MUST WE SUFFER OUR WAY TO DEATH?

CULTURAL AND THEOLOGICAL PERSPECTIVES ON DEATH BY CHOICE

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CHAPTER 1

Managing Death: The Growing Acceptance of Euthanasia in Contemporary American Society

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The great majority of Americans die within the confines of health care institutions (McMillan et al. 1990). In the social group formed by the patient, physicians, nurses, other health professionals, and the patient's family and friends, decisions are made and sanctioned regarding how, precisely, the patient's death and dying optimally shall be handled (Prigerson 1992). The physician in particular has considerable control over the manner of death, determining the treatment instituted to forestall death, the degree of pain relief (Wilson et al. 1992), the medical interventions withheld or withdrawn (Smedira et al. 1992; Christakis and Asch 1993), and the facts patients have about their illness (Miyaji 1993). As a result of both the proliferation of medical technology and the sequestration of large numbers of dying patients in institutions, contemporary American physicians, more so than ever before, influence the timing, rapidity, and painlessness of patients' deaths. Nevertheless, they exercise this influence under pressure from patients and society.

Euthanasia can be seen as just one of several expressions of physicians' control over the manner of death; it is an almost logical extension of the physician's role in managing death. Recent events in American

society point to an increasing public awareness and acceptance of such a role for physicians. Nearly half of the voters in California and Washington voted to accept bills permitting physicians to practice euthanasia (Reinhold 1992; Steinfels 1993; Misbin 1991). Grand juries in Michigan have repeatedly refused to indict pathologist Jack Kevorkian for his very public practice of euthanasia (Margolick 1993). Editorials in the popular press call for a review of proscriptions against the practice (Caplan 1990; Engram 1990). Surveys show that the majority of the public favors both allowing patients to die (Harvey and Shubat 1989; Frampton and Mayewski 1987)² and euthanasia ("The Ethics of Choosing Death" 1990). In the context of considerable physician control over death in American society, euthanasia appears to have found increasing acceptability.

In this chapter I examine features of American society and medicine—both recent trends and timeless values—that militate for the acceptance of euthanasia. I focus on forms of aid in dying that involve physicians, including euthanasia and physician-assisted suicide, and on the way in which recent trends are vitiating the physician's role within society, particularly with respect to the management of death.

The change in attitudes regarding euthanasia has largely been forced upon the medical establishment by exogenous forces, most prominently by patient dissatisfaction with current ways of dying. Modern modes of death and dying have become so problematic that euthanasia is achieving new legitimacy. The most fundamental reason for this, as the examples below make clear, is that modern medicine—whatever else it does—seems often to increase suffering when it prolongs life. Moreover, this increase in suffering takes place in a setting wherein, for example, patients see front-page newspaper headlines asserting that "doctors are lax in easing pain" (Haney 1991) and "doctors admit ignoring dying patients' wishes" (Brody 1993). Patients appear to want not just the right to die but also the right to be killed (Areen 1991).

People are dissatisfied with the technicalization, medicalization, professionalization, institutionalization, and sanitization of death in modern American society. Euthanasia stands in opposition—often paradoxically—to these developments. Euthanasia is finding acceptability both within American society and within institutionalized medicine because it is congruent with several large-scale social and medical trends and values, including naturalism, individualism, anti-authoritarianism, and secularism. These trends, directly or indirectly, tend to detechnicalize, demedicalize, deprofessionalize, and deinstitutionalize death.

Physicians and Death in American Society

Other people's deaths are part of physicians' workaday routines. Physicians try to forestall our death, tend to us before death, and care for us at death. Indeed, in our society, one is not legally dead until a physician so pronounces. Moreover, contact with death and dying plays an important role in how physicians are trained and socialized. For example, at the center of the socialization process of medical students is contact with death in the anatomy and pathology labs (Fox 1988:51–77, 78–101). And training time spent in intensive care units, wherein the patients are critically ill and mortality rates are high, is particularly valued by resident physicians as an opportunity to hone their skills "on the borderland between life and death."

Nevertheless, physicians have generally reviled and avoided death, fearing it as a mark of failure. For example, the function of prognostication in clinical practice was, for a long time, to help physicians avoid contact with dying patients. The Hippocratic texts suggest that one function of prognosis is to protect physicians from assuming responsibility for unmanageable or terminal patients and to help absolve themselves of blame in cases with adverse outcomes (Lloyd 1983:170; Unschuld 1979). Modern surgeons will sometimes refuse to operate on a critically ill patient for fear that they might be blamed for the patient's

presumably inevitable demise or for fear that they might have poor mortality statistics. And many internists still neglect their patients once a terminal diagnosis is made, avoiding associating with them, if possible (see Mizrahi 1986:72).

Although this pattern began to change in the 1960s, for many years there was a pattern of institutional denial regarding death in — American medicine. Physicians and patients did not directly discuss death. Physicians tended to reassure dying patients that everything was fine. Amongst themselves, physicians referred to dead patients as having merely been "transferred" to "Ward X" or to the "fifteenth floor" in a building with only fourteen floors. This reticence about death was not always self-serving. Many physicians avoided discussion of death out of a beneficent concern for the patient's well-being. One physician characterized the thinking as follows:

When I started [in the 1940s], you didn't tell anybody that they were going to die, unless they really pushed you. And I think it is all wrong that [today] we operate in medicine the way we used to in the army, with a "standard operating procedure," and that standard operating procedure seems nowadays to be that you tell people when they have a malignancy, or if they have a problem [you tell] them just how big of a problem it is. And I don't think that all patients can tolerate this. Medicine is something that just can't operate with an s.o.p. It is something that should be thought about and something where you treat the patient as an individual, and that you involve the family as well as the patient. I don't think that every patient ought to know that they're going to die. That's just my feeling. But it's a whole new ethos that's developed during my time in medicine. . . .

