This article, part of a larger anthropological investigation of how death occurs in the hospital, explores the relationship of elderly deaths in the intensive care unit to the cultural conversation about the desire for "death with dignity." Based on participant observation, it provides three case studies that focus on the unfolding of events surrounding patient treatment, decision making, and family involvement. The cases are interpreted in the context of four sources of the culturally defined "problem" of death: (a) how medicine operates as the dominant conceptual framework for understanding both old age and death; (b) the power of the technological imperative to determine events; (c) ambivalence regarding end-of-life goals; and (d) the incommensurability of lay and medical knowledge.

Key Words: Medical ethnography, End-of-life care, Bioethics

Intensive Care, Old Age, and the Problem of Death in America

Sharon R. Kaufman, PhD

Over the last decade, the cultural conversation about the problem of death in America has become increasingly prominent in American life. That conversation focuses largely on the seemingly insoluble tension between the idea of "death with dignity," a "good death," and personal control in dying on the one hand, and on the other hand, the pain, suffering, loneliness, and lack of autonomy brought about by the use of advanced technology medicine in the hospital setting. The essential feature of this cultural discourse is a notion of patient- and family-centered care and respect in conflict with inhumane life-prolonging treatments for those who are dying.

Two common examples illustrate the way this conflict is reflected in practice. First, the tension between "heroic" and "humanistic" medical care is played out in countless daily scenarios in hospitals as health professionals and the public on both sides of the debate struggle with defining responsible and ethical practice, especially in the case of very old and frail patients. Volumes have been written about the need to redefine and reorient the goals of clinical medicine to be person-centered and to focus on "quality of life" rather than disease and cure (e.g., Callahan, 1993; Cassell, 1991; Institute of Medicine, 1997). Many individual practitioners attempt to emphasize those goals in their daily work. Yet structural, economic, and political realities of medical training and health care delivery preclude the widespread acceptance in practice of the values of communication and empathy and the relief of suffering (Lo, 1995; Nuland, 1994). Second, patient (and family or surrogate) participation in medical decision making, although hailed as a positive development in contemporary medicine, confounds notions of responsibility and communication. In the process of offering multiple choices for end-of-life conditions and advocating patient use of advance directives, physicians' expertise and experience is devalued, their accountability is potentially or actually abdicated and eroded (Brody, 1992; Christie & Hoffmaster, 1986), and patients and families are thrust into situations for which they are entirely unprepared.

Discussion about the problem of death in America is now widespread and manifests itself in many institutions and arenas, including: the 1990 federal Patient Self Determination Act, through which hospital patients are informed of their right to make treatment choices; the U.S. Supreme Court's consideration of physician-assisted death in 1997; ballot initiatives in California, Oregon, and Washington to legalize euthanasia; newspaper editorials on the difficulty of dying; hospital ethics committee deliberations; articles in medical, nursing, and bioethics journals; the emergence of private philanthropic foundation support for programs to change the ways in which death occurs; and various grassroots "right to die" movements and organizations whose goals include improved palliative care and control of the means, timing, and location of death. Because more than half the deaths in the United States occur in acute care hospitals, and because a frequent institutional response is to forestall death with the most up-to-date and sophisticated means available, a great many adult Americans have personally participated in this cultural conversation either as a patient, family member, friend, or health care provider.

The study on which this article is based was funded by the National Institute on Aging, Grant No. AG13636, to Sharon R. Kaufman, primary investigator. The author thanks the hospital staff, patients, and families who participated in this project; co-primary investigator Guy Micco for his support and insights; project staff Karen Van Leuven and Chris Wood for their assistance; and Jessica Muller for her suggestions on an earlier draft of this article.

1Address correspondence to Dr. Sharon R. Kaufman, Institute for Health & Aging, Dept. Of Social and Behavioral Sciences, and Medical Anthropology Program, Box 0646, University of California, San Francisco, CA 94143-0646. E-mail: kaufman@itsa.ucsf.edu
The goal of this article is to present to the gerontological community findings from an ongoing, anthropological investigation of how death occurs among older adults in a community hospital in order to make one point: that the cultural conversation, which tends to emphasize discrete entities in opposition—"palliation" versus "treatment," "technology" versus "care," "control" versus "powerlessness," "choice" versus "inevitability"—ignores the lived experiences of health professionals, patients, and families in the hospital setting. I suggest that ambivalence about what to do as a person's condition deteriorates and ambiguity about goals as death approaches are common. The ethnographic study on which this article is based aims to describe how dying is approached and understood by health professionals, patients, and families, and to examine how death occurs in one midsize urban community hospital. The study addresses the interpersonal, structural, and ideological contexts in which death takes place. I found that the actual unfolding of activities surrounding the end of a person's life, the practice of dying, is in many cases much more muddled than the cultural conversation suggests. The clarity of the abstract concept of "death with dignity" largely disappears in the very real and compelling world of hospital technology and regulations and in the process of caring for and tending to both critically ill and declining patients. I hope that findings from this study will contribute to our understanding of why it is so hard to die in America by delineating some of the complexities of the dying process and the practices surrounding the dying transition in a community hospital.

