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## Introduction

BIOETHICS HAS been preoccupied with making judgments about troublesome moral problems and justifying those judgments, with doing what has been aptly called “quandary ethics.”<sup>1</sup> Following the lead of philosophical ethics, justification is regarded as a matter of providing “good reasons” for judgments, and that, in turn, is taken to require an appeal to moral rules or principles or to moral theories. Bioethics, in this view, is situated in rationality and generality. It prescind the messy details and attachments that give our lives meaning and vigor, the nagging contradictions that make us squirm and struggle, and the social, political, and economic arrangements that simultaneously create and constrain us. Because they are yoked to the abstractions of reason and theory, judgments about matters of bioethics frequently outstrip the contexts that generate and shape those matters and ignore the agonizing experiences of the people who grapple with them.

Given the emphasis on theoretical justification in bioethics, it is no surprise that social scientists have remained at its margins. Justifying decisions or judgments is the concern of *normative* ethics, and normative ethics is about what *ought* to be the case—what decision ought to be made, what action ought to be taken, what policy ought to be adopted. *Descriptive* ethics, in contrast, is “the factual investigation of moral behavior and beliefs” (Beauchamp and Childress 1994:4–5). Social scientists—anthropologists, sociologists, and historians—engage in descriptive ethics when they investigate and interpret the actual moral beliefs, codes, or practices of a society or culture, but such nonnormative work is regarded as “secondary to the enterprise of normative ethics” (Beauchamp and Childress 1979:9) and thus secondary to the enterprise of bioethics.<sup>2</sup>

This volume has two related goals: to show that bioethics is as much about *understanding* as it is about *justification*, and to give social scientists a prominent position in a reoriented bioethics. Indeed, it would seem that understanding has to accompany, if not precede, any genuine form of justification, so that, contrary to the prevailing view, what social scientists can tell us is neither independent of nor ancillary to the enterprise of bioethics.

In fact, the interpretations of moral life and moral phenomena provided by social scientists reveal that a rigorous separation of the descriptive and the normative is practically untenable. A dichotomy between the descriptive and the normative (or between fact and value, “is” and “ought”) seems to be simply an artifact of the theoretical project of justification, not an intrinsic feature of moral experience.

How, though, is moral understanding to be acquired? One important ingredient of that understanding is an appreciation of the contexts within which moral matters arise and are addressed. Putting bioethics in personal, social, and cultural contexts opens the way for modes of moral deliberation that are not general, rational, and impartial but that embrace the distinctive histories, relationships, and milieus of people and engage their emotions as much as their reason. Such a bioethics also recognizes the multiple backgrounds—institutional, economic, historical, and political—that structure moral problems and give meaning to moral concepts. This is a bioethics situated in lived human experience. The qualitative research approaches of the social sciences, ethnography in particular, can be used to explore the moral dimensions of that experience and thus to enhance our understanding of the nature of morality and its place in our lives. The ultimate goal of this endeavor is a bioethics that is more attuned to the particular and more sensitive to the personal—a bioethics that is more humane and more helpful.

But, the skeptic will insist, even if this call is appealing in the abstract, what does it mean in practice? How would a bioethics more influenced by social scientists and more directed to understanding be different from and better than the existing version? To suggest how that question should be answered requires a survey of what social science forays into bioethics have already produced.

## FOUR SOCIAL SCIENCE EXAMPLES

The justificatory apparatus of traditional bioethics: (i) assumes that real-life moral problems come sorted, labeled, and ready for the manipulation of rules, principles, or theories; (ii) disregards the extent to which moral concepts and norms derive their meaning and their force from the social and cultural surroundings in which they are embedded; (iii) neglects the ways in which moral problems are generated and framed by the practices, structures, and institutions within which they arise;

and (iv) ignores the means by which social and cultural ideologies, and the power relationships they entrench, can both perpetuate moral inertia and effect moral change. Kaufman's (1997) study of how medical responsibility is constructed in geriatric medicine, Gordon and Paci's (1997) investigation of the nondisclosure of cancer diagnoses and prognoses in Italy, Anspach's (1987, 1993) examination of neonatal intensive care, and Lock's research on menopause (1993) and reproductive technologies (1998) in Japan address, respectively, these four failings.

Kaufman's interviews of physicians who practice geriatric medicine tellingly reveal that there is no clear demarcation between the moral and the clinical. One cannot focus exclusively on the clinical aspects of a problem at one moment, then shift exclusively to the moral aspects at another moment because, as Kaufman concludes, problems are "irreducibly 'clinically-moral'" (1997:20). That irreducibility complicates the very identification of moral problems and raises questions about what the upshot of labeling a problem "moral" ultimately is.