I think a physician always ought to let the *family* know [however]. Long ago, my wife's father had angina and he came to our city, and I went over him, and there was nothing you could really do in those days. His electrocardiogram was all right, his chest X ray was all right. It was clear that he had angina. And, uh, I guess I told him that he had a problem and so forth and that he did have

heart disease, but I told my wife and his wife that he was probably going to die one of those days and die suddenly. But I didn't tell him that.

And what really happened was that sometime a year later, he was digging in the garden—he had always wanted to know whether he should stop digging in his garden, given his heart problem, and what he should do if he got pain [while digging] and I said, "Well, stop when you get the pain"—but anyway, digging in the garden, which he loved to do, he collapsed and died. Now, you know, I guess people today express various things to patients that this or that would happen to them. But anyway, my wife was very understanding about it and so was his wife. . . . We just didn't tell patients in those days. (Christakis field notes, 10 April 1992)

This ethos of beneficent silence persists today among some physicians and in certain relatively traditional subcultures within American society (for example, the Hispanic community).⁸

In reaction to this avoidance of discussions about death—and consonant with then-contemporary societal trends toward "consciousness raising" and questioning of authority—a death-awareness movement emerged in the 1960s, led by books such as Herman Feifel's Meaning of Death (1959) and Elisabeth Kübler-Ross's On Death and Dying (1969). Kübler-Ross showed, among other things, that dying patients did not wish to be isolated, abandoned, or misled by their physicians. These books, both authored by psychiatrists, galvanized the public and spurred a rethinking of conventional medical practice. This pattern prefigured the way that popular ideas about euthanasia are currently leading the way to a change in professional ideas.

The sentiment that patients and physicians should discuss death more openly eventually gave way, in the 1970s and 1980s, to the compulsion that they do so. The ethics of the profession changed, and what has since been criticized as "terminal candor" took hold (Lear 1993). By today's standards, physicians have the duty to inform their patients of their illness, and patients have a right to know. As we shall see, this rep-

resents a displacement of the locus of control over death from the physician to the patient, a displacement that has contributed to the greater acceptability of euthanasia.

A physician expressed his own uneasiness about the haste to tell patients the worst this way:

I don't think if I were Dr. Smith, my son's doctor, that I would have expressed the whole thing—my son's prognosis—quite as early as he did. It was like out of the blue. I sat there when Dr. Smith told him, and I think that's what they do with everybody!

Or I had a colleague who had a carcinoma of the breast. And someone told her, just after she had a breast removed, while she was still recovering from the anesthesia and had just got back to her room, that she had six nodes positive. And I thought, Hell, you don't need to discuss all those things that early. But there seems to be a real feeling on the part of physicians today that the more open they are the better, but I don't think that's always true. (Christakis field notes, 10 April 1992)

Despite the resurgent intellectual interest and the critique of the prevailing thinking about death that began in the late 1960s, there was nevertheless relatively little change initially in the clinical care of the dying or in doctor-patient communication. This lack of change in physician behavior had to do with the social roles assumed by physicians. In a differentiated, modern society, citizens and institutions acquire specific social roles with specific duties. Technical advances and discoveries in medicine have held such promise that, from the turn of the century, society has endowed physicians with the duty and the privilege to eradicate disease (see Starr 1982). From this triumphal perspective, death connotes failure—not just of the therapeutic armamentarium to achieve its objective, but also of the physician to fulfill his or her social role. When physicians speak of the death of their patients, they often use expressions that suggest a mistake that might be rectified, such

as "we lost the patient," or a failing on the part of the patient, such as "that patient died on me." Physicians' rituals (for example, giving false reassurance to the dying) and institutional practices (for example, rapid sequestration of dead bodies in hospitals) served to protect the physicians from being identified with the failure to fulfill this role. It reflects both irony and arrogance that physicians feel guilt when their patients die—irony because they are not (ordinarily) truly responsible for the patient's death and arrogance because they believe that they are so powerful they might have prevented it.

Physicians have thus tended to regard their patients' deaths as personal failures (Mauksch 1975). Powerful emotional and intellectual strands within the professional culture of medicine also contribute to this perspective: optimism, activism, meliorism, and a hubristic, "against-the-odds" attitude are endemic in physicians. Sociologist Renée Fox has noted both the deeply held values underlying this thinking about death and the troubling questions raised by a medical technology capable of extraordinary life-support measures:

The Judeo-Christian tradition emphasizes that, because human life is divinely given, it is inherently sacred and important, has absolute, inestimable worth and meaning, and should be protected and sustained.... [But] in recent years, the unqualified commandment to support and sustain life has become increasingly problematic in American society, particularly in the medical sector. The sanctity of life ethic has helped to push physicians, nurses, and other medical professionals into a pugilistic tendency to combat death at any cost, and to define its occurrence as a personal and professional defeat. This heroically aggressive, "courage to fail" stance has been reinforced by the development of more powerfully effective forms of medical technology that increase the medical team's ability to save and maintain life. However, some of the consequences of doing everything possible to keep all chronically afflicted and terminally ill patients alive have come to be questioned. (Fox 1988:429-30)

Over the last twenty years, the material and psychic costs of this institutional denial of death have come to light; patients and physicians are addressing the suffering that the prolongation of life may entail for the dying person, and, as the nation's health care system has come under public scrutiny, many question the squandering of resources in the care of the dying.