Here I report on data collected from observations of elderly patients who died in the intensive care unit (ICU). Although not all ICU deaths are considered ethically troublesome or difficult by hospital staff or families, this article presents precisely the kinds of deaths the cultural conversation identifies as the most problematic. By focusing on three ICU cases, this article illustrates: (a) how palliation and treatment are defined and negotiated for each patient in the context of institutional culture and patient and family demands; (b) the power of the "technological imperative" (Fuchs, 1974) to determine events; (c) the ambiguity regarding end-of-life goals that perplexes much of geriatric medical care; and (d) the difficulty of knowing and evaluating, from the perspective of immediate concern, what constitutes a satisfactory or unsatisfactory action and, in fact, a good death.

**Background: Elderly Patients and Hospital Deaths**

At the present time, about 55–60% of persons older than 65 die in the hospital, though patterns vary considerably across the nation (Anders, 1997; Institute of Medicine, 1997). Those persons fall into two distinct groups. The first includes elderly adults who were functioning independently until they were struck by a serious illness—heart attack, stroke, fractured hip, for example. Because of their prior history of relatively good health, they are not the type of patient for whom "no code" orders (no cardiopulmonary resuscitation [CPR] in the event of cardiac arrest) are likely to be written. Most of those patients receive relatively intensive care. The second group includes people who are older, frail and debilitated, and have multiple degenerative conditions, but are not clearly dying. The second group is larger, comprising 70% to 80% of elderly patients in the hospital. That group may require repeated hospitalizations for supportive or intensive care to stabilize conditions and treat acute problems (Battin, 1994; Scitovsky & Capron, 1986). It is well known that the costs of medical care, and especially the costs of intensive care, are high in the last months of life (Lubitz & Riley, 1993; Scitovsky, 1984; Scitovsky & Capron, 1986) and debates about rationing health care to elderly adults in order to reduce health care costs are well known (Binstock & Post, 1991; Callahan, 1987; Wikler, 1992). In addition to ongoing debates about rationing, a vast literature in bioethics illustrates dilemmas in treatment and care for older persons at the end of life for which there are competing claims and no clear-cut solutions (Callahan, 1990; Cassel, 1985; Moskowitz & Nelson, 1995).

ICU treatments of elderly patients who subsequently die on the unit are particularly troublesome because those patients—whose lives are maintained and extended by technological and pharmaceutical support and whose treatments may cause pain and suffering—embody the most recalcitrant dilemmas about the value and purpose of life prolongation. Treatments for very ill elders are pursued for at least two reasons. First, physicians think that perhaps a critical situation can be resolved so they hesitate to define a severely ill patient as dying (Muller & Koenig, 1988). Second, families hope that ICU treatments will ensure recovery. They are often extremely reluctant to forego consideration of intensive treatments or to stop them, especially if they are not sure that death is inevitable. Although ICU outcome studies among older patients are difficult to summarize and assess because of different age limits, medical conditions, and surgical procedures studied (Schechter, 1994), research on ICU deaths in patients older than 65 shows mortality rates similar to studies for all age ranges in the ICU: 9% to 38% (Kass, Castriotta, & Malakoff, 1992; Wu, Rubin, & Rosen, 1990). The relatively low overall mortality rate both legitimizes ICU care for frail and very old people and contributes to the creation of ethical problems in individual cases. Yet the mortality rate range reflected in various studies does not consider survival following CPR in the ICU. In one recent study, only 3% of ICU patients survived the procedure (Karetzky, Zubair, & Parikh, 1995).

