almost absolute principle that further motivates whites to be blind to continuing racial discrimination and injustice.<sup>6</sup>

So racism involves either the idea that some racial groups are inferior to others or that some deserve dislike or hostility. It can be manifested in personal beliefs, attitudes, and actions, or in the activities, rules, or policies of governments and organizations. It can harm people through institutions and procedures—even when the persons behind those systems do not themselves harbor any racial prejudice.

Racism is widely regarded as a kind of moral failing, something of which most people would want never to be guilty; nor would they ever want to be called a racist, whether or not they are guilty of the charge.

Racism is morally wrong. But why?

Inferiorizing racism is morally wrong mainly because it is a violation of fundamental moral principles (discussed in Chapter 1). It violates the principle of *respect for persons*, the precept that persons are possessors of ultimate inherent worth and should be treated as such. Persons have rights—the rights of free expression, choice, and privacy, the right not to be coerced, enslaved, cheated, or discriminated against.

This form of racism also violates the *principle of justice*, the idea that people should get what is fair or what is their due or, more generally, that equals should be treated equally. People should be treated the same unless there is a morally relevant reason for treating them differently—and racial difference is *not* morally relevant.

Antipathy racism is morally blameworthy because hatred, hostility, and bigotry are vices, especially when they are directed against people who have been made to suffer solely because of their membership in a racial group. Antipathy racism, like the inferiorizing kind, has led to, and still leads to, racial conflict, suffering, injustice, and violence.

For many ethicists, racism is morally wrong simply because it hurts people. This is an appeal to another moral principle, the principle of *utility*, which says we should produce the most favorable balance of benefit over harm for all concerned. It is obvious that racist beliefs, words, and actions can do harm or lead to harm, and the harm is magnified when racism operates through institutions, corporations, governments, and the law.

Many today believe that racism and racial discrimination, despite a few racist incidents here and there, are a thing of the past. But most experts who have studied racism and race relations would strongly disagree. They say racism is indeed a significant problem in America, as evidenced by widespread racial inequalities at nearly every level of society. Naomi Zack asks,

How is it that in a post-civil rights age of racial equality, people of color are disproportionately undereducated, poor, incarcerated, and more likely to be treated violently by police? The contradiction between equality as stated in law and humanitarian and scientific consensus versus the reality of social inequality and injustice cannot be adequately addressed as a psychological or ethical issue, on the level of individuals. Deeper cultural, political, and economic analyses are required to explain why and how people behave in ways that appear to violate their highest and most general legal and moral principles.<sup>7</sup>

Here's a sketch of some of the more striking examples of racial inequality today, from the social scientist and race scholar Eduardo Bonilla-Silva:

Blacks and dark-skinned racial minorities lag well behind whites in virtually every area of social life; they are about three times more likely to be poor than whites, earn about 40 percent less than whites, and have about an eighth of the net worth that whites have. They also receive an inferior education compared to whites, even when they attend integrated institutions. In terms of housing, black-owned units comparable to white-owned ones are valued at 35 percent less. Blacks and Latinos also have less access to the entire housing market because whites, through a variety of exclusionary practices by white realtors and homeowners, have been successful in effectively limiting their entrance into many neighborhoods. Blacks receive impolite treatment in stores, in restaurants, and in a host of other commercial transactions. Researchers have also documented that blacks pay more for goods such as cars and houses than do whites. Finally, blacks and dark-skinned Latinos are the targets of racial profiling by the police, which, combined with the highly racialized criminal court system, guarantees their overrepresentation among those arrested, prosecuted, incarcerated, and if charged for a capital crime, executed. Racial profiling on the highways has become such a prevalent phenomenon that a term has emerged to describe it: driving while black. In short, blacks and most minorities are "at the bottom of the well."<sup>8</sup>

How do we explain these inequalities? And how is it that many Whites claim not to see racism? According to Bonilla-Silva,

Nowadays, except for members of white supremacist organizations, few whites in the United States claim to be "racist." Most whites assert they "don't see any color, just people"; that although the ugly face of discrimination is still with us, it is no longer the central factor determining minorities' life chances; and, finally, that, like Dr. Martin

Luther King Jr., they aspire to live in a society where “people are judged by the content of their character, not by the color of their skin.” More poignantly, most whites insist that minorities (especially blacks) are the ones responsible for what “race problem” we have in this country. . . . Most whites believe that if blacks and other minorities would just stop thinking about the past, work hard, and complain less (particularly about racial discrimination), then Americans of all hues could “all get along.”<sup>9</sup>

If Whites do see contemporary racial inequality, says Bonilla-Silva, they are likely to blame it on nonracial factors:

Whites rationalize minorities’ contemporary status as the product of market dynamics, naturally occurring phenomena, and blacks’ imputed cultural limitations. For instance, whites can attribute Latinos’ high poverty rate to a relaxed work ethic (“the Hispanics are mañana, mañana, mañana—tomorrow, tomorrow, tomorrow”) or residential segregation as the result of natural tendencies among groups (“Does a cat and dog mix? I can’t see it. You can’t drink milk and scotch. Certain mixes don’t mix.”).<sup>10</sup>

For many people, racism is basically **individual racism**, person-to-person acts of intolerance or discrimination. But as we’ve seen, a prevalent, seldom acknowledged kind of racism is **institutional or structural racism**, unequal treatment that arises from the way organizations, institutions, and social systems operate. This is inferiorizing or antipathy racism that functions almost unseen in corporations, government agencies, schools, the labor market, and systems of health care, housing, and criminal justice. The people who work within such systems may or may not be racially prejudiced, but the systems themselves cause racial discrimination and inequality through their policies and procedures.

Both individuals and systems can perpetuate racial prejudice or racial discrimination. **Racial prejudice** is antipathy toward a racial group based on a faulty view of that group. **Racial**

**discrimination** is unfavorable treatment of people because of their race. Of course, prejudice and discrimination can be directed at traits other than race, including sexual orientation, age, gender, ethnicity, religion, and national origin.

Overt, individual racism (the kind voiced publicly in racial slurs, for example) may be less common these days, but scholars insist that institutional or structural racism is common and nearly invisible. According to Bonilla-Silva:

Contemporary racial inequality is reproduced through “new racism” practices that are subtle, institutional, and apparently nonracial. In contrast to the Jim Crow era, where racial inequality was enforced through overt means (e.g., signs saying “No Niggers Welcomed Here” or shotgun diplomacy at the voting booth), today racial practices operate in a “now you see it, now you don’t” fashion. For example, residential segregation, which is almost as high today as it was in the past, is no longer accomplished through overtly discriminatory practices. Instead, covert behaviors such as not showing all the available units, steering minorities and whites into certain neighborhoods, quoting higher rents or prices to minority applicants, or not advertising units at all are the weapons of choice to maintain separate communities. In the economic field, “smiling face” discrimination (“We don’t have jobs now, but please check later”), advertising job openings in mostly white networks and ethnic newspapers, and steering highly educated people of color into poorly remunerated jobs or jobs with limited opportunities for mobility are the new ways of keeping minorities in a secondary position. Politically, although the civil rights struggles have helped remove many of the obstacles for the electoral participation of people of color, racial gerrymandering, multimember legislative districts, election runoffs, annexation of predominately white areas, at-large district elections, and anti-single-shot devices (disallowing concentrating votes [on] one or two candidates in cities using at-large elections) have become standard practices to disenfranchise people of color.<sup>11</sup>

Today Blacks fare much worse than Whites in income, wealth, education, employment, home ownership, and health (discussed in the next section). These inequalities are caused by racist policies and conditions of the past, and they have in most cases been allowed to continue or been made worse by inequalities in the present.

A good example is racial inequalities in wealth. Income is the money an individual earns from work, but wealth consists of a person's total assets—cash and property (land, houses, cars, savings, investments), minus debt. In the United States, in 2016, the typical Black household could claim just \$13,024 in wealth, while a typical White household had \$149,703.<sup>12</sup> The vast difference can be explained by a history of official and unofficial anti-Black discrimination. According to Golash-Boza:

One of the main reasons for the inability of blacks to build wealth has been the creation of housing segregation within U.S. cities. . . .

A combination of three forces led to residential segregation: collective racial violence carried out by whites, federal housing programs and policies that exclusively benefited whites, and practices created and reinforced by the nascent real estate industry. . . .

The Federal Housing Administration (FHA) was established in 1934 with the purpose of bolstering the economy and, in particular, the construction industry. . . . The FHA created the conditions under which banks could loan people money to purchase homes with small down payments and at reasonable interest rates. . . .

Banks used FHA guidelines to decide who should be permitted to borrow money. The 1938 *Underwriting Manual* of the FHA stated that "if a neighborhood is to retain stability, it is necessary that properties shall continue to be occupied by the same social and racial classes." . . . The *Manual* also endorsed a practice known as *redlining*, in which communities where loans were not recommended were outlined in red on a map. Those communities where loans were denied were primarily black.