The emergence of euthanasia as a desirable option, though a departure from tradition in that it puts the doctor face-to-face with death and seems to represent surrender to death, is, as we shall see, in other (somewhat paradoxical) senses a return to the traditional roots of clinical medicine and an exertion of control over modern ways of dying. Within the context of modern medical practice, total control over life is achieved only through control over death. At the same time, the increasing acceptance of euthanasia represents another step—evolutionary more than revolutionary—in the development of the physician's relationship to death and dying: an increasing acceptance of the inevitability and, in some circumstances, desirability of death.

The Detechnicalization and Demedicalization of Death

Since the 1960s, there has been a resurgent current of naturalism in American society expressed in ways as diverse as the "natural look" in appearance, organic cuisine, environmental activism, natural childbirth, and the glorification of the traditional family. This trend runs counter to the rampant technological advances present in modern society, advances that many view as distancing human beings from nature itself.

Though some forms of dying might at first glance seem completely unnatural (such as physician-assisted suicide or euthanasia), they, like allowing to die and the withholding of life support, actually stand in contradistinction to that which, today, is regarded as truly unnatural: death in an institution, perhaps in an intensive care unit, removed from one's family, surrounded by strangers, invaded by machines and devices, and needlessly enduring iatrogenically prolonged pain and suffering. Ironically, it is artificially sustained living, not dying—even by euthanasia—that has become inhumane in modern medicine.

A fundamental shift is now occurring in our society with respect to perceptions of medical technology. After years of great confidence in the promise of modern medicine, people are becoming concerned with the unseemly side of technical advances. The technicalization of death finds its chief expression in the provision of intensive care to patients just before death in the ICU. Patients have expressed deep sadness, frustration, and anger with modern medical care of all patients, but especially of the extraordinary measures taken for the dying in ICUs. For example, the son of one patient opened an editorial in the *New York Times* by stating, "The hospital was a torture chamber. Doctors were the torturers." This man—whose ninety-four-year-old mother developed colon cancer and, after surgery, developed multiple organ system failure requiring admission to an ICU—wrote of his anger with the medical community:

My mother's face was swollen beyond recognition. Her lips were raw from the respirator.

... A young doctor called to say that my mother had died. Momentary relief overshadowed anger. Now anger will linger for a long time:

Anger at a system that makes torture legal.

Anger at the medical profession that fights hard to protect its own prerogatives but has shown little courage in fighting inhumane legal restrictions which make doctors accomplices in torture.

Anger at doctors who are so wedded to charts and monitors that they seem oblivious of patients' pain.

At the funeral parlor I was told that I would be required to identify my mother. A few minutes later the men who were dealing with the body reversed that. They wanted to spare me a final look at the havoc modern medicine had wreaked on her. ("They Tortured My Mother" 1991)

This same theme of torture appears in a physician's evocative description of ICU care, entitled "The Prisoner":

The lights came on at exactly 5 am, revealing more clearly the gaunt elderly man lying naked amidst the disordered sheets on the bed. In response to the blinding light, the old man awoke, opened his eyes, then shut them just as quickly against the painful glare from above. Now awake, he struggled to resist the sound that had plagued him in the previous days (weeks? months?) of his imprisonment. The stiff gag in his mouth prevented him from talking and caused a constant pain in his throat. Alarms and other strange noises unceasingly assaulted him. His arms and legs throbbed from the multiple cuts they had inflicted upon him.

Under the brilliance of the lights, he became aware of his nakedness. Ashamed by this newest form of torture, he tried frantically to cover himself, but found his arms and legs tied down. . . .

Suddenly his captors surrounded the bed, each masked, each clamping down on his arms and legs. He tried desperately to tell them he had done nothing wrong, that they had imprisoned the wrong man, but the gag in his mouth prevented him from uttering a sound. Unable to talk or to free himself, he continued to resist. His captors kept him subdued and spoke loudly among themselves, seemingly unaware of the writhing, shriveled form beneath them. . . . To the masked figures rushing by the bed, only [the] constant movement of the old man's chest distinguished him from a bloodless corpse. (Eveloff 1992:313–14)

A similar description was offered by a son of a patient—here, both patient and child were physicians: "It has been more than a year since my father died, and I have come to believe that the circumstances of his death demonstrate much of what is wrong with our medical system. . . [My father] held me and whispered that everything would be O.K. 'Norman, I have been a surgeon for almost fifty years,' he said. 'In that time, I have seen physicians torture dying patients in vain attempts to prolong life. I have taken care of you most of your life. Now I must

ask for your help. Don't let them abuse me. No surgery. No chemotherapy'" ("Making a Living" 1992). The parents of yet another patient, a young man with AIDS, described their son's experience in an ICU thus:

Mother: Well, you know, you could die from all those medicines [that they gave him]. . . . Every time they moved those IV's, and they had to move them all the time because there were too many things flowing through him. There was no skin left on him anyway. He was in excruciating pain [as a result].

