

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.¹

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.² (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.”³

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. . . .

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

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.

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

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.⁴

Such physician–patient conflicts are commonly described as confrontations about

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

From childrenshealthcare.org.

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

sanctity 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

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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.*”⁵

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.⁶

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."⁷ 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 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 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

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.*

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?

*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.*

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?

*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.*

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?

*Sylvia Moreno, "Case Puts Futile-Treatment Law Under a Microscope," *Washington Post*, April 11, 2007.

FURTHER READING

Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), 176–94, 283–336.

Charles E. Gessert, "The Problem with Autonomy," *Minnesota Medicine*, <http://www.minnesotamedicine.com/Past-Issues/Past-Issues-2008/April-2008/Commentary-April-2008>.

Helga Kuhse and Peter Singer, *A Companion to Bioethics* (Oxford: Blackwell, 2001).

Ravi Parikh, "When Paternalism Doesn't Work for Patients," *Huffington Post*, May 29, 2015, http://www.huffingtonpost.com/ravi-parikh/doctor-patient-relationship_b_7447236.html.

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Gregory E. Pence, *The Elements of Bioethics* (New York: McGraw-Hill, 2007).

Robert M. Veatch, "The Dying Cancer Patient," in *Case Studies in Medical Ethics* (Cambridge, MA: Harvard University Press, 1977), 141–47.

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.

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.*

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

better and not let him use his discretion whether he wants to get smarter, more healthy or more honest.

—GENERAL HERSHEY

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

From *The Monist: An International Quarterly Journal of General Philosophical Inquiry* 56, no. 4 (October 1972): 64–84.