Between 1933 and 1978, U.S. government policies enabled over 35 million families to increase their wealth through housing equity. As homeowners, millions of Americans were able to begin to accumulate tax savings, home equity, economic stability, and other benefits associated with homeownership. White Americans benefited disproportionately from this shift for two primary reasons: (1) it was easier for white people to purchase homes, and (2) the homes that whites bought increased in value more rapidly than those purchased by blacks because of the perceived desirability of all-white neighborhoods. . . .

The final factor that contributed to residential segregation was *racially restrictive covenants*—contractual agreements that prevent the sale or lease of property within an area to non-whites—created and enforced by the real estate industry. By the 1920s, deeds in nearly every new housing development in the northern United States prevented the ownership or rental of houses in the development by anyone who was not white. . . .

In 1948, the Supreme Court declared racially restrictive covenants unenforceable. And in 1968, the passage of the Fair Housing Act made these covenants illegal. Once the covenants became illegal, real estate agents developed new tactics to preserve residential segregation. One of the most common activities was *steering*, in which real estate agents would show homes in white neighborhoods only to whites and homes in black neighborhoods only to blacks. For these and other reasons, over sixty years after the passage of the Fair Housing Act, we still have high levels of residential segregation, exacerbating wealth inequality.<sup>13</sup>

Racial disparities in education have also been linked to racial segregation, prejudice, and discrimination—while many Whites incorrectly assume the inequalities are due to minority children's mental deficiencies. Most scholars reject this psychological explanation, as Lawrence Blum explains:

The idea that conventionally defined racial groups differ in intelligence has been largely

discredited by contemporary science, and popular adherence to it has declined sharply. But it has by no means entirely disappeared in popular thought, and a more statistically based form has arisen in genetic science as well. In the United States, both forms are encouraged by a basic fact on the ground in education—often referred to as the “achievement gap”—that by almost every plausible measure, black, Native American, and Latino students do not do as well in school as white and Asian students. This gap encourages the view that there is something educationally deficient about black, Latino, and Native American students. Racial achievement gaps can be explained by a range of factors, most of which concern black and Latino students’ circumstances rather than their innate capacities—poorer health among disadvantaged racial minorities; less parental education, which disadvantages students in various different ways; lower parental socio-economic status (SES), often leading to unstable home and living situations and moving from school to school; stress from not having decent and regular employment; teacher racial prejudice, ignorance and insensitivity; living in neighborhoods of concentrated disadvantage; and cultural factors relating to school engagement among minority youth.<sup>14</sup>

## **HEALTH DISPARITIES AND RACE**

*Health disparities* are differences among population groups in mortality and disease. For thirty years, researchers have been finding significant health disparities between Whites and minorities, with the latter often faring worse.<sup>15</sup> The urgent question is why these disparities exist, and more recent investigations have been yielding answers.

Researchers have found the most telling—and most worrisome—disparities in three areas: infant mortality, life expectancy, and age-adjusted death rates.

Infant mortality is a sign of both infant and maternal health and is regarded as a key indicator of the health of a country. Infant mortality

rates are expressed as the number of infants who die before their first birthday per 1,000 live births. According to a landmark report on health disparities from the National Institutes of Health (NIH),

U.S. infant mortality rates have decreased since 2005 for the overall population and within each racial and ethnic group; however, sharp racial and ethnic disparities persist. In 2013, as in previous years, the infant mortality rate among African Americans (11.1 per 1,000 live births) was double the rate among whites (5.06 per 1,000 live births). American Indians/Alaska Natives and Puerto Ricans also experienced higher infant mortality rates (of 7.61 and 5.93 per 1,000 live births, respectively) than whites. . . . If white America and black America were two separate nations, white America’s infant mortality rate would rank 49th in the world, while black America’s would be ranked 95th out of 224 nations . . . following Botswana, Sri Lanka, the United Arab Emirates, and Turks and Caicos Islands. . . .

In 2015 the percentage of low-birthweight infants rose for the first time in 7 years. For white infants, the rate of low-birthweight infants was essentially unchanged, but for African American and Hispanic infants, the rate increased.<sup>16</sup>

Premature birth signals an increased risk of infant death. In 2014, non-Hispanic Black mothers had a higher percentage of preterm births than any other racial or ethnic group.

Life expectancy is a measure of the overall health of a population, typically expressed as the average number of years a newborn would be expected to live. It reflects the degree to which fundamental living conditions of a society—socioeconomic, environmental, and health care related—help people live a long and healthy life. From the NIH report:

Better living conditions and better access to health care-related resources throughout the lifespan extend longevity. From 1980 to 2014, U.S. life expectancy (at birth) increased by

approximately 6 years for males, reaching 76.4 years, and increased 3 years for females, reaching 81.2 years. Racial and ethnic disparities decreased, but they were not eliminated. In 2014, the life expectancy for African American males was 72.0 years, while that for white males was 76.5 years and that for Latino males was 79.2 years. In the same year, life expectancy was 78.1 years for African American females, 81.1 years for white females, and 84.0 years for Latina females.<sup>17</sup>

Age-adjusted mortality rates sum up deaths in a population from all causes except old age. The age-adjusted death rate per 100,000 (for the years 2012–2014) was 729.1 for Whites and 858.1 for Blacks.<sup>18</sup> The death rate due to heart disease was 165.9 deaths per 100,000 for Whites and 206.3 deaths for Blacks. For cancer the death rate was 161.9 for Whites but 185.6 for Blacks; for diabetes, 19.3 for Whites, 37.3 for Blacks.<sup>19</sup>

Another important benchmark is the potential life lost due to early death, measured in “person-years per 100,000 before the age of 75.” On this score, non-Hispanic Whites lost 6,659.4 years; non-Hispanic Blacks lost 9,490.6 years; and American or Alaska Natives lost 6,954.0 years.<sup>20</sup>

What causes all these health disparities? It is tempting to lay most of the blame on what sociologists call socioeconomic status (income, education, etc.), but this explanation is too simplistic. According to the NIH,

It is well documented that low socioeconomic status (SES) hampers an individual’s ability to achieve optimal health by limiting access to health-preserving resources. However, SES does not fully explain health disparities based on race and ethnicity, sexual orientation and gender identity.<sup>21</sup>

Most research on this question points instead to society’s structural inequities, the systematic disadvantage of particular social groups in relation to others. When racial groups are affected in this way, the problem is structural racism, a well-documented fact of American life.<sup>22</sup> The NIH report says,

The evidence linking racism to health disparities is expanding rapidly. A variety of both general and disease-specific mechanisms have been identified; they link racism to outcomes in mental health, cardiovascular disease, birth defects, and other outcomes. Which racism mechanisms matter most depends in part on the disease and, to a lesser degree, the population. The vast majority of studies focus on the role of discrimination; that is racially disparate treatment from another individual or, in some cases, from an institution. Among the studies not focused on discrimination, the majority examine segregation. Generally, findings show that members of all groups, including whites, report experiencing racial discrimination, with levels typically, though not always, higher among African Americans and, to a lesser degree, Hispanics than among whites.<sup>23</sup>

Racial discrimination can lead to health disparities via several paths:

The mechanisms by which discrimination operates include overt, intentional treatment as well as inadvertent, subconscious treatment of individuals in ways that systematically differ so that minorities are treated worse than nonminorities. Recent meta-analyses suggest that racial discrimination has deleterious effects on the physical and mental health of individuals. Significant percentages of members of racial and ethnic minority populations report experiencing discrimination in health care and non-health care settings. Greater proportions of African Americans than members of other groups report either experiencing discrimination personally or perceiving it as affecting African Americans in general, even if they have not experienced it personally. Hate crimes motivated by race or ethnicity bias disproportionately affect Hispanics and African Americans. . . .

Discrimination is generally associated with worse mental health; greater engagement in risky behaviors; decreased neurological responses; and other biomarkers signaling the dysregulation of allostatic load [cumulative burden of chronic

stress and life events]; hypertension-related outcomes, though some evidence suggests racism does not drive these outcomes; reduced likelihood of some health protecting behaviors; and poorer birth-related outcomes such as preterm delivery. . . .