Father: There was one particular incident, and I think that was when he decided that he wanted out, that was when they put an IV in incorrectly, and he complained about the burning, and it stayed in for several hours, and they then discovered that it was infiltrated. And they took it out.

Mother: Then they were going to do that subclavicle thing [place a central venous line, a type of intravenous catheter] on him and that's when he said "I want out of here."

Father: I think it was that incident that was the end!

Mother: I mean it hurts like hell. (Christakis field notes, 23

April 1992)

Patients fear being victimized by a technology and a medical system run amok. One fifty-one-year-old woman, suffering from amyotrophic lateral sclerosis, paralyzed, and ventilator dependent, "used her eyes to ask to die," a newspaper headline declared. Her eighteen-year-old daughter told the judge in the case: "All I want is for you to see her and see what she's going through. She could continue to suffer for another week and another week and another week. [Please] do something for her" ("She Uses Eyes to Ask to Die" 1990).

Another illustration of the horror felt by some physicians at this needless prolongation of suffering is a tasteless joke that some physicians at my hospital have expropriated in order to characterize what often happens to patients in an ICU. They characterize the torture they feel they inflict on terminal patients as "mamba." The joke is as follows: Three

travelers are captured by vicious cannibals. The chief asks the first one whether he prefers death or mamba. Naturally presuming that nothing is worse than death, the first traveler picks mamba. He is subjected to unspeakable torture and then is killed. The same choice is posed to the second traveler. Uneasily, he picks mamba. He is also tortured and then killed. The chief then asks the third traveler to choose. Cognizant of the experience of his colleagues, the traveler says, "I choose death." "That is fine," the chief replies, "but first a little mamba." Many physicians feel that ICU care can be cruelly unnecessary, simply delaying an otherwise inevitable death. The implication, moreover, is that even when patients wish to die, the system refuses to let them. 10

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It is in this context, in a setting where medical care is equated with "excruciating pain," "imprisonment," and "torture," that euthanasia in all its forms finds increasing acceptability. 11 Such technical and invasive therapy is viewed as both violating the person (causing meaningless suffering) and violating the body (even making it unfit to be seen). These perceptions of modern medicine frame public desires and make euthanasia more acceptable.

Euthanasia, consequently and paradoxically, represents (1) the quintessential relief of suffering, (2) the firm repudiation of life-support technology, and (3) the paradigmatic exercise of physicianly restraint epitomized by the Hippocratic aphorism "First, do no harm" (Lloyd 1983:67). 12 The last point illustrates how traditional medical values are being recast: in the past, "do no harm" was used to limit medical practice and prevent death; now it may be used to limit medical practice and foster death. This paradoxical state of affairs has arisen because, compared to current, high-technology treatments, death is often perceived as less noxious. The practice of euthanasia, while ancient, assumes new meaning because it throws into relief the terrible bind of modern physicians: they can do more to treat their patients, but at a greater physical and psychic cost. The physician's increased power to heal is coupled with increased power to harm.

Euthanasia symbolically reasserts the patient's and the physician's control over suffering, over machines, and over dying. It symbolizes the fact that there are limits to technology. It is countertechnical: it involves the removal of machines and, if anything, the administration of a simple, lethal drug. Euthanasia is construed as facilitating the inevitable, as preserving the occurrence of what is natural. Just as society commends aggressive intervention to restore the otherwise healthy—but for disease—back to their natural health, ¹³ society commends aggressive intervention to restore the otherwise dead—but for modern medicine—back to their natural death. Modern medicine is construed as an unnatural impediment to a normal life event.14

If modern medicine, with its advanced life-support technologies, ranging from mechanical ventilation to hemodialysis to extracorporeal membrane oxygenation to cardiopulmonary resuscitation, medicalizes death, then euthanasia to a great extent demedicalizes it (see Fox 1988:465-83). The increasing acceptability of euthanasia reflects a societal response to and backlash against the increasing technicalization of medicine and death and the misery rather than the promise that technology is currently felt to offer. 15

The Deprofessionalization and Deinstitutionalization of Death

The increasing acceptability of euthanasia is also part of a trend granting greater autonomy to patients in general and granting greater control to patients over their deaths in particular, reactions against both the paternalism of medicine and the professionalization of death. Elements of the trend against the professionalization of medicine over the last two decades include the emergence of the hospice movement (James and Field 1992), the increasing popularity of patient-controlled analgesia (Kerr 1988), the rise of the home care movement (Steel 1991; Sankar 1991), and legal and legislative developments such as advanced directives, living wills, and the Patient Self-Determination Act (Greco et al. 1991). Patients are being encouraged more and more to care for thein-selves rather than to rely so heavily on the services of physicians and medical institutions. These efforts are "not so much a change in [American] values as the initiation of action intended to modify certain structural features of American medicine, so that it will more fully realize long-standing societal values" (Fox 1988:482). These values include equality, independence, and self-reliance. Moreover, euthanasia is consonant with anti-authoritarian trends in American society, such as the consumer advocacy movement, the civil rights movement, and the women's movement. It returns control over death to patients.