A troubling clinical-moral issue for every health care professional is determining the boundaries of responsibility. An inner-city internist whom Kaufman interviewed related a story about a seventy-nine-year-old woman who cares for her twelve-year-old grandson and nine-year-old granddaughter because her son is a homeless heroin addict. The grandchildren's mother, who was also a heroin addict, is dead. Because the grandmother is becoming progressively more demented, it is not clear how much longer she can care for her grandchildren. Her son is a patient of the internist, but the grandmother is not. The grandmother participates in the Grandparents Who Care program at the internist's public health center, though, and the internist facilitated a support group to which the grandmother belonged. The internist also has done respite care for the family and has taken the children on outings. Even though the grandmother is not an official patient, she is someone the internist "cares about, feels an obligation toward, and 'treats' in the context of a grandparent support group which she started because so many patients (and family members) need psychological and material, as well as medical, support" (1997:11). The internist agonizes about the boundaries of her medical and personal responsibility and even goes so far as to consider adopting the two children. Kaufman summarizes what is at stake here:

The dominant theme of the tale is the problem of how to ensure the well-being of the entire family. Adoption as a potential solution to the

dilemma-tale projects a moral self who ponders and problematizes the role of physician: if she cannot give what she considers to be adequate or optimal care *as a doctor*, perhaps she could—and should—become *family* in order to create a substitute for the “missing” middle generation. Stepping into that space herself as both concerned parent and child would, in her view, get to the crux of the problem. (1997:11–12; emphasis in original)

This is not a typical bioethics problem. To some, it might not even be a recognizable bioethics problem, yet it concerns the fundamental matter of medical-moral responsibility and the clinical-moral issues of who is a patient and what should be treated. The internist’s dilemma shows how clinically entangled and fluid is the notion of the moral. Given the mutuality and the irreducibility of the clinical and the moral, the content of bioethics cannot be segregated in a set of normative principles and rules that are brought to bear on the factual goings-on of the clinic.

Gordon and Paci’s study of concealment and silence around cancer in Italy reveals how deeply and widely the values and beliefs pertinent to bioethics are embedded in social and cultural ways of being. At the particular, individual level Gordon and Paci trace Dr. J.’s practice of not informing patients of diagnoses and prognoses to the practices of not telling and not knowing that he learned before entering medicine and that he employed in a variety of situations. Reflecting on his upbringing, Dr. J. relates a general lesson he was taught: “If someone had a problem that bothers him, we were brought up to keep it inside, to not say anything about it, because you are sorry to involve others in this suffering, especially if there is nothing they can do about it” (1997:1445). And a description of the common practice of “parents waiting to leave until a child is distracted or using little lies to cover up or ease a separation or pain,” strikes a chord with Dr. J.: “Yes, yes, they teach you early on to lie, from childhood. That sounds right! I learned that’s how it is. You mustn’t say things as they are. You are better for it, I am better for it!” (1997:1445) Although Dr. J.’s biography is idiosyncratic, Gordon and Paci report that “it echoes themes heard repeatedly in other accounts . . . and draws upon common cultural and social resources shared to varying extents by people of the same age, gender, class, city, region, country, and religion that together constitute the cultural field of this local world” (1997:1445). Moreover, what goes on in health care manifests those “common cultural and social resources”:

[C]oncealment, silence or ambiguity are not just practices of protection from death and illness in the health sector but also ways of keeping problems and emotions “private” and out of the social arena, of avoiding conflict, disobedience and punishment, of asserting autonomy for the dominated . . . of coping by avoiding facing problems or painful topics, of expressing love, protecting another, and being responsible by sparing others’ suffering. (1997:1445–1446)

Those shared practices and understandings are, Gordon and Paci argue, “embedded in and contribute to the construction and reconstruction of larger meta-narratives” about matters such as personhood, individuality and sociality, hierarchy, time, and the good life (1997:1447). Their exploration of the background to the nondisclosure of cancer diagnoses and prognoses leads Gordon and Paci to conclude:

[O]ne senses a strong social field or force operative [*sic*] in this context, one that effectively creates reality, that defines morality, that can make people comply, that can pass on emotions, that can pull one out of sorrow through distraction. . . . This strong social field works on open, socially porous, “suggestable,” [*sic*] “fragile” people and ways of being-in-the-world. (1997:1448)

That shared social background is what injects morality with practical meaning and force, what gives morality the significance it has in our lives.