Though people may experience overt forms of racism (e.g., being unfairly fired on the basis of race), the adverse health effects of racism appear to stem primarily from the stress of chronic exposure to seemingly minor forms of “everyday racism” (i.e., racial microaggressions), such as being treated with less respect by others, being stopped by police for no apparent reason, or being monitored by salespeople while shopping. The chronic exposure contributes to stress-related physiological effects. Thus, discrimination appears to exert its greatest effects not because of exposure to a single life traumatic incident but because people must mentally and physically contend with or be prepared to contend with seemingly minor insults and assaults on a near continual basis. The implications appear to be greatest for stress-related conditions such as those tied to hypertension, mental health outcomes, substance abuse behaviors, and birth-related outcomes (e.g., low birth weight and premature birth) than for other outcomes.<sup>24</sup>

Racial segregation is also a powerful force driving health disparities:

Residential segregation—that is, the degree to which groups live separately from one another—can exacerbate the rates of disease among minorities, and social isolation can reduce the public’s sense of urgency about the need to intervene. . . . Racial segregation contributes to disparities in a variety of ways. It limits the socioeconomic resources available to residents of minority neighborhoods as employers and higher SES individuals leave the neighborhoods; it reduces health care provider density in predominately African American communities, which affects access to health care; it constrains opportunities to engage in recommended health behaviors such as walking; it may be associated with greater

density of alcohol outlets, tobacco advertisements, and fast food outlets in African American and other minority neighborhoods; it increases the risk for exposure to environmental hazards; and it contributes to the mental and physical consequences of prevalent violence, including gun violence and aggressive policing.<sup>25</sup>

## **IMPLICIT BIAS IN HEALTH CARE**

A substantial body of evidence shows that racial and ethnic bias is a serious problem in health care. In 2003, after reviewing over one hundred studies, the Institute of Medicine (IOM) issued a momentous report concluding that bias and prejudice led to widespread differences in health care by race and ethnicity.<sup>26</sup> In the two decades that followed, mounting evidence confirmed the original findings. Scholars commenting on the report said the IOM

documented that from the simplest to the most technologically advanced diagnostic and therapeutic interventions, African American (or black) individuals and those in other minority groups receive fewer procedures and poorer-quality medical care than white individuals. These differences existed even after statistical adjustment for variations in health insurance, stage and severity of disease, income or education, comorbid disease, and the type of health care facility. Very limited progress has been made in reducing racial/ethnic disparities in the quality and intensity of care.

This is a shocking finding, especially considering what we know about the benign attitudes and motivations of health care providers. A scholar who has thoroughly investigated this inconsistency is Dayna Bowen Matthew. She notes that

When compared with other professionals, health providers express overwhelmingly altruistic, fair, and equitable motivations towards their work and the patients they serve. Doctors are well educated and therefore can be expected to be enlightened

about equality matters. They are self-described as members of a “helping” and “healing profession,” and throughout their training they adhere to a commitment to “first, do no harm” to patients. Many physicians are actively dedicated to achieving equity and distributive justice in health care, often giving their time freely to serve needy populations at home and abroad. . . .

However, a vast body of social science research describes hundreds of experiments, in scores of medical journals, across virtually every major medical specialty that confirm that a patient’s race and ethnicity continue to influence physicians’ medical conduct and decision-making, well beyond the limits of what is clinically justifiable.<sup>27</sup>

What is the explanation for this contradiction? The NIH, the IOM, and a host of investigators point to the phenomenon of **implicit bias**, a negative attitude toward a group of people that operates *unintentionally* or *unconsciously*. Four decades of research have demonstrated that virtually everyone has implicit biases, that discriminatory behavior can be predicted based on such biases, and that implicit biases often have a more powerful impact on behavior than explicitly held beliefs. Physicians are not immune to this very human failing. As Matthew says,

The empirical evidence that race and ethnicity influence physicians to make harmful distinctions in how they treat and interact with white patients versus patients of color is overwhelming. A preponderance of evidence compels the conclusion that the vast majority of provider discrimination causing disparities is a product of implicit, not explicit bias. Physicians’ implicit biases lead to unintentional and in some cases, even unconscious discrimination. The resulting biased behavior may directly contradict the physician’s sincerely held, explicit beliefs and intentions to provide excellent care to all patients regardless of their race or ethnicity.<sup>28</sup>

The NIH report concurs:

Much of the public health literature has focused on the implicit biases of health care providers, who with little time to devote to each patient can provide care that is systematically worse for African American patients than for white patients even though the health care provider never intended to do so. The evidence is clear that unconscious racialized perceptions contribute to differences in how various individual actors, including health care providers, perceive others and treat them. Based on psychology lab experiments, functional magnetic resonance imaging (fMRI) pictures of the brain, and other tools, researchers find that white providers hold implicit biases against African Americans and that, to a lesser degree, some minority providers may also hold these biases. Although not limited to health care professionals, the biases lead providers to link negative characteristics (e.g., bad) and emotions (e.g., fear) with people or images they perceive as being African American. As a result of such implicit biases, physicians treat patients differently depending on the patient’s race, ethnicity, gender, or other assumed or actual characteristics.<sup>29</sup>

Matthew asks us to imagine this scenario:

If a white, male family-practice physician with a largely white patient population walks into a new patient’s room and encounters an elderly African American woman, immediately and automatically the physician begins to retrieve information from his memory to help him navigate this unfamiliar scene. Even before speaking his first words, the physician will subconsciously recall images stored in memory to help him interact with his new patient. Those images—his “social group knowledge”—may be from television news stories about blacks in poverty, African American incarceration rates, or the war on drugs in black and Hispanic neighborhoods. The physician may be well-read and familiar with studies reported in the *Wall Street Journal* or the *Los Angeles* or *New York Times* about the rate at which African

Americans graduate from college, drop out of high school, or lag in their standardized test performances. . . . Taken together, all of these images “trigger” stereotypes in the subconscious mind. . . .

If asked, the physician would truthfully admit to harboring no ill will toward African Americans generally or toward this African American patient specifically. Yet, without consciously thinking about it, the physician is likely to have made some implicit assumptions about his patient even before meeting her. . . . But the fact that this physician’s assumptions and stereotypes—his implicit biases—are neither irrational nor consciously chosen, does not mean that the discrimination that arises from them will not be extremely harmful to his new patient’s health. Indeed, her health and health care are quite likely to be adversely affected by these biases from the moment the clinical encounter with her begins. Even in those instances when physicians react with sympathetic compassion in response to the negative stereotypes triggered in their subconscious, the evidence is that the treatment choices they make as a result, such as withholding complex information or deferring expensive treatments, are more likely

to harm rather than improve a minority patient’s health.<sup>30</sup>

## RACIAL PROFILING IN MEDICINE

Using race as a factor in determining appropriate treatment for patients has been called “race-based medicine,” and it is controversial. Some physicians see race as a useful data point in customizing treatments for persons perceived to belong to particular racial groups. But a growing number of experts say the practice is built on a groundless supposition—that race is a reliable indicator of genetic differences—and that basing treatments on considerations of race may harm patients. They argue that using race this way is a form of racial profiling that is as morally suspect as racial profiling in law enforcement.

One of these experts is the philosopher Michael Root:

Many doctors believe that racial profiling in medicine is reasonable and fair even if racial profiling in law enforcement is not; stopping a motorist based on [his] race is wrong, but, in their

### IN DEPTH CAN IMPLICIT BIASES BE CHANGED?

The good news about implicit biases is that they are alterable. Matthew summarizes the relevant research:

Social scientists have developed a body of empirical evidence that shows implicit biases are malleable over the past quarter century. The empirical record is now well established and offers strong evidence that implicit attitudes are neither inaccessible nor inescapable; they are

not impossible to control; they are not out of reach. In fact, implicit associations can be influenced both by the individual who unconsciously holds these stereotypes and prejudices and by external factors. Researchers have reported and reviewed numerous studies that put two important misconceptions about implicit biases to rest. First, the evidence demonstrates that unconscious implicit attitudes are responsive to the deliberate choices and influences of an individual even though that person is not consciously experiencing the bias. Second, implicit biases are not impervious to relatively short-term change even though they arise from social knowledge that was acquired slowly, and over a lifetime.<sup>31</sup>

eyes, prescribing a drug to a patient based on his race is unobjectionable.<sup>32</sup>

Consider this scenario, Root says, where doctors use race in deciding which drug treatment to use:

According to recent population-level studies of drugs for congestive heart failure, whites respond better to some drugs, such as angiotensin-converting-enzyme (ACE) inhibitors, than blacks do. Based on these studies, doctors use race as a proxy for a response to an ACE inhibitor when they target their white patients for the drug but not their black ones. . . . Doctors do not know how an individual patient will respond to the drug, but they know or think they know a patient's race, and given the correlation between drug response and race, they predict that a white patient will respond well to an ACE inhibitor, whereas a black one will not.<sup>33</sup>

But using a patient's race to make predictions like this is problematic:

First, to select whites but not blacks for a drug treatment based on a population-level study ignores intraracial differences in response to the drug and adversely affects black patients for whom the "white" drug would be an effective treatment. Though the ACE study showed that whites and blacks as a group respond differently to the drug, it also showed that a significant number of blacks respond as well as whites do to the drug.