Part of the demedicalization trend in American society has involved efforts to make the doctor-patient relationship less hierarchical and more egalitarian. Patients are being given a slew of rights—with corresponding duties being placed upon physicians: the right to treatment, the right to information, the right to informed consent, the right to privacy, and the right to die. Patient autonomy in terminal care may manifest itself in several ways: patients may choose not to initiate medical therapy (including lifesaving therapy), they may refuse lifesaving therapy, and, with ultimate self-determination, they may end their own lives. The last right to die is gradually being extended to include the right to euthanasia.

Such patient rights are emerging at a time when medicine as a profession is coming under attack. In a paper titled "When Self-Determination Runs Amok," philosopher Daniel Callahan is critical of euthanasia in part because it treats physicians as "hired hands" rather than as moral agents (Callahan 1992). Yet there is no arguing that this is happening. That is, to some extent, physicians are themselves being deprofessionalized in contemporary American society. Their role is being commercialized as it is coming to be construed as one of serving their clients as much as treating their patients. Physicians have voluntarily and involuntarily abrogated many of their fiduciary duties. They must

answer to insurance companies, government agencies, quality assurance committees, professional review boards, malpractice attorneys, their employers, and their patients. Physicians are coming to be more *employees* than professionals (Friedson 1970). Indeed, the very term *physician-assisted suicide* places the physician in a secondary role of an assistant.

Thus, the issue is coming to be framed as a question of what role to allow physicians in helping patients to exercise their "rights." More generally, physicians are deprived of their authority over dying. Indeed, one of the remarkable things accomplished by the availability of books like Derek Humphry's Final Exit—which, in describing in specific detail how patients might end their own lives, achieved best-seller status—is to make it possible to remove physicians altogether from the social network responsible for euthanasia. Patients are empowered, with varying degrees of family assistance, to end their own lives, painlessly and with dignity. Euthanasia itself, in other words, while still involving a knowledge of toxicology and physiology, is largely deprofessionalized and deinstitutionalized; it takes place outside of a health care institution, with laypeople assuming functions such as pain relief and drug administration previously reserved for physicians, and with laypeople in decision-making roles. This development is analogous to patients' taking responsibility for their own health.

When physicians have proven to be unwilling or unable to forgo painful or unnecessary therapy or unwilling to practice euthanasia, patients have sometimes shown themselves willing and able to take matters into their own hands, either inside or outside the hospital. There has been a spate of stories in the popular press concerning family members insisting on the withdrawal of life support and assisting relatives with suicide. In a sense, people outside the medical profession, patients and their families, are leading the way, with the medical and bioethical communities following (Fox 1994).¹⁶

Recurrent themes in the cases of family-assisted suicide are frustration with an overly aggressive medical system and deep love and

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almost ritualistic pacts between the family members. These cases sometimes wind up in court. One man was brought to trial for manslaughter when he "kept his promise" to his seventy-nine-year-old mother by handing her a pistol the day she was told by her doctors that she had terminal liver cancer. She killed herself minutes after he left the room ("Trial Begins" 1992). 17 In another case, a daughter desperately tried to "free" her mother from the "trap" of inoperable ovarian cancer and obtained pills for her to kill herself with ("I Helped" 1992). Sometimes family members will volunteer to be of assistance; they prepare themselves to help a patient kill himself even when the patient says nothing (Cranford 1989). In a particularly heartbreaking case, Rudolfo Linares—in desperation over his profoundly brain-injured infant's prolonged stay in an ICU-swept into his son's room and, keeping hospital personnel at bay with a handgun, disconnected his son's respirator and cradled him until he died thirty minutes later. His actions were supported by many, and a grand jury refused to indict him ("Armed Man Pulls" 1989; "Father Speeds" 1989; "Father Who Pulled" 1989). It is a sad commentary on modern medicine that such desperate action was necessary to achieve an end that all participants regarded as desirable. One has the sense that part of the reason this case was so newsworthy was that Linares was acting as the public felt that physicians should have. In a profoundly American way, he took matters into his own hands so that justice might be served.

Sometimes doctors go so far as to suggest to families that they commit euthanasia. On the one hand, this complies with physicians' duty to do no harm in treating their patients, but, on the other, it is an abrogation of their responsibility and shifts the burden to others. Suggestions to families that they take matters into their own hands are sometimes met with surprise and sometimes without resistance. In the case of a young AIDS patient, a doctor suggested to the patient's parents that they themselves might wish to help their son to die. The parents described the situation as follows:

Mother: When I was questioning the doctor as we were leaving, I was really very concerned. My son was a wreck. And he was in awful pain, and all those medicines had just done this number on him. I said that I had to be able to keep him comfortable: "You're giving me this new prescription for Dilaudid [a powerful narcotic]; do I give him two, do I give him four, how much. . . . What's reasonable, how frequently?" And he looked me level in the eye and gave me a progression: "If one doesn't work give him two, if two don't work give him three, and if you can't make him comfortable and you want to, just give him the whole bottle." And I believe I understood him clearly. He didn't think there was anything good coming down the pike for my son.

Interviewer: Do you think that he was suggesting to you that you take your son's life or that you provide him the means to take his own life?

Mother: I think he was suggesting that if what it took . . . if he was so miserable and so uncomfortable . . . if what it took to put him out of his misery was an overdose, it was a good idea. I think that was exactly what he was saying.