Moral problems are, as well, a function of institutional and structural factors, as Anspach’s study of neonatal intensive care demonstrates. Anspach found that a consensus around moral principles does not remove controversy about the treatment of seriously ill newborns because doctors and nurses frequently disagree about the prognoses for these infants. Those discrepant prognostic judgments result from the different work experiences that doctors and nurses have. Doctors, who spend relatively little time with the infants in a neonatal intensive care unit (NICU), base their conclusions on physical findings, the results of diagnostic tests, and the literature of medical research. Nurses, who spend concentrated and extended periods of time with these infants, rely on their personal and social interactions with the infants. There is, as a result, a clash between what Anspach calls the different “modes of knowing” of the two groups (1987:227).

Those two modes of knowing, Anspach discovered, emanate from how work is divided and organized within an NICU. Because attending physicians visit the unit for brief periods of time, because house staff

rotate through the unit on short cycles, and because physicians in tertiary care institutions often have research interests, doctors are both organizationally and personally detached from these infants and their parents. The information they rely on to formulate a problem and resolve it is the technical and, in the case of research findings, general information they possess and value. Because nurses, in contrast, are intimately and continuously involved with the care of these infants, they are organizationally and personally attached to them. Their perceptions of problems and their responses to them arise from their interactions with the infants.

But, as Anspach also observes, the “technological cues” of the doctors and the “interactive cues” of the nurses are not valued equally: “[T]he interactive cues noted by the nurses are *devalued data*” (1987:229; emphasis in original). Why is that? One obvious answer ties the devaluation of the nurses’ data to prevailing gender roles in society. Another answer, offered by Anspach, appeals to the history of diagnostic technology and locates newborn intensive care in a “postclinical” medical culture, that is, a culture in which the science of medicine has displaced the art of medicine. In such a scientistic culture, the soft “subjective” information of the nurses is no match for the hard, “objective” data of the doctors. From beginning to end, the moral disagreement between the doctors and the nurses is framed and settled by factors well beyond the confines of traditional bioethics.

Lock’s research on menopause and reproductive technologies in Japan reveals how deeply and how intractably moral beliefs and values can be embedded in cultural backgrounds suffused with unexamined assumptions and unequal power relationships. In Japan, for instance, a dominant moral ideology dictates that women should stay at home and raise their children because this practice is “natural” and because women are biologically programmed to nurture others. Women who use babysitters other than their own mothers are frowned upon. As well, the Japanese government and medical profession do not promote artificial insemination with donor sperm or any form of surrogate motherhood because a dominant moral ideology holds that biological and social parenting should coincide and that these reproductive technologies threaten notions of the family and correct parenting that must remain inviolate. Many Japanese women, not just committed feminists, are familiar with theories of autonomy and Western feminist ideas.

They also know that their society puts the family first, and they usually have many doubts about “the West” and its devotion to individualism and autonomy. They recognize that the dominant ideology in Japan values communalism and family, and they recognize that this ideology has drawbacks; but they do not, by any means, fully support American or French feminism or wish it on Japanese women. They are acutely aware of these tensions, just as they are aware that their government has a moral agenda for Japanese women.

Appraising the moral plight and reactions of Japanese women requires an understanding of the extent to which dominant, culturally infused ideologies are congruent with everyday practices and why congruence, or the lack thereof, exists. Are these ideologies internalized to such an extent that people do not even recognize them as troubling or do not resist them? Or do they ignore them or actively work against them? Qualitative research methods such as ethnography can suggest some answers. Ethnography can tease apart relationships among cultural traditions, power, and emerging and existing ideologies, and it can illuminate what is “normal,” “natural,” and “right” among particular groups in discrete circumstances and where ruptures and tensions exist among values. When morality is situated in experience, it cannot be severed from the seamless heterogeneity of that experience, and understanding morality *as it is lived* shows how intimately it is intertwined with culturally grounded knowledge, power, institutions, and practices.

The chapters in this volume explore the themes that these four examples illustrate. They show how bioethics problems are the product of institutional, social, historical, and cultural contexts and how power gets wielded within those contexts. They reveal how strikingly absent contextual considerations can be from the work of bioethics and how that absence gets in the way of good bioethics. They render those who have to make and live with moral decisions more visible. The chapters strive to broaden bioethics beyond the theoretical confines within which it largely operates. They also strive to connect bioethics more closely to people’s lives and the situations in which moral problems arise. But this volume is only a first step on an exploratory journey. The chapters suggest what the destination could be and point toward that destination. The motivation for embarking on this journey is the prospect of a bioethics that is more realistic and more helpful.