Second, targeting blacks assumes that race is the best predictor available, but the rate at which a drug is metabolized varies as a result of many factors, including environment and lifestyle. Most studies that show a racial difference in drug response do not control for differences between black and white patients in socioeconomic status (SES) or other factors that are known to influence drug metabolism. . . .

Third, even if the difference between blacks and whites in drug response is due to a biological (genetic) difference, there is no reason to treat race as an independent variable that causes or explains the difference, since the genes

controlling drug response vary independently of race.<sup>34</sup>

Race is biasing many of the standard tools used by physicians to make decisions about patient care. According to a recent report in the *New England Journal of Medicine*:

Despite mounting evidence that race is not a reliable proxy for genetic difference, the belief that it is has become embedded, sometimes insidiously, within medical practice. One subtle insertion of race into medicine involves diagnostic algorithms and practice guidelines that adjust or "correct" their outputs on the basis of a patient's race or ethnicity. Physicians use these algorithms to individualize risk assessment and guide clinical decisions. By embedding race into the basic data and decisions of health care, these algorithms propagate race-based medicine. Many of these race-adjusted algorithms guide decisions in ways that may direct more attention or resources to white patients than to members of racial and ethnic minorities. . . .

Most race corrections implicitly, if not explicitly, operate on the assumption that genetic difference tracks reliably with race. If the empirical differences seen between racial groups were actually due to genetic differences, then race adjustment might be justified: different coefficients for different bodies.

Such situations, however, are exceedingly unlikely. Studies of the genetic structure of human populations continue to find more variation within racial groups than between them. Moreover, the racial differences found in large data sets most likely often reflect effects of racism—that is, the experience of being black in America rather than being black itself—such as toxic stress and its physiological consequences. In such cases, race adjustment would do nothing to address the cause of the disparity. Instead, if adjustments deter clinicians from offering clinical services to certain patients, they risk baking inequity into the system.<sup>35</sup>

Root thinks stratifying health statistics by race is reasonable—as long as income, education, employment, housing, and other factors are

stratified by race. “But to use race as a proxy for a response to a medical treatment,” he says, “is questionable because members of the same race often differ as much in their response to a medical treatment as members of different races do.”<sup>36</sup>

### KEY TERMS

- implicit bias
- individual racism
- institutional or structural racism
- racial discrimination
- racial prejudice
- racism

### SUMMARY

Racism presupposes the idea that distinct races exist and that important, inherent differences among them can be distinguished. This presupposition alone, however, does not constitute racism. Racism is the additional belief that some races are inferior in these important ways or are otherwise deserving of dislike or hostility. The two essential elements in this definition are *inferiorization* and *antipathy*.

Racism is morally wrong, and it is also empirically wrong—it is based on assumptions about the world that science has shown to be unfounded. The consensus among scientists and scholars is that the traditional view of races—that there are distinct groups of people sharing significant biological characteristics—is false. But even though races in the biological sense don’t exist, “racialized groups”—groups that people *believe* are discrete races and treat as such—do. Scholars contend that despite the non-existence of biological race, giving up entirely our ability to talk and think about racialized groups and racial realities would have disastrous effects—which is why so many observers condemn the notion of racial color blindness.

Although many today believe racism and racial discrimination are a thing of the past, most experts who have studied racism and race relations strongly disagree. They say racism is indeed a significant problem in America, as evidenced by widespread racial inequalities at nearly every level of society. For many people,

racism is basically individual racism, person-to-person acts of intolerance or discrimination. But a prevalent, seldom-acknowledged kind of racism is institutional or structural racism, unequal treatment that arises from the way organizations, institutions, and social systems operate. An enormous body of sociological and historical evidence shows that huge inequalities between Whites and minorities exist in education, wealth, health, and home ownership—and these disparities have been caused and perpetuated largely through discrimination, segregation, and other forms of structural racism.

Health disparities are differences among population groups in mortality and disease. For thirty years, researchers have been finding significant health disparities between Whites and minorities, with the latter often faring worse. The most worrisome disparities can be found in infant mortality, life expectancy, and age-adjusted death rates. Research suggests that a significant cause of these disparities is various forms of structural racism.

Research reveals that a widespread problem in health care is implicit bias, a negative attitude toward a group of people that operates unintentionally or unconsciously. Decades of studies have demonstrated that virtually everyone has implicit biases, that discriminatory behavior can be predicted based on such biases, that implicit biases often have a more powerful impact on behavior than explicitly held beliefs, and that health care providers are not immune to this very human failing.

Using race as a factor in determining appropriate treatment for patients has been called “race-based medicine.” Some physicians see race as a useful data point in customizing treatments for persons perceived to belong to particular racial groups. But a growing number of experts say the practice is built on a groundless supposition—that race is a reliable indicator of genetic differences—and that basing treatments on considerations of race may harm patients. They argue that using race this way is a form of racial profiling that is as morally suspect as racial profiling in law enforcement.

## Cases for Evaluation

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### CASE 1

#### Racial Bias in Health Care Algorithms

(*Nature*)—An algorithm widely used in US hospitals to allocate health care to patients has been systematically discriminating against black people, a sweeping analysis has found.

The study, published in *Science* on 24 October 2019, concluded that the algorithm was less likely to refer black people than white people who were equally sick to programmes that aim to improve care for patients with complex medical needs. Hospitals and insurers use the algorithm and others like it to help manage care for about 200 million people in the United States each year.

This type of study is rare, because researchers often cannot gain access to proprietary algorithms and the reams of sensitive health data needed to fully test them, says Milena Gianfrancesco, an epidemiologist at the University of California, San Francisco, who has studied sources of bias in electronic medical records. But smaller studies and anecdotal reports have documented unfair and biased decision-making by algorithms used in everything from criminal justice to education and health care.

“It is alarming,” says Gianfrancesco of the latest study. “We need a better way of actually assessing the health of the patients.”

Ziad Obermeyer, who studies machine learning and health-care management at the University of California, Berkeley, and his team stumbled onto the problem while examining the impact of programmes that provide additional resources and closer medical supervision for people with multiple, sometimes overlapping, health problems. . . .

The scientists speculate that this reduced access to care is due to the effects of systemic racism, ranging from distrust of the health-care system to direct racial discrimination by health-care providers.\*

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*Who, if anyone, should be held responsible for the harm caused by this algorithm? What should be done to ensure that racially biased algorithms stop causing unjust outcomes?*

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\*Heidi Ledford, “Millions of Black People Affected by Racial Bias in Health-Care Algorithms,” *Nature*, October 24, 2019.

### CASE 2

#### Using Race to Calculate Risk

(*New England Journal of Medicine*)—The Society of Thoracic Surgeons produces elaborate calculators to estimate the risk of death and other complications during surgery. The calculators include race and ethnicity because of observed differences in surgical outcomes among racial and ethnic groups; the authors acknowledge that the mechanism underlying these differences is not known. An isolated coronary artery bypass in a low-risk white patient carries an estimated risk of death of 0.492 percent. Changing the race to “black/African American” increases the risk by nearly 20 percent, to 0.586 percent. Changing to any other race or ethnicity does not increase the estimated risk of death as compared with a white patient, but it does change the risk of renal failure, stroke, or prolonged ventilation. When used preoperatively to assess risk, these calculations could steer minority patients, deemed to be at higher risk, away from surgery.\*

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*Is this surgery risk calculator unfair to African Americans and ethnic groups? Does it make sense to use race and ethnicity in the calculator even though the mechanism behind the observed differences in surgical outcomes among racial and ethnic groups is unknown? Is this use of race and ethnicity as a proxy for risk legitimate?*

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\*Darshali A. Vyas, Leo G. Eisenstein, and David S. Jones, “Hidden in Plain Sight—Reconsidering the Use of Race Correction in Clinical Algorithms,” *New England Journal of Medicine* 383(2020): 874–82.

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**CASE 3****Racial Bias in the Emergency Room**

(*Harvard Health Blog*)—A patient of mine recently shared a story with me about her visit to an area emergency room a few years ago. She had a painful medical condition. The emergency room staff not only did not treat her pain, but she recounted: “They treated me like I was trying to play them, like I was just trying to get pain meds out of them. They didn’t try to make any diagnosis or help me at all. They couldn’t get rid of me fast enough.”