Interviewer: This seems to trouble you.

Mother: It didn't trouble me. It surprised me . . . that somebody was giving me leave to go home and take this medication and do with it as I saw fit. That's not usually what you get from a doctor. But it was humane.

Father: It was just shocking to us because we have no experience and, you know, you hear something like that from a health professional—who is supposed to be there to save life no matter what. . . .

Interviewer: You said a minute ago that there may be a tension between the duty of health professionals to save life and this function [of ending life].

Father: I was just trying to explain where my wife is coming from. One grows up in our society with the expectation that doctors are somebody special. And why are they special? They are special because they help and [because] they save lives. And for them to now say that here it is okay for them to execute somebody, that goes against the grain of what we in our society are culturally

accustomed to. Intellectually, I can agree with the doctor. On the other hand, it does go against the grain in some way. We may overlook it, or push it back, or ignore it, but I at least realize that there is a conflict in me thinking about that.

Mother: So, suddenly, here you are. You've got this person in front of you who is dying. And the physician says to you, "We've pretty much done all we can do." It's going to take its own course: he's going to die. On the other hand, acknowledging that you don't want him to suffer too much, there is a way maybe to speed that process, especially if he's very uncomfortable. It's taking the physician out of the role of—as my husband says—healer, and it's putting him in the position of saying, "I can't help you or protect you any more; the best I can do for you is to make this person's end . . . [be] with as little pain as possible." You just don't expect it! It is admitting defeat! (Christakis field notes, 23 April 1992)

Despite their ultimate willingness to facilitate their son's death, this couple did not refer to the action the doctor suggested as "euthanasia" but rather—demonstrating a distinction made in society-at-large—referred to it as "killing" or "executing" the patient. For them, when a doctor commits this action, it is euthanasia, but when they do, it is not. Similarly, Humphry refers to such patient actions as "self-deliverance," not as self-euthanasia.

Nevertheless, it is noteworthy that, in general, when practiced by nonphysicians outside of health care institutions, such deaths are not, in fact, referred to as euthanasia but rather as "suicide," whether or not the individual was assisted by a physician or relative. This suggests that the public still desires that physicians assume the serious responsibility of ending life, that only physicians can be socially sanctioned to bring about the death of another person by "euthanasia." However uncomfortable our society might be with euthanasia practiced by physicians, it is that much more uncomfortable when it is practiced by laypeople. This observation also suggests that, from a societal perspective, since physicians are assigned the task and honor of preventing death, only

they can properly cause it; physicians, not laypeople, are still the only ones that society permits to practice euthanasia.

Sometimes doctors encourage euthanasia and encounter both surprise and resistance from families. When they do so, they often invoke an emerging theme in American bioethics: futility. A futile action is one that cannot achieve the goals desired of the action (Schneiderman et al. 1990). Thus, providing medical therapy in order to improve health in a case where such therapy cannot improve health is futile. Even when therapy is futile, however, doctors rarely seek to withdraw life support against the wishes of the family. The case of Helga Wanglie became famous in part because doctors are ordinarily so reluctant to advocate publicly the death of a patient, but also because the family was opposed to the doctors' intentions. In addition, the very public admission of impotence by the physicians was also cause for consternation in a society accustomed only to claims of heroic successes in modern medical care. In this case, the doctors argued that further life support for eightyseven-year-old Mrs. Wanglie, who was in a persistent vegetative state, was futile. Her husband disagreed ("As Family Protests" 1991; see also "Atlanta Court" 1991). Mr. Wanglie contended that he and his wife felt that human life was sacred and God-given and that only God could take it. The director of the hospital replied that they did not feel obliged to provide inappropriate treatment that was not in the patient's medical interest.

The recent emergence of futility as an important theme in American medicine and bioethics reflects the moral desirability of acknowledging medical limitations and the practical necessity of allocating scarce resources (Jecker and Schneiderman 1992; see also Fox 1994). Futility and euthanasia may have the same roots. Although futility runs counter to the quintessential American ethos of limitless medical progress and virtually omnipotent physicians, it is nonetheless consonant with other important values within medicine, such as non-maleficence and rationality.

One assumption underlying the increasing acceptance of euthanasia in American society is that dying is a private, individual, personal, intimate event. Dying in modern contexts connotes a fear of losing control, which loss is antithetical to a core American value. The option to be killed restores control. This is not necessarily so in other societies, where the death of one person may be viewed as the concern of the entire community. This American perception of death is contingent on a quintessentially individualistic view of the person (De Craemer 1983). To this view, however, some are opposed on moral grounds (Callahan 1992). Indeed, to insist that dying is a private act does, to some extent, eliminate public accountability and oversight.

Anti-authoritarianism, individualism, and autonomy are also manifest as anti-institutionalism—here, in particular, as a rejection of death at a hospital in favor of a more natural and autonomous death at home. Hospitals are increasingly viewed as singularly unsuited not only to a "natural" but also to a painless and dignified death. The juxtaposition in a hospital of high technology, bureaucracy, and professionalism on the one hand and the most fundamental and unchanging of human experiences—such as birth, death, and pain—on the other hand is increasingly viewed as inauspicious (see Rosenberg 1987:3). Studies have shown that terminally ill people would prefer to die at home rather than in a hospital (see McCormick et al. 1991), and home death is increasing (McMillan et al. 1990). People are rejecting both biomedical therapy and biomedical institutions.