## PRACTICAL IMPLICATIONS

Putting bioethics in context should have important practical implications. For one thing, this enterprise could expose gaps between theory and practice and explain why the achievements of bioethics have sometimes been modest and even disappointing. For example, although bioethics emphasizes respecting the autonomy of patients and their families and obtaining informed consent, those goals are imperfectly realized at best. Anspach reports that "although professionals in both intensive-care nurseries I studied acknowledged the importance of involving the parents in the decision-making process, an assent model, rather than an informed consent paradigm, was most frequently used" (1993:92). Moreover, the assent that was given could, of course, be manufactured by "slanting" the clinical information presented to parents (1993:96). And Anspach found that departures from the ideal of informed parental consent were not haphazard: "[I]n both nurseries . . . the decision-making process was organized so as to limit parents' options—even to the extent of eliminating them from some decisions altogether. The actual, if sometimes unstated, aim of the conference with parents was to elicit their agreement to decisions staff had already made" (1993:95–96).

Sociologists who have studied the medical care of adults reach similar conclusions. Robert Zussman found that informed consent played "only a small role" in the two intensive care units in which he did his fieldwork (1992:83). Daniel Chambliss's observation is even more sobering: "In major medical centers, 'informed consent' represents at best a polite fiction" (1993:651). Why and how does such a discrepancy between theory and practice exist?

Zussman's study of intensive care (1992) provides one answer. Those in positions of power in a hospital can subvert the theoretical goals of bioethics through conceptual gerrymandering. Vesting decision-making authority in patients has put physicians in the uncomfortable position of having to do things they believe are professionally or morally wrong, but when physicians get pushed too far, they resist. Zussman describes how:

In stressing physicians' resistance to the wishes of patients and families, I do not question the sincerity with which they accept patients' legitimate priority in matters bearing on values. Physicians do not typically defend their discretion by claiming explicit jurisdiction over such matters. Indeed,



physicians rarely question the values of their patients. . . . Rather, when physicians do resist the wishes of patients and their families, they justify that resistance by moving decisions from the realm of values to the realm of technique. Thus, physicians argue, frequently and insistently, that some decisions are not value laden at all but simply technical. As such, many physicians argue, they are beyond the proper range not only of patients and families but of both the law and ethics more generally. (1992:141–142)

Nowhere is that strategy clearer than with the controversial but clinically well-entrenched notion of futility. Physicians can parry the demand to “do everything” for a critically ill patient on the basis of their “technical” judgment that further treatment would be “futile.” That is an inviting strategy because “a technical judgment raises no issues of values and requires no consultation with family or friends. Ethics is transformed into medicine” (Zussman 1992:151).

Anspach’s and Zussman’s studies of intensive care show how moral prescriptions about what ought to be done can be blocked by the decision-making procedures and the power relationships that exist in a hospital. Instituting moral and social change consequently requires more than education and rational argument and persuasion (see Jennings 1990). Putting bioethics in context helps to expose the institutional, social, and cultural forces that create gaps between theory and practice and points bioethics in directions that are more likely to produce moral reform.

At the same time, though, putting bioethics in context could have sobering consequences for those who engage in bioethics. Perhaps surprisingly given his own life and writings, Milan Kundera characterizes the novel as “a *realm where moral judgment is suspended*. Suspending moral judgment is not the immorality of the novel; it is its *morality*. The morality that stands against the ineradicable human habit of judging instantly, ceaselessly, and everyone; of judging before, and in the absence of, understanding. From the viewpoint of the novel’s wisdom, that fervid readiness to judge is the most detestable stupidity, the most pernicious evil” (1995:7; emphasis in original).

It would be foolish to suggest that patients, their families, and health care professionals abstain from making moral judgments. It would be equally foolish and irresponsible to suggest that practitioners of bioethics judge “instantly, ceaselessly, and everyone.” But it is not foolish to suggest that the judgments of right and wrong so common in and expected of bioethics should be made more cautiously and more circumspectly,

that suspending moral judgment might often be the morality, not the immorality, of bioethics. For the judgments of bioethics need to rest on more than philosophically respectable “good reasons”—they need to proceed from and manifest an understanding of morality as lived human experience. That bioethics can come to embrace that kind of understanding is the hope of this volume.

## NOTES

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1. This approach is not only because of the nature of the field but also because of the analytic philosophical tradition that has so strongly influenced contemporary bioethics. See, for example, “Quandary Ethics” in Pincoffs 1986:13–36.