There was nothing in her history to suggest that she was pain medication seeking. She is a middle-aged, churchgoing lady who has never had issues with substance abuse. Eventually, she received a diagnosis and appropriate care somewhere else. She is convinced that she was treated poorly by that emergency room because she is black.\*

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*Assuming this story is true, and given the well-documented existence of racial bias in health care, how likely is it that the woman was treated poorly because she is Black? Would it be reasonable to dismiss her story out of hand, as some people might be tempted to do? If you were in charge of the personnel and policies of this emergency room, what changes, if any, would you make to ensure that such incidents do not happen in the future?*

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## READING

### Racial Profiling in Medicine

MICHAEL ROOT

Root explains how race as a category is used both in population studies to track mortality and morbidity and in the clinic to diagnose and treat patients. He argues that for several reasons assigning race to people is a dubious process and that using race in the treatment of patients is a form of racial profiling that may harm patients.

Race is used as a category in the biomedical sciences at two levels: the population and individual. In population-level studies, race is used to describe or explain variations in morbidity and mortality; at

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From Michael Root, "Race in the Biomedical Sciences," in *The Oxford Handbook of Philosophy and Race*, Naomi Zack, ed. (New York: Oxford University Press, 2017), 463–473.

the individual level, race is used in the clinic in the diagnosis and treatment of individual patients. Both uses are controversial and raise questions about the nature and importance of racial categories in science and everyday life. But one, the use of race in the clinic, is more controversial.

The use of race in the biomedical sciences at the population level is considered in the first five

sections and at the individual level in the last three. The first two sections describe the history of racial categories and their use in population surveys in the United States and especially within epidemiology. The third section considers how individuals are assigned to today's official racial categories, the fourth the category of mixed race, and the fifth the relation between race and ancestry. The sixth section considers the use of race as a proxy and the seventh and eighth consider racial profiling in medicine.

### Racial Categories

The term "race" first appeared in English in the sixteenth century and was used to pick out and group people based on their looks, customs, and (suspected) origin or ancestry. However, in the eighteenth and nineteenth centuries, "race" acquired a specifically biological meaning, and the groups picked out as different races came to be viewed as different subspecies or lineages of man (Banton 1977). The biological concept of race was accompanied by the belief that members of some races are superior in ability or virtue to members of others and was often invoked to justify the control of one group of people by another and, in particular, to defend the Atlantic slave trade and the colonization of Africa and Asia by the countries of Europe.

Biological conceptions of race persist and, though contested by social as well as biological scientists, continue to shape how race is understood or talked about. Ashley Montague argued in a number of popular books and articles (Montague 1980) that race is a social rather than biological category, and Franz Boas showed that the cross-cultural generalizations advanced by proponents of the biological conception of race were mistaken (Boas 1982). Richard Lewontin maintained, based on research in population genetics, that the genetic differences between blacks in the United States are as great as any between blacks and whites (Lewontin 1972). At the level of genes, Lewontin argued, blacks do not differ from whites any more than they differ from one another; race, in this respect, is not biological.

People in the United States have classified each other by race since the founding of the country but not always in the same way. The federal government

has classified people in the United States by race since the first Census in 1790, but the racial groups into which people were placed changed from one decade to another. There were nine Census races in 1930 and five in 2000, and six of the nine races in 1930 were not races at all in the 2000 Census (Bennett 2000).

In 1930, ethnic Japanese and ethnic Koreans in the United States were members of different races. In 2000, they were members of the same. Many blacks in 2000 would have been mulattos had they lived in 1880. To the extent that race is a social rather than biological category, an individual's race can change with time and place even if his skin color and ancestry remain the same.

To classify members of a population by race, a member has to be assigned to one or more of a fixed number of racial categories. Most biomedical researchers, when classifying members of the US population by race, rely on the classification system and standards for the collection and presentation of data on race adopted by an agency of the federal government, the Office of Management and Budget ([OMB] 1997).

According to an OMB directive (Directive 15), there are five races, with five racial categories (black; white; American Indian or Alaskan Native; Asian; Native Hawaiian or Other Pacific Islander) into which members of the United States are to be classified or grouped whenever their race is counted or reported. These five categories provide a minimum standard for maintaining, collecting, and presenting data on race for federal reporting purposes and are used to code all health data collected by an agency of the US government.

Population studies of health risks in the United States rely on these government data and on the federal government's five racial categories in describing or explaining how the risk of mortality and morbidity in the population varies with race. These categories are also used to classify patients within a hospital or clinic; patients are routinely assigned an OMB race when they enter, and their assigned race becomes part of their medical record.

Most biomedical researchers follow the federal government and treat race and ethnicity as different categories. A member of the US population,

according to the OMB, can be Hispanic and a member of any of five races, and a member of any OMB race can be Hispanic or belong to any of a variety of different ethnic groups. As a result, Hispanics in the United States can be either black or white, and the health risks of black and white Hispanics can be different.

### **Population Studies**

Using the five OMB categories in their studies of differences in health within the US population, epidemiologists routinely find that the rates of many diseases, including major infectious diseases, many cancers, diabetes, asthma, and stroke, are different between the races. In addition, they find that blacks in the United States are seven times as likely to die of tuberculosis as whites and three times as likely to die of HIV/AIDS. Black infants are twice as likely to die as white infants, and black adults are twice as likely as white adults to die of stroke, heart disease, and diabetes. All-cause mortality rates in the United States, research shows, are 50 percent higher for black than white women and 70 percent higher for black than white men. In short, with a few exceptions, people classified as “black” have a poorer health profile than those classified as “white” (Agency for Healthcare Research and Quality 2008). Given the differences between the OMB races in rates of morbidity and mortality, race, in the view of most biomedical researchers, is an important descriptive and analytic variable in population studies of health in the United States.

In epidemiology, race is used to describe or explain differences within a population in the risk of injury, illness, or death much as race is used in sociology to describe or explain differences in the risk of poverty, homelessness, or incarceration or the rates of graduation or unemployment. While epidemiology and sociology draw on data collected by federal, state, or local government, sociology uses race to describe or explain how members of the US population differ in social or economic status, and epidemiology uses race to describe or explain how they differ in measures of health.

Epidemiology is not the only biomedical science that uses race as a variable in population research; pharmacology does as well. Studies of drug

disposition and sensitivity show differences between the OMB races in the metabolism of a number of different drugs. Blacks and whites, according to a variety of drug studies, differ in response to cardiovascular drugs, psychotropic and central nervous system drugs, morphine, and beta-blockers (Yasuda 2008). These differences are clinically significant for they recommend differences in treatment; if blacks respond to a given drug therapy differently than whites, then a physician, in choosing a therapy for a patient, might want to know the race of her patient and adjust the therapy accordingly.

Using race as a descriptive or analytic variable in population research is different from using race at the individual level in the clinic as a reason to treat one patient differently from another; nevertheless, the statistical generalizations that result from the population-level research are often employed in individual decision making and are a basis for what has come to be known as racial profiling in medicine.

### **Assigning Race**

The current OMB standard for collecting and reporting data on race lists five categories but is silent on how members of the population should be assigned a race and how to decide whether a member is one race (e.g., black), rather than another (e.g., white). While the US Bureau of Census assigns members an OMB race based on the race they report themselves to be, the National Center for Health Statistics assigns them a race based on the race on their birth or death certificate. However, a member’s self-reported race can be different from the race on his birth or death certificate. As a result, he can be assigned one race at birth, a different race as a young adult, and a different one again when he dies (Hahn 1992). When measuring errors in mortality statistics, researchers routinely treat a decedent’s race on his death certificate as his “apparent” race and his race on an earlier population survey or birth certificate as his “actual” one, if the two are different. They assume that a member’s race cannot change, but that his race can be misreported.

In the United States, self-reported race has become the most common way of assigning race

(“the gold standard”) to members of a population in biomedical research (Friedman 2000). Assigning a member the race he assigns himself is often the easiest or most respectful way to assign him to a racial category. By allowing each individual to be the arbiter of his or her own race, the researcher displays the subjective and social nature of our system of racial classification and gives individuals control over their own identity. Nevertheless, the easiest or most respectful way to identify someone’s race might not give race as much descriptive or explanatory power as a less easy or respectful one.

Self-reports are used in biomedicine to assign members to a variety of categories, to demographic categories like race and ethnicity and to categories of health and illness as well. However, there is evidence that self-reports do not measure the true value of some variables, and that their value is different from the self-reported one. In the study of alcohol abuse, for example, alcohol consumption is routinely measured by self-reports. Individuals are counted as lifetime abstainers if they report themselves to be that on a survey of alcohol consumption. A recent examination of the accuracy of these reports compared the never-drinking responses of respondents in three surveys and found that only 46 percent of the respondents gave the same response in all three and that many members reported being moderate drinkers when their actual consumption was greater (Rehm 2008).

Epidemiologic studies of cancer routinely use self-reports to measure cancer history. Studies of the accuracy of the reports compare them with medical records and show that only 33–61 percent of documented cancers were reported in interviews or surveys and the overall rate of false-negative reporting is also very high (Desai et al. 2001). The self-reports of cancer and alcohol consumption are proxies, and their accuracy is measured by how well they match a clinical measure of the variable, and, as many studies show, they do not always match them very well at all.