Terminally ill patients think of hospitals as "buildings full of strangers" (Belkin 1992) and regard them as unwelcoming, uncaring, and alienating. Patients reject what they see as the meaninglessness and indignity of dying in a hospital and prefer death at home, removed from high technology. Hospitals are coming to be seen as a necessary evil for the curable but an unnecessary evil for the incurable.

One twenty-nine-year-old cancer patient who had been hospitalized eight times in the preceding two years refused to go back to the

hospital, arguing: "I want to die at home. My doctor calls me stubborn. I'm not stubborn. I'm taking control" (Belkin 1992). The husband of another patient, a fifty-eight-year-old woman with breast cancer, observed of his wife: "In the hospital, they could have kept her alive for a few days, maybe a few weeks. For what? What kind of life is that? She cried whenever she had to go back to the hospital. All she would do there is stare at the ceiling" (Belkin 1992). Indeed, terminally ill patients often prefer to die rather than be aggressively treated in what they perceive to be the wrong fashion in the wrong setting. Euthanasia thus provides escape from the hospital, an institution which many regard as an impersonal monolith "little concerned with needs that [cannot] be measured, probed, or irradiated" (Rosenberg 1987:3). As care has become more and more impersonal, patients have lost confidence that their true needs will be met, and so euthanasia has become more appealing.

This observation may partly explain the hostility between the right-to-die, pro-euthanasia movement and the hospice movement. The hospice approach to the care of terminally ill patients emphasizes attention to patients' physical, 'emotional, and spiritual suffering; its primary goal is the palliation and relief of this suffering rather than treatment of the patient's underlying disease. Proponents of hospice feel that if patients were better cared for, they would not be demanding euthanasia. Indeed, one physician titled his book on hospice care Euthanasia Is Not the Answer, arguing that uncontrolled pain and suffering lead to a desire for euthanasia (Cundiff 1992). 18 In my field interviews, hospice personnel indicated that they are pleased with American Medical Association and American Bar Association opposition to pro-euthanasia laws. Hospice personnel regard death reverently; they feel that euthanasia is irreverent, meaningless, and undignified. From the hospice perspective, euthanasia is meaningless because it is the ending of a life without the relief of the suffering. It does not address the pain of the patient's family or the psychiatric and spiritual suffering of the patient. Proponents of hospice regard death as incidental to the relief of suffer36

ing. In contrast, proponents of euthanasia regard death as instrumental to the relief of suffering. Nevertheless, like the hospice movement, which rejects unnecessary medical technology and bureaucracies in favor of personal, simple, traditional, low-technology health care for the terminally ill, advocates of euthanasia also reject unnecessary medical technology (Mor et al. 1988).

Other Social Factors

Several other trends contribute to the increasing acceptability of euthanasia in American society. First) the post-World War II era has seen a trend toward the progressive secularization of our society, evidenced in the elimination of school prayer, falling church attendance, and the waning of religious influence over everyday life. With respect to euthanasia, this trend has found expression in the desacralization of death and healing. In a secular and humanistic society, euthanasia becomes more permissible. Second, over the last two decades, there has been a progressive societal obsession with physical fitness. At a minimum, this glorification of fitness may foster a general feeling that it is better to die than to become infirm. Physical and mental deterioration prompts patients and their families to opt for a way out-for example, through family-assisted spicide-rather than face a slow senescence, even when the senescence is not painful. Those that are mentally or physically infirm feel so socially deviant that euthanasia is legitimized. Third, public concern with cost containment and setting limits in health care also unavoidably makes euthanasia an attractive alternative to lengthy and costly terminal hospitalizations. Like the proverbial elderly Eskimo wandering onto the ice floes in self-sacrifice rather than burdening his or her clan, the practice of euthanasia is consonant with the husbanding of what are increasingly viewed as limited societal resources for health care. Finally, as the American population ages, greater attention is being given to the problems and needs of the aged in our society;

the growing numbers of aged patients may lead to increased pressures for euthanasia as an alternative to an extended, hopeless debilitation.

Eliminating Suffering

The increasing acceptability of euthanasia in American society is thus congruent with a number of values of American society, including especially naturalism, individualism, and anti-authoritarianism.

Paradoxically, physician-assisted suicide and the other forms of euthanasia we have been considering represent a retrenchment to the humanitarian ethos that used to guide medicine. Euthanasia, at its best, represents an atavistic phenomenon. When physicians do support euthanasia, they couch it in the best traditions of their profession, as a humanitarian act that represents an ultimate act of good doctoring (Quill 1991). It is a bedside practice. It is a relief from suffering. Typically, it is done in circumstances where the doctor has known the patient for a long time. Euthanasia and its greater acceptability can thus be seen as part of an effort to rehumanize medicine and return it to its roots.

The public and professional debate about euthanasia revolves not just around its acceptability but also around its definition. If euthanasia is acceptable, under what terms is this so? Who may commit it? Who may succumb to it? When and why is it acceptable? Many physicians would say that their duties include both the prolongation of life and the relief of suffering. But American society is poorly equipped to handle situations where the two conflict. Which has precedence? Who decides?