2. This quotation from the first edition of *Principles of Biomedical Ethics* is deleted in the three subsequent editions. In those succeeding editions, though, the authors continue to insist that they are concerned primarily with normative ethics. The distinction between normative ethics and descriptive ethics is an article of faith for those who come to bioethics from a philosophical background. In his examination of the just distribution of health care services, Daniels, for example, explains: “I will concern myself with what I think ought to be the case and not just with what a moral anthropologist surveying our practice might discover is the case” (1985:116).

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# 1 Clinical Narratives and Ethical Dilemmas in Geriatrics

BY NOW the critique of traditional bioethics, based on tenets of Western philosophical rationalist thought (Marshall 1992), is well known in the medical social sciences. Clinicians and others have commented on the remoteness or ineffectiveness of moral theory for actual problem solving (Anspach 1993; Hoffmaster 1992, 1994; Smith and Churchill 1986). Social scientists have noted the lack of attention to culture, ethnicity, and economics in North American bioethics and the primacy it grants individualism and self-determination as these notions have emerged in the Western (predominantly Anglo-American) industrialized world (Fox 1991; Kleinman 1995; Marshall 1992).

Ethnographers studying physician training (Bosk 1979; Muller 1992; Muller and Koenig 1988), the doctor-patient relationship (Good et al. 1990; Gordon 1990; Taylor 1988), decision making in a variety of medical contexts (Anspach 1993; Bosk 1992; Clark, Potter, and McKinlay 1991), and the impact of new technologies on patient care and values in medicine (Fox and Swazey 1992; Kaufman 1993; Koenig 1988) are broadening the conceptual boundaries of ethical inquiry by delineating a range of dilemmas in clinical practice from a grounded, empirical point of view. Their detailed studies of local situations, attention to structural, cultural, and political sources of dilemmas, and analyses of moral problems from patient and practitioner viewpoints show the limitations of existing moral theory for understanding the scope and complexity of dilemmas that physicians, patients, and families actually face. This chapter adds to the growing ethnographic literature on the nature of dilemmas in medical practice through an exploration of narratives as modes of clinical-moral reasoning<sup>1</sup> in the field of geriatrics.

Through analyzing narrative accounts of dilemmas in geriatric medicine, this chapter illustrates how one dimension of bioethics is the "lived experience"<sup>2</sup> of physicians whose stories of primary care are morally problematic for them. The intent of this chapter is to contribute

to the conversation among social scientists and medical ethicists about what constitutes ethical concern and activity in actual medical practice and what methods best access that concern. It uses two strategies. First, it opens the *content* of bioethics to a range of underdiscussed topics (such as risk, sufficient action, and the ambiguity of “comfort care”) that physicians in geriatrics cite as deeply troubling. Second, it expands the *nature* of bioethics beyond rational ethical deliberation per se to show that clinical-moral deliberation and actual problem solving are dynamic activities situated both in local worlds where explicit institutional structures, demands, and expectations shape practices, and in broader contexts of cultural discourse and debate, ideology, and value that more tacitly frame the knowledge, construction, and understanding of medical problems and their potential solutions.

In addition, this chapter pays attention to two conceptual concerns of social scientists interested in further articulating the ethical dimensions of medical practice. First, awareness of the multiple contexts of health care delivery—not only the physical setting of the acute care hospital—is essential for understanding the range of physicians’ ethical concerns. Bioethics as both a profession and a social representation of public distress over expanding medical authority emerged in the United States from troubled decision making about the use of technology in the hospital. Much bioethics debate continues to focus on conflicts between life prolongation and attendant suffering, on the one hand, and “comfort,” pain reduction, and “dignity,” on the other. Yet doctor-patient interactions, wherever they occur physically, are situated also in structural, political, and socioeconomic environments that influence the construction of clinical-moral problems. Sources of dilemmas are in many cases beyond the literal walls of hospital, clinic, home, and office and are located, more importantly, in the organization and financing of health care delivery, the press to make use of intensive care units and nursing homes, the perceived “need” to utilize the newest technologies, the priority on action, and other features of the cultural field in which physicians practice (Fox 1991; Rhodes 1993). Socioeconomic and cultural features have been neglected or devalued in the construction of bioethics as a profession and applied discipline.