Though many self-reports of health are unreliable or inaccurate, most biomedical researchers assume that self-reports of race are reliable and accurate. Why? Because, on their view, the different ways of assigning race to members of a population usually

give the same result; most members are assigned the same race whether their race is assigned by self-reports, other reports, or race on a birth or death certificate. As a result, a member’s race is taken to be a fact about him that can be picked out in a number of different ways but remains the same whichever way is used to assign him to a racial category.

However, a workshop at the National Academy of Sciences concluded that research is needed to compare the race members of the US population assign themselves and the race they are most likely to be assigned by others (Edmonston 1996). Studies conducted since suggest that self-reports and other reports of a member’s race are sometimes different, and many foreign-born and Hispanic members of the population do not take themselves to be the race they are most often taken to be by others (Harris et al. 2002). Other studies show that the self- and other-reported race of mixed-race members of the population (the off-spring of parents of different OMB races) are often different or that the race that many members of the population report themselves to be varies with how, when, and by whom they are asked their race (Waters 2000).

Many members of the population seem to have a variety of context-specific self-identities, but, despite their self-identities, if many are consistently identified as black by others, then a researcher who is interested in racial discrimination or how access to housing, education, mortgage lending, employment opportunities, or morbidity or mortality varies with race has a reason to take other reports rather than self-reports as the best measure of the person’s race. Officials who decide social or health policy have a reason to take other reports as the best measure as well.

### **Mixed Race**

Some members of the US population report themselves to be mixed race, rather than one or more of the five OMB races, if “mixed” is one of the racial categories they are able to choose from. Between 1990 and 1997, many individuals and groups lobbied Congress and the OMB to alter the list of official races to include a stand-alone multiracial classification and include “mixed” as an option in the 2000 Census (Project Mixed Race 1997).

However, if “mixed” was an official option, on what basis should a member of the population be assigned to that category, on the basis of a self-report, the race of his parents, or the race others take him to be? Moreover, should a member be counted as mixed if one of his parents is mixed or only if his parents belong to two different OMB races?

“Mixed” is not a racial category in the US Census but neither is the category used in most studies of racial differences in health. In most studies of differences in infant mortality, for example, an infant’s mothers race is usually taken to be his actual race, whatever the race of his father, and no infant is taken to be mixed race rather than one of the five OMB races (Kleinman and Kessel 1987).

Beginning in 1989 the race of infants in the United States was based on that of the mother in all natality statistics. Prior to 1989, an infant’s race was based on a father’s race as well, and an infant could be both black and white. If the 1989 practice were to be applied retrospectively to births in 1987, white births would increase by 1.7 percent and black births would decrease by 4.7 percent (Hahn and Stroup 1994). If “mixed” was a category in infant mortality studies, the rate of black infant death would decrease, but the amount of decrease would depend on how “mixed” was assigned to infants. Using his mother’s race to predict an infant’s risk of morbidity or mortality (the current practice) biases the estimate of black-white differences in risk if infants with parents of different races have different risks of morbidity or mortality than infants with same-race parents.

### Race and Ancestry

Though humans differ from one another genetically, in the frequency of many genes or alleles (including medically relevant ones), the existing racial categories do not capture these differences very well. Geographic ancestry captures them better, since there is less genetic variation within groups identified by common ancestry than groups identified by race.

Scores on college admission tests are used as a proxy for first-semester college grades when admissions officers choose between applicants based on the scores; race is used as a proxy for performance

when employers practice what economists call “statistical discrimination” and use race to choose between applicants for a position, and race is used as a proxy in law enforcement when police officers base traffic stops on the race of motorists. To use race as a proxy, in any of these circumstances, is to engage in what has come to be called “racial profiling.”

### Racial Profiling in Medicine

When doctors use race as a proxy for a drug response or police officers for crime, they engage in racial profiling; how they treat a patient or motorist depends on the race they take him to be. The doctors’ use of race, however, seems reasonable, whereas the police officers’ use does not for, according to population-level studies, while drug response varies with race, crime does not. Arrests vary with race but since many criminals are not arrested and many of the arrested are not criminals, arrests are not markers of crime. Many doctors believe that racial profiling in medicine is reasonable and fair even if racial profiling in law enforcement is not; stopping a motorist based on this race is wrong, but, in their eyes, prescribing a drug to a patient based on his race is unobjectionable.

According to recent population-level studies of drugs for congestive heart failure, whites respond better to some drugs, such as angiotensin-converting-enzyme (ACE) inhibitors, than blacks do (Exner et al. 2001). Based on these studies, doctors use race as a proxy for a response to an ACE inhibitor when they target their white patients for the drug but not their black ones. Drug response is the material trait, whereas race is the proxy. Doctors do not know how an individual patient will respond to the drug, but they know or think they know a patient’s race, and given the correlation between drug response and race, they predict that a white patient will respond well to an ACE inhibitor, whereas a black one will not.

However, for a doctor to use a patient’s race to predict his response to a drug is problematic for at least three reasons. First, to select whites but not blacks for a drug treatment based on a population-level study ignores intraracial differences in response to the drug and adversely affects black patients for whom the “white” drug would be an

effective treatment. Though the ACE study showed that whites and blacks as a group respond differently to the drug, it also showed that significant number of blacks respond as well as whites do to the drug. Thus, treating all black patients the same, denying the drug to all of them, denies some blacks an effective treatment for congestive heart failure.

Second, targeting blacks assumes that race is the best predictor available, but the rate at which a drug is metabolized varies as a result of many factors, including environment and lifestyle. Most studies that show a racial difference in drug response do not control for differences between the black and white patients in socioeconomic status (SES) or other factors that are known to influence drug metabolism. As a result, the studies do not offer good evidence that the differences in response are due to race rather than to a third factor that varies with drug response and race. If differences in SES or lifestyle explain most of the variance between the black and white patients in response to a heart drug, it would be more reasonable for a doctor to use these as a proxy for the response than race.

Between 20 and 30 percent of self-reported blacks and whites in the United States, according to some estimates, have mixed African and European ancestry (Parra et al. 1998). The median proportion of European ancestry among self-reported blacks is 18.5 percent, and the average proportion is 14 percent (Tishkoff and Bustamonte 2009). Proportions vary from region to region of the United States, and self-reported blacks in California have the highest proportion of European ancestry and in Georgia the lowest (Parra et al. 1998). However, in every region of the United States, many people who identify themselves as black have both African and European ancestors and many who identify as white do as well.

If a small percentage of African ancestry is enough to count as black, then many members of the US population who take themselves to be white are black since between 20 and 30 percent of self-reported whites in the United States are estimated to have between 2 and 20 percent African ancestry. While the apparent race of 20 to 30 percent of self-reported whites would be white, their actual race would be black if “black” were defined as more than 0 percent African ancestry. If 20 to 30 percent of

self-reported whites are black, then the US Bureau of Census overcounted the number whites or blacks in the United States in 2000 by between 20 and 30 percent.

Though race is associated with ancestry, the relationship between ancestry and today's racial categories is loose since self- and other-reported OMB race vary independently of ancestry, and OMB race is most often assigned to members of the US population based on self- or other reports. While more and more Americans are of mixed ancestry, most are assigned to one of the five OMB races rather than counted as “mixed” when Census or other survey responses are combined or aggregated.

Biomedical researchers cannot capture something as complex as race with a single measure of race. Race has a number of different dimensions and one measure of race, one way of assigning members of a population to racial categories, can be a better measure of one dimension and a worse measure of another. As a result, at the population level, the way race is assigned to individuals, some researchers suggest, should be allowed to vary (rather than remain fixed) from one risk to another, and an individual taken to be one OMB race in relation to one risk and different race in relation to another (Root 2009). To allow the methods of assigning race to vary would follow a recommendation of the National Research Council that reports of race should rely on multiple methods of measurement rather than one, since no one measure can capture all the different ways races can affect the health of members of a population (National Research Council 2004).

### Race as a Proxy

While epidemiologists often use race as a population variable in their studies of differences in morbidity and mortality, at the individual level, doctors often use race in the clinic as a proxy to predict how a patient will respond to a treatment. One variable X is used as a proxy for another Y when X is used in the place of Y to make a judgment or decision. Let Y be a variable that cannot be measured directly but is material to an interest I; let X be a variable that can be directly measured and, though not material to I, correlates with Y. X is a proxy for Y if used instead

of Y in making a judgment or decision in order to further I.

Third, even if the difference between blacks and whites in drug response is due to a biological (genetic) difference, there is no reason to treat race as an independent variable that causes or explains the difference, since the genes controlling drug response vary independently of race. Race, in this respect, is different from sex as a marker of biomedical difference. While there are no race genes or chromosomes, there are sex chromosomes and genes. As a result, a gene that controls drug metabolism or sensitivity might be located on a sex chromosome and, if so, would vary with sex though independently of race, and sex would explain why male and female patients differ in their response to a drug.