The debate about the acceptability of euthanasia in our society unavoidably—if inexplicitly—raises important questions about the ideal relationship of a doctor to death. Much energy has gone into resisting any change in the physician's relationship to death—as evinced by opposition to physician-assisted suicide and active euthanasia, which are felt

to be a perversion or inappropriate extension of the physician's social role—but less energy has been expended examining what the proper relationship to death should be. How should the physician usher us out of this world? How should the physician view death? In our society, we generally expect physicians to study and learn from dead bodies, certify death when it has occurred, attend the death of their patients, and relieve the suffering associated with it. Yet we expect our physicians, while doing all this death-related work, to be on the side of life, to preserve and extend it. Some of the triumphalism that used to characterize the relationship of the doctor and death is now giving way to a new realism, as contemporary physicians, emerging from an era of unbridled optimism and success, are finally reaching and recognizing their limits.

Euthanasia in many of its forms has come to be seen as salvation, not only as release from the suffering and pain of the underlying disease but also as relief from the suffering, pain, and alienation engendered specifically by modern medicine and modern health care institutions. It provides deliverance from both the disease and the therapy. In the past, euthanasia was often construed as a repudiation of a moral good, namely life itself, and was therefore unacceptable. Moreover, to commit it was to acknowledge incompetence on the part of the physician in curing disease and relieving human misery. Now, euthanasia may often represent the repudiation of an evil, namely iatrogenic suffering. The equation of hospitalization and medical care with suffering has to some extent made death less feared. Euthanasia does what therapy seemingly cannot: relieve the suffering. In so doing, it calls into question the status of suffering in contemporary American society (Kleinman 1988; Cassell 1991).

Relief of physical suffering is in principle relatively easy. Yet physicians, in practice, do as poor a job relieving physical suffering as they do relieving psychic and spiritual suffering. For many, euthanasia addresses—nay, eliminates—all three.

NOTES

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- 1. In 1986, the most recent year with available data, 83 percent of aged Americans who died did so in health care institutions (McMillan et al. 1990).
- 2. For example, in a 1988 survey, 78 percent of physicians and 73 percent of the public favored the withdrawal of life support for hopelessly ill patients (Harvey and Shubat 1989).
- 3. The original study was Solomon et al. 1993.
- 4. Sociologist Everett C. Hughes notes, in his discussion of professions and work, that "one man's routine of work is made of the emergencies of other people" (1971:316).
- 5. This function is particularly intriguing, but, even more intriguing, the performance of this function by physicians is generally assumed and unexamined. Even Ivan Illich does not criticize physicians for the arrogation of this priestly function (1976).
- 6. From my field notes for 10 April 1992. The research for which these field notes were obtained is an effort to understand the use of prognosis in modern clinical practice, particularly as it influences physician behavior at the end of a patient's life (Christakis 1995). Prognosis is a key element in a physician's decision to withdraw or withhold life support, administer lethal medicines, refer a patient to a hospice, or perform euthanasia. Among other methods, the research involves interviewing physicians, patients, and their families. Subsequent references to these field notes appear in the text.
- 7. This use of prognosis is not restricted to Western medical systems; similar themes appear in the texts of other literate medical traditions, such as Ayurveda and traditional Chinese medicine (Unschuld 1979).
- 8. Some patients and their families are calling for its return and criticizing contemporary practice (Lear 1993:17). This beneficent silence is widely practiced in Europe, China, Japan, Latin America, and other parts of the world (Freedman 1993).
- 9. This pattern appears to have been the case for quite some time, at least with respect to active euthanasia (Fye 1978).
- Some doctors have described their agony and embarrassed complicity in participating in futile medical care. For a case described by one physician, see Hansen-Flaschen 1990.
- 11. I should add that proposals to reform the medical system's approach to the dying and to foster the hospice approach arise from similar sources.
- 12. The oath also contains the following statement: "I will not give a fatal draught to anyone if I am asked, nor will I suggest any such thing."

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- 13. This "restoration" is nevertheless often felt to be unnatural in any case. For example, medical technology applied to such patients is spoken of as "artificial"—such as the artificial kidney or heart. Similarly, physicians euphemistically refer to "end-stage" rather than "terminal" renal disease (see Fox and Swazey 1978).
- 14. In a way, "natural death" is the counterpart of "natural childbirth." For an excellent consideration of "new metaphors" for birth, including "pure child-birth" and "home birth," see Martin 1987, chap. 9. Indeed, there are interesting parallels between the professionalization and deprofessionalization of death and birth in general.
- 15. See also Illich 1976:102-3: "The modern fear of unhygienic death makes life appear like a race towards a terminal scramble. . . . The patient's unwillingness to die on his own [without a physician nearby] makes him pathetically dependent. He has now lost his faith in his ability to die, the terminal shape that health can take, and has made the right to be professionally killed [i.e., euthanasia] into a major issue."
- Regarding the pattern of reaction rather than proaction by the bioethics community see Fox 1994.
- 17. Ironically, in this case, the doctor's diagnosis was in error, and the patient might have survived ("Trial Begins" 1992).
- 18. For more on the antipathy of hospice proponents toward euthanasia, see Thompson 1984.
- 19. Indeed, the furor over the Debbie case was in large part motivated by the fact that the doctor in question did not know the patient. The furor over Dr. Kevorkian's practice has similar roots.

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