Second, the notion of an autonomous and completely unencumbered individual (in this case the doctor) as the locus of responsibility for therapeutic choice (Kleinman 1995; Koenig 1993) is misguided. Various social

scientists have shown how the locus of responsibility for moral choice making is embedded in structural features of medical practice, institutional priorities, social characteristics of the physician and patient, and in shifting and interlinked power relations among individual players (Anspach 1993; Bosk 1992; Clark, Potter, and McKinlay 1991; Hoffmaster 1992; Lindenbaum and Lock 1993). Actual decision making often is not a deliberate, rational, or autonomous act on the part of an individual clinician, as bioethical theory would have it. In fact, decisions are not always "made" in an active, premeditated sense. Rather, they sometimes "happen" as events unfold. "Decisions" actually encompass a variety of practices, some articulated as conscious choice making, others taken for granted as routine steps in an undifferentiated process of clinical activity. Thus decisions may emerge during negotiations with patients, family members, other health professionals, and agency or institutional representatives. They may occur without overt discussion. They may evolve slowly and, at times, invisibly.

Even when decision making is an explicit act, it can be a murky enterprise. Doctors who were subjects in an anthropological study of ethical dilemmas in geriatrics<sup>3</sup> reported that they often do not know what the best clinical-moral choice is among a range of care options, yet they usually feel compelled to be active and do something. Their choices, gauged from the vantage point of the supreme value placed on action in the service of diagnosis, management, and cure, are not always comfortable for them. The discomfort and tension that exist between individual professional sensibilities and quandaries about care, respect, and the purposes of medical intervention, on the one hand, and the structural pressure to institutionalize and use the technological armamentarium available, on the other, are not recognized in theoretical, analytical, principle-based bioethics.

## METHOD: THE USE OF NARRATIVE

Narrative, used here in a limited sense to refer to accounts or stories that relate subjective experiences, the unfolding of events or conversation, and causal explanations, has been increasingly employed in the last few years by scholars and clinicians who seek to extend the boundaries of bioethical understanding to include socioeconomic conditions, everyday practices, and the impacts of cultural trends on medical knowledge,

practice, and uncertainty. Toward this end narrative, as both method and text, has been invoked in the following ways: to describe patient-centered perspectives of illness and suffering, including patients' moral worlds (Frank 1995; Good 1994; Kleinman 1988; Kleinman and Kleinman 1991); to understand the process of clinical judgment, the evaluation of treatment choices, and the incommensurability of physician and patient reasoning (Hunter 1991); to illustrate how actors in medical scenarios frame intentionality (Mattingly 1994) and time (Good et al. 1994); to discern what is "good" for patients (Mattingly 1991, 1993; Smith and Churchill 1986); to investigate power relations between patients and providers (Mishler 1984; Waitzkin 1991); and, generally, to give weight to the gender, life stories, and cultural identities of moral agents, whose unique, contextualized perspectives and positions have been ignored or muted in traditional bioethics (Frank 1995; Pellegrino 1994). Advocates of narrative argue that, as a method, it captures and constitutes both lived morality and experience and the dynamics of social practices and conditions, thus revealing an open, richer field of ethical reasoning and ethical behavior than abstract perspectives allow (Muller 1994).

Here I use narratives drawn from interviews I conducted with physicians who treat older patients: (1) to explore tensions and ambiguities in geriatric medical practice—as well as the cultural sources of those tensions—that may not be revealed through other approaches; (2) to give voice to the lived, practical concerns of the most powerful players in the health care arena; and (3) to look for relationships between "culture" and "ethics" that are embedded in this particular form of cultural expression.

## THE STUDY AND SAMPLE

The interviews are part of a larger investigation of physician conceptualizations that underlie clinical-ethical decision making in geriatrics. Thus the stories physicians told were both deliberately solicited and consciously and reflectively offered.<sup>4</sup> The important inclusion criterion for the study was clinicians' experience with an elderly population. Twenty-nine of fifty-one physicians treated mainly persons over sixty-five (60 percent to 100 percent of their patients). The other twenty-two physicians noted that 20 percent to 50 percent of their patients were elderly. This was a convenience sample generated by "snowball" techniques. I began by interviewing several internists and family practitioners known to me. At

the end of those interviews, I asked for the names of other physicians who treat elderly patients. Those individuals were asked also to recommend colleagues to be interviewed. I made every attempt to solicit physicians from different specialties and a range of practice settings. I also tried to interview doctors from a broad range of ages and ethnic groups. The snowball approach generated the entire sample and included the following: fourteen general internists, four cardiologists, two gastroenterologists, eleven family practitioners, seventeen geriatricians, and three critical care specialists. Practice settings included: seventeen in private or group practice, fourteen in community clinics, seven in public hospitals, four in university hospitals, two in community hospitals, two in health maintenance organizations, and five in nursing homes. The age range was thirty-two to seventy-one. There were twenty-one women and thirty men. In addition, the group included thirty-eight White, five Hispanic, three African American, and five Asian American physicians.