There is no reason to believe that when doctors assign a race to their patients, their assignments match the assignments of race on which a study of drug response relies. Drug studies routinely rely on self-reported race, subjects are assigned the race that they assign themselves when asked. However, there is considerable evidence that self-identification is not robust and how individuals report their race varies with who is asking and the choices a person is given (Harris 2000). Individuals with mixed parents, for example, are likely to describe themselves as mixed race or multiracial if given the option but as a member of an OMB race if they are not. The subjects in most drug studies were not given a mixed-race option, and had they been, the results of the study would likely have been different.

Some doctors assign patients a race other than their self-reported one, and different doctors sometimes assign a different race to the same patient. A patient can be white to one doctor and black to another. As a result, the race a doctor assigns a patient might not be the race he would have been assigned had he been enrolled in the drug study.

When doctors use race as a proxy for a patient's response to a treatment, they employ a particular form of statistical inference and reason as follows: (1) a high percentage of blacks with this medical condition do not respond as well to treatment A as to treatment B; (2) this patient is black and has the condition; thus, (3) this patient is likely to respond better to B than A.

The inference is reasonable only if (1) and (2) include the best available evidence relevant to whether the patient will respond better to one treatment than the other. That is, (3) should be judged on an evidential base that includes the best available evidence, for the credence which it is rational to give a statement at a time is determined by the degree of confirmation that the statement possesses on the best evidence available at the time (Hempel 1965).

Most doctors consider age, environment, and lifestyle as well as race, if they consider race at all, when they choose a treatment for a patient. The question is how or whether a doctor should allow race to enter into the treatment decision. Ideally, a doctor would treat a patient as an individual rather than a representative of a group, but if the doctor treats him as a representative of any group at all, the group should not be identified by race if race masks a population-level variable that bears more directly on a treatment response.

Proxies are only useful when we lack direct access to a material trait. A college does not need to use test scores or high school rank to infer a student's college grades if it has access to the student's college transcript. Doctors, given advances in genetic technology, may soon have access to a patient's genetic transcript. Should she have his transcript, the doctor will not need to infer from his race whether he is disposed to respond better to one treatment rather than another.

However, even when the technology is available, doctors will have access to some but not all patients' genetic profiles, for patients will not have equal access to this technology anymore than they do to present-day health care. For patients who are not able to afford or who refuse the genetic tests, proxies will continue to have a use in diagnosis and treatment, but race should not be used as a proxy if other variables have more predictive power and, unlike race, do not require doctors to draw a color line or decide which of their patients are black and which are white.

### **Defense of Profiling**

Supporters of racial profiling in medicine often remind us that not many years ago we objected to drug research that tested the safety or efficacy of a

drug, especially heart drugs, on white males and applied the findings to blacks and females. In response to these objections, doctors began to look for differences in drug response between the races and sexes and, finding differences, began to discriminate between their patients based on their sex or race. As a result, profiling, the supporters say, is an enlightened and salutary response to the doctors' past indifference to differences in response.

Sex, however, is a much better proxy than race for a response to a drug. A gene encoding a drug-metabolizing enzyme could vary with a gene on a sex chromosome, but there are no race genes or chromosomes for an enzyme-encoding gene to vary with. As a result, doctors have a better reason to study sex differences than racial differences in drug response and a better reason to use sex than race as a proxy for a response when deciding how best to treat an individual patient for a medical condition.

Should race ever be used in medicine as a proxy for a patient's response to a drug? I suggest we divide the question in two. First, we might ask how an individual doctor should view his patient's race and, second, how doctors as a group should view the race of their patients. Some black patients might be better off if their doctor selects one drug for them rather than another (e.g., a beta-blocker rather than an ACE inhibitor) because of their race, while, as a group, black patients might be worse off if doctors, as a group, base their choice of drugs on race. The practice of basing drugs on the race of patients could leave blacks less well off as a group, even if some individual black patients benefit from the practice given the variation within each racial group in response to a drug and the variation in how doctors assign a race to their patients. While individual doctors might be permitted to choose a drug for a patient based on his race, doctors as a group might adopt a policy of ignoring race when choosing drugs for patients. While the policy would recommend a race-blind choice of drugs, individual doctors would be permitted to make a race-conscious one.

### Conclusion

To stratify health statistics by race is reasonable, as long as employment, housing, income, education,

or health care is stratified by race; but to use race as a proxy for a response to a medical treatment is questionable because members of the same race often differ as much in their response to a medical treatment as members of different races do, and racial profiling in medicine, no less than in law enforcement and schooling, helps to sustain a harmful racial ideology. The question at the population level is not whether race should be used as a population variable in health research but which racial categories should be used and how members of a population should be assigned to them. The question at the individual level is whether race should matter at all, given the variation within each race in the response of patients to medical treatments.

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# Answers to Chapter 1 Exercises

## EXERCISE 1.1

1. People should keep their promises. Noah promised to drive Thelma to Los Angeles, so he should stop bellyaching and do it.
2. The authorities have a moral obligation to intervene when refugees are being shot at and lied to. The refugees were shot at and lied to, and the authorities did nothing to stop any of this. The authorities should have intervened.
3. The United States is justified in invading another country only when that country poses an imminent threat. There was never any imminent threat from the Iraqi government, so the United States should not have invaded Iraq.
4. The Indian government posed an imminent threat to Pakistan and the world. When a foreign government poses an imminent threat to Pakistan and the world, Pakistanis are justified in attacking that government. So the Pakistanis were justified in attacking Indian troops.
5. Anyone who uses a gun in the commission of a crime deserves to receive a long prison sentence. Burton used a gun in the commission of a crime; therefore, he should get a long prison term.
6. Anyone who knows that murder is going to take place has a moral obligation to try to stop it. Ellen knew that a murder was going to take place. It was her duty to try to stop it. (Often people who put forth an argument like this also assume that a person is obligated to intervene only if it's physically *possible* for him or her to intervene.)
7. Any procedure that is unnatural should not be permitted for use on people. In vitro

fertilization is unnatural. Ahmed should never have allowed his daughter to receive in vitro fertilization.

8. Doctors should never experiment on people without their consent. The doctors performed the experiment on twenty patients without their consent. Obviously, that was wrong.
9. Hacking into a database containing personal information on thousands of people and invading their privacy is immoral. You hacked into a database containing personal information on thousands of people and invaded their privacy. Therefore, what you did was immoral.
10. If someone does another person a favor (performs a service for no pay), that other person is obligated to return the favor by doing a minimum service ("the least you can do"). Ling spent all day weeding Mrs. Black's garden for no pay. The least Mrs. Black should do is let Ling borrow some gardening tools.

## EXERCISE 1.2

1. *Conclusion:* Janet should be arrested. *Premises:* (1) Anyone who runs away from an automobile accident should be arrested. (2) Janet ran away from an automobile accident. [If premise 1 is true (and we assume that premise 2 is a reliable report of Jane's behavior), the argument is *sound*.]
2. *Conclusion:* Fears [about a group home] are very much unfounded. *Premises:* (1) The [group] home in which my sister resides is large, lovely, brand new, well staffed, and well maintained. (2) It does nothing but enhance the community, bring neighbors together, and create a wonderfully diverse

- neighborhood. [Since it can be difficult to generalize from one particular group home to all group homes, we are not justified in regarding this inductive argument as *cogent*.]
3. *Conclusion:* Ms. Leet's characterization of offensive graffiti as protected by the First Amendment and "not a hate crime" is outrageous. *Premises:* (1) Such graffiti can cause tremendous hurt and damage, especially when a professor defends it. (2) Words can be just as destructive as physical violence.
  4. *Conclusion:* Yolanda shouldn't have taken that money. *Premises:* (1) People shouldn't steal unless they are destitute. (2) Yolanda took the money from petty cash, even though she had plenty of money in her pocket.
  5. *Conclusion:* Stem cell research is immoral. *Premises:* (1) We should never do anything to disrespect human life. (2) The artificial use of human cells—as scientists are now doing in stem cell research—shows a complete disregard for human life.