## INTERVIEWS

An open-ended interview guide was constructed to elicit physician perspectives about decision making and responsibility in clinical medicine with elderly patients. The questions were intended to be relatively nondirective so that physicians could describe in their own words the dilemmas they face and the choices they make. Interviews elicited discussion of the following topics: description of current practice; problems and rewards in geriatric medicine; actual decision-making dilemmas; roles and responsibilities in treating the elderly who are frail and in the dying process; moral conflicts about the termination of life; relationships with family members; constraints on practice; and explanations of frailty and medical futility. Each interview was face-to-face and lasted approximately one hour. Interviews were audiotaped, and the tapes were later transcribed verbatim.

The physicians gave narrative accounts in response to my questions about difficult treatment decisions and the dilemmas they pose. They outlined the clinical problem and contextual features of at least one case (but often three or more), described the patient's problem(s) and their own response, emphasized the decision points and why those were troublesome, and, if the case had resolved, gave its final outcome. Their stories illustrate the uncertainty integral to much decision making in



clinical medicine—not only in geriatrics—and the fact that the physicians may never know if they did the “right” thing.

## NARRATIVES AND PHENOMENOLOGY

This chapter contributes to a phenomenology of clinical medicine<sup>5</sup> by exploring the definitions and meanings of patient-care dilemmas as physicians both construct and attempt to solve them in their narrative tellings. Phenomenologically, narratives work in at least two ways. First, their everyday discourse reveals naturally occurring concerns, meanings, and actions (Benner 1994). Narratives illustrate ways in which the storyteller remembers, engages, and anticipates both the problem and the relationship with the patient. The accounts reveal what concerns the storyteller—morally, medically, and practically—and illustrate how those aspects of concern cannot be disentangled. When physicians are given the opportunity to describe in detail their own subjective experience vis-à-vis patient care and concern, their narrative explanations—although constructed in response to an anthropologist’s request—are presented as self-evident, spontaneous, and taken for granted. Full of language signifying emotion and values, they reveal how clinical dilemmas actually are understood and lived. The language of these narratives is a language of feelings at least as much as it is a language of rational deliberation.

Second, narratives illuminate features of the cultural and structural background to individual moral thought, feeling, and reflection. Narratives are built from shared but implicit understandings of the cultural world, problems, reasoning, and what works. Those understandings are the scaffolding on which clinical-moral quandary and deliberation rest. The stories physicians told constitute and are embedded in particular, yet open, cultural fields (Gordon 1994). For example, the stories depict the world of contemporary American medical practice delivered in a large urban setting, where the full range of biotechnologies, intensive care, nursing care, and ancillary social services are considered necessary and useful and are available frequently to all patients regardless of age or socioeconomic status. They emerge from the existing structures of health care delivery: the acute care hospital in which technologies create the need for diagnostic testing and life-prolonging care; the multidisciplinary team that manages all aspects of life and works toward risk reduction; and the intricacies of payment in which intensive care for elderly people

is government financed, but housekeeping, transportation, medication, and hearing aids are not. In addition, the narratives express and locate some perplexing ironies of geriatric medicine, a domain fraught with ambiguity about the distinction between "natural" old age and disease process, conflict about whether disease should be treated, and questions about the role of medicine in dictating behavioral change and in prolonging life (Kaufman 1994, 1995). Stories also reflect tensions and oppositions characteristic of Anglo-American society more generally: surveillance versus freedom; care versus neglect; and dependence versus self-reliance. Physician narratives are thus conceived as cultural documents. As dynamic texts, they push cultural boundaries through their questioning of existing ways of knowing and acting and through their creation of avenues of choice. In addition, they interpret what is desirable, permissible, acceptable, or morally questionable.

## DILEMMAS: THE NATURE OF CLINICAL-MORAL REASONING

In the analysis of the data, five kinds of dilemmas stood out as most commonly articulated by the fifty-one physicians, and each is posed here as a question or set of related questions: (1) How much intervention or treatment should there be: whether to treat or leave alone, hospitalize, treat as an outpatient, employ invasive diagnostic tests, treat with surgery or with drugs, place in the intensive care unit, place in a nursing home, how much to spend on an intervention? (2) How aggressive should one be with technologies for prolonging life? (3) How should one proceed with treatment: when there are differences of opinion about how to proceed and when medical judgment differs from patient or family wishes; when there is confusion about the nature of the patient's wishes; when the patient wants one thing, the family wants another, and the physician feels caught in the middle; when physicians disagree with one another about kinds of treatment to employ? (4) What does one do when the patient wants to remain independent in the community but is failing, according to family or other health providers? (5) How can one be certain where the lines are drawn between comfort care and life prolongation, for example, or between comfort care and euthanasia? How does one implement comfort care?

Having created this organized list of dilemmas out of the "flow" of data, I wish to emphasize that, articulated in narratives, actual dilemmas

rarely emerged as discrete entities in the physicians' accounts. I have isolated them here for analytic purposes, to highlight the range of problems physicians describe. In the interviews themselves, two or more of these types of dilemmas frequently converged in the description of a particular case scenario, illustrating the phenomenological impossibility of the physician coming to terms with any one of them as a separate entity in the course of actual decision making. Ethical theorists have tended to approach such questions as though they were perceived by practitioners to be discrete and isolated, but the dilemmas expressed by these physicians rarely were unidimensional.

The narratives that follow enable us to discern ways in which physicians understand problematic issues in the treatment of their patients. They reveal how dilemmas cluster, merge with, and compound one another in physicians' reasoning. The narratives illustrate that clinical problems are neither conceived nor addressed by isolating their component parts; rather, they show the irreducible nature of dilemmas. Perhaps most significantly for bioethics, the narratives illustrate the fundamental connectedness of *clinical* and *moral* reasoning in the decision-making process.

I have chosen nine narratives from the data<sup>6</sup> to illustrate a range of long-term care problems that frequently confront practitioners who treat older patients. I have arranged them in three topical sets to reflect what I perceive to be a multidimensional chain or web of dilemmas in the phenomenology of geriatric medicine, rather than a discrete problem list. And I have placed them in groups of three to highlight variation in physicians' conceptualizations of certain themes.

The overarching clinical problem expressed by the fifty-one doctors, *degrees and means of intervention*, dominates all the chosen narratives and, in fact, most of the data collected. That problem is rooted in medicine's well-known and often-criticized directive—do something rather than nothing. The activist stance is shown here to be deeply troubling for practitioners in a broad range of circumstances. In the contexts of a growing elderly population, burgeoning chronic illness, and an overwhelming commitment to using technology, that fundamental directive, an essential feature of medicine's identity, has become a matter of profound ethical concern. The examples and discussion below contribute to the specification of the problem.

I begin with the broadly conceived issue of autonomy. The first set of narratives (Examples 1, 2, 3) illustrates a cultural conflict—permeating

American society beyond the boundaries of medicine—between safety and risk reduction, on the one hand, and freedom and independence, on the other. That conflict finds expression in the clinical dilemma: How much should and can one intervene? In the next set of cases that question becomes compounded with another: How aggressive should treatment be? Examples 4, 5, and 6 in the second set ponder issues of choice and responsibility in medicine in the face of the technological imperative. The last set of narratives joins the following additional questions to those posed by the others: What is comfort care? How does one provide it? And how can one reconcile comfort care with aggressive treatment?

*How Much Should and Can One Intervene? Safety, Risk, and Surveillance*

EXAMPLE 1

There is a guy who is about 78 or so who clearly has dementia and has had a couple of CVAs [strokes] and lives with his wife who is probably schizophrenic, psychotic to some degree. Their house is a disaster zone and the wife is housebound and she's just as obnoxious as she can be. This is one of the home care patients. The resident goes into this home and there are clothes everywhere and it smells of urine. There is not a big roach or rat history, but there is clutter and it's messy.

The resident, the case manager, and probably even Adult Protective Services are involved in this case. They all want to place this guy in [the county nursing home]. They are all saying, "He's in danger because his wife is so nuts, the house is a mess, and his quality of life is terrible." And I don't think he should be placed. My gut feeling is that they'd probably lived in a messy house even before he became ill. The evidence we have is that while the wife is nuts, she's also very committed to him. She tied a string around his waist, which is not an uncommon thing, it's a folk remedy. There are plenty of other patients who come in with strings around their waists. Probably she doesn't feed him right; that's the other thing. It brings up the issue of what do you do with people who have dementia but who are very clear, consistently, about their choice?

This guy does not want to be admitted to [a skilled nursing facility]. And there is a marginal living situation. I have spent hours and hours talking to people about this case. I feel like I really want to argue and advocate for him. It represents a class of problems you see in eldercare: older people who live in what are clearly less than ideal circumstances, who tolerate it fairly well, who aren't a danger to themselves. But it's really uncomfortable for us. You walk into somebody's house and it's disgusting. It's dirty and smelly and you say, "Get them out of there!"