#### **EXERCISE 1.3**

1. Any form of expression or speech that offends people of faith should not be tolerated. *Penthouse* magazine definitely offends people of faith. Ban it! *Evaluation: The first premise is dubious, for it would have us violate the autonomy of persons—by, for example, dramatically curtailing freedom of speech.*

2. Anyone who disagrees with the basic moral dictums of the prevailing culture should be censured. Dr. Tilden's graduation speech clearly was inconsistent with the prevailing moral opinions on campus. She should be reprimanded. *Evaluation: The first premise runs counter to several plausible moral principles, including respect for autonomy, freedom of speech and conscience, and tolerance.*

#### **EXERCISE 1.4**

1. It is immoral to do harm to others. The movie *Lorenzo's Oil* does harm to others by giving people false hope about a deadly disease and by misleading people about the medical facts. The movie is therefore immoral (or, those who produced and promoted the movie have acted immorally).
2. Regardless of whether the victims are Muslim or not, the vicious murder of innocent human beings is reprehensible and repugnant, an affront to everything Islam stands for. Al Qaeda has viciously murdered innocent human beings—both Muslim and non-Muslim. Therefore, these acts committed by Al Qaeda are reprehensible and repugnant. No one should have any sympathy for an organization that murders innocent human beings. Therefore, the Saudis should have had no sympathy for Al Qaeda after the May bombings.

## GLOSSARY

- abortion** The ending of a pregnancy.
- active euthanasia** Performing an action that directly causes someone to die; “mercy killing.”
- act-utilitarianism** The view that the rightness of actions depends solely on the relative good produced by individual actions.
- applied ethics** The use of moral norms and concepts to resolve practical moral issues.
- autonomy** A person’s rational capacity for self-governance or self-determination.
- availability error** Relying on evidence not because it’s trustworthy but because it’s memorable or striking.
- bioethics** Applied ethics focused on health care, medical science, and medical technology.
- blinding** A procedure for ensuring that subjects and researchers do not know which interventions the subjects receive (standard treatment, new treatment, or placebo).
- chromosome** A stringlike, gene-containing molecule in the nucleus of a cell.
- clinical trial** A scientific study designed to test systematically a medical intervention in humans.
- cloning** The asexual production of a genetically identical entity from an existing one.
- cloning, reproductive** Cloning aimed at the live birth of an individual.
- cloning, therapeutic or research** Cloning done for purposes other than producing a live individual.
- competence** The ability to render decisions about medical interventions.
- confidentiality** An obligation or pledge of physicians, nurses, and others to keep secret the personal health information of patients unless they consent to disclosure.
- confirmation bias** The tendency to look for and recognize only information that confirms our existing view.
- consequentialist theory** A moral theory asserting that the rightness of actions depends solely on their consequences or results.
- contractarianism** Moral or political theories based on the idea of a social contract or agreement among individuals for mutual advantage.
- cultural relativism** The view that right actions are those sanctioned by one’s culture.
- cycle (in assisted reproductive technology)** A sequence of steps involved in trying to achieve pregnancy through ART (assisted reproductive technology), typically extending from egg retrieval to embryo transfer.
- deductive argument** An argument intended to give logically conclusive support to its conclusion.
- deontological (or nonconsequentialist) theory** A moral theory asserting that the rightness of actions is determined partly or entirely by their intrinsic nature.
- descriptive ethics** The study of morality using the methodology of science.
- distributive justice** Justice regarding the fair distribution of society’s advantages and disadvantages.
- divine command theory** The view that right actions are those commanded by God and wrong actions are those forbidden by God.
- doctrine of double effect** The principle that performing a bad action to bring about a good effect is never morally acceptable, but performing a good action may sometimes be acceptable even if it produces a bad effect.
- Dunning-Kruger effect** The phenomenon of being ignorant of how ignorant we are.
- egalitarian theories of justice** Doctrines affirming that important benefits and burdens of society should be distributed equally.
- epidemic** The phenomenon in which a disease occurs in larger numbers than expected in a particular population and geographic area.
- ethical relativism** The view that moral standards are not objective but are relative to what individuals or cultures believe.
- ethics** The study of morality using the tools and methods of philosophy.

**eugenics** The deliberate attempt to improve the genetic makeup of humans by manipulating reproduction.

**euthanasia** Directly or indirectly bringing about the death of another person for that person's sake.

**evidence** Something that makes a statement more likely to be true.

**gene** The fundamental unit of biological inheritance.

**gene therapy** The manipulation of someone's genetic material to prevent or treat disease.

**genetic discrimination** The use of genetic information by employers, insurance companies, and others to discriminate against or stigmatize people.

**genetic testing** Procedures used to check for genetic disorders by looking for changes in a person's DNA.

**genome** An organism's entire complement of DNA.

**implicit bias** A negative attitude toward a group of people that operates unintentionally or unconsciously.

**in vitro fertilization** The uniting of sperm and egg in a laboratory dish.

**induced abortion** The intentional termination of a pregnancy through drugs or surgery.

**inductive argument** An argument intended to give probable support to its conclusion.

**infertility** The inability to get pregnant after one year of unprotected sex.

**informed consent** The action of an autonomous, informed person agreeing to submit to medical treatment or experimentation.

**involuntary euthanasia** Bringing about someone's death against her will or without asking for her consent while she is competent to decide.

**libertarian theories of justice** Doctrines holding that the benefits and burdens of society should be distributed through the fair workings of a free market and the exercise of liberty rights of noninterference.

**managed care** A system for providing health care to a particular group of patients (members of the system) using restraints to control costs and increase efficiency.

**medical futility** The alleged pointlessness or ineffectiveness of administering particular treatments.

**metaethics** The study of the meaning and justification of basic moral beliefs.

**moral absolutism** The belief that objective moral principles allow no exceptions or must be applied the same way in all cases and cultures.

**moral argument** An argument whose conclusion is a moral statement.

**moral objectivism** The view that there are moral norms or principles that are valid or true for everyone.

**moral theory** An explanation of why an action is right or wrong or why a person or a person's character is good or bad.

**morality** Beliefs regarding morally right and wrong actions and morally good and bad persons or character.

**motivate reasoning** Reasoning for the purpose of supporting a predetermined conclusion, not to uncover the truth.

**natural law theory** The view that right actions are those that conform to moral standards discerned in nature through human reason.

**nonmaleficence** The moral principle that says we should not cause unnecessary injury or harm to others.

**nonvoluntary euthanasia** Euthanasia performed when patients are not competent to choose it for themselves and have not previously disclosed their preferences.

**normative ethics** The search for, and justification of, moral standards, or norms.

**pandemic** An epidemic that has spread worldwide.

**passive euthanasia** Allowing someone to die by not doing something that would prolong life.

**paternalism** The overriding of a person's actions or decision-making for his own good.

**physician-assisted suicide** A patient's taking her own life with the aid of a physician.

**placebo** An inactive or sham treatment.

**principism** A moral theory consisting of multiple moral principles that must be weighed and balanced against one another to determine right actions.

**quarantine** The separation from others of people who have been exposed to a disease.

**quickening** At about 16 to 20 weeks of pregnancy, a pregnant woman's experience of fetal movement inside her.

**racial discrimination** Unfavorable treatment of people because of their race.

**racial prejudice** Antipathy toward a racial group based on a faulty view of that group.

**racism** The belief that some races are inferior in important ways or are otherwise deserving of dislike or hostility.

**racism, individual** Person-to-person acts of intolerance or discrimination.

**racism, institutional or structural** Unequal treatment that arises from the way organizations, institutions, and social systems operate.

**randomization** The assigning of subjects randomly to both experimental and control groups.

**right to privacy** The authority of persons to control who may possess and use information about themselves.

**rule-utilitarianism** The view that a right action is one that conforms to a rule that, if followed consistently, would create for everyone involved the most beneficial balance of good over bad.

***self-isolation*** The practice of asking people who are sick with a contagious disease or have symptoms to stay home and go out only in an emergency.

***spontaneous abortion (miscarriage)*** An abortion due to natural causes such as a birth defect or maternal injury.

***strong paternalism*** The overriding of a person's actions or choices, even though he is substantially autonomous.

***subjective relativism*** The view that right actions are those sanctioned by a person.

***surrogate*** A woman who gestates a fetus for others, usually for a couple or another woman.

***therapeutic abortion*** Abortion performed to preserve the life or health of the mother.

***therapeutic privilege*** The withholding of relevant information from a patient when the physician believes disclosure would likely do harm.

***triage*** The sorting and allocation of treatments to patients in an emergency to maximize the number of survivors in medical emergencies.

***utilitarian theories of justice*** Doctrines asserting that a just distribution of benefits and burdens is one that maximizes the net good (utility) for society.

***utilitarianism*** The view that right actions are those that result in the most beneficial balance of good over bad consequences for everyone involved.

***viability*** The development stage when the fetus can survive outside the uterus.

***virtue ethics*** A moral theory that focuses on the development of virtuous character.

***voluntary euthanasia*** Euthanasia performed when competent patients voluntarily request or agree to it.

***waiver*** The patient's voluntary and deliberate giving up of the right to informed consent.

***weak paternalism*** Paternalism directed at persons who cannot act autonomously or whose autonomy is greatly diminished.



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