The largest and most recent study ever conducted on the process of dying in the hospital was carried out in five university hospitals across the United States over a four-year period beginning in 1989 (SUPPORT Principal Investigators, 1995). In the first two-year phase of the project, 4,300 patients with a median age of 65 diagnosed with life-threatening illnesses were enrolled in order to understand the character and quality of dying in the hospital. The SUPPORT investigators concluded that the dying
process in the hospital was not satisfactory. For example, only 47% of physicians knew when their patients wanted to avoid CPR; 38% of patients who died spent 10 or more days in an ICU preceding death; 46% of “Do Not Resuscitate” (DNR) orders were written within two days of death even though 79% of the patients had a DNR order; and for 50% of the conscious patients, families reported moderate to severe pain at least half the time in the three days preceding death. A second two-year intervention phase involving approximately 5,000 different patients (about half in a control group, half in an intervention group) was intended to affect positively the perceived quality of hospital deaths by enhancing the flow of information between doctors and patients. The startling results were that interventions aimed at improving physician-patient communication and physician knowledge of prognoses and patients’ end-of-life wishes did not change the practice of medicine regarding the use of ICU treatments, timing of DNR orders, avoidance of CPR, or provision of pain relief, nor did those interventions alter the quality of patient and family experience. (SUPPORT Principal Investigators, 1995; Moskowitz & Nelson, 1995). Even when a focused and concerted effort was made to reduce pain and to respect patient wishes regarding end-of-life care, no overall improvement in care or outcomes was made.

Methods

The Ethnographic Study

This article on ICU deaths is part of a larger anthropological investigation of how dying and death are approached and understood by health professionals, patients, and families and how dying and death occur among older adults in one community hospital. The study is based on the collection of data by participant observation on the adult wards in one midsize acute care hospital and by conversations and interviews with physicians, nurses, social workers, chaplains, patients, and family members. Over a 12-month period (calendar year 1997), I observed the course of events surrounding hospitalization and death for 80 individuals aged 50 and older. Thirty-one of the 80 individuals I observed died in the ICU. Based on statistics available from the medical records department of the hospital, 370 people aged 50 and older died during that year, one third of them in the ICU. In all, I observed activities surrounding about 20% of hospital deaths for older adults over a one-year period.

Specific data collection procedures throughout the hospital consisted of the following activities: (a) attendance at daily (ICU) and weekly (other adult medical wards) multidisciplinary rounds in which the cases of patients, including their diagnoses, prognoses, treatments and treatment plans, family dynamics, and discharge options were discussed; (b) conversations with health professionals after rounds or at other times about those patients who were near death or who were critically ill and might die; (c) where possible, discussions with family members or friends who came to the hospital to visit patients; (d) conversations with patients (but none with patients in the ICU); (e) review of patient charts; and (f) attendance at family conferences in which various health professionals discussed with family members the patient’s condition, possible and preferred treatment plans, prognoses, the possibility of death, and choices—from the medical standpoint—that family members were confronting. In all these activities, data were collected by descriptive notetaking including verbatim notation during some conversations and conferences.

Intensive Care Cases

The case studies presented in this article are drawn from my notes on the 31 ICU patients whom I followed from admission to death. I have selected them because they are not routine; they are considered problematic cases by the players I observed. Taken together, they illustrate some of the ways in which ICU deaths fuel the broad cultural discourse I have described. Many readers in the health professions will be familiar with the following scenarios. Although they illustrate the situations of unique individuals, they are also common cultural narratives, common forms of death. Stories like these unfold across the United States everyday, and the multiple dilemmas they raise are reported and pondered widely in the literature. These three cases exemplify the apparent incommensurability of the cultural ideal of “death with dignity” on the one hand, and actual deliberations, goals, and pressures that surround hospital practices on the other.

Partial Truths and the Problem of Representation

The act of ethnographic reconstruction is problematic for all textual analyses and has been widely discussed in the anthropological literature (Clifford & Marcus, 1986; Geertz, 1988; Jackson, 1996). I faced that problem directly in deciding which data were important to collect in the first place and how to represent individual patient cases from my lengthy notes written during rounds, informal discussions, formal interviews, and conferences. I was only a part-time witness to the cases I observed; my interpretation is dependent on what I saw and recorded. I was in the hospital 20–30 hours per week and was privy to activities, meetings, and conversations with people I could locate and who consented to my presence during the time I was on-site. Each time I returned, I asked others to reconstruct the flow of events that had occurred during my absence. The cases presented here are my reconstitution of the events that unfolded around three particular patients, based on my field notes and chart reviews. The cases include what I consider to be the main topical points of each story. I chose certain features from the field notes in order to set the stage, first, for the exploration of ambiguity, confusion, and conflict about goals at the end of life; second, for the portrayal of incommensurability between medical and lay worlds of knowledge and understanding; and third, for questions about action, frailty, and heroics. Thus the cases that follow offer a
was clear that she didn’t want her dying prolonged, added, “But she’s hardly responsive.” He told me that stable, not any worse than two days ago.” And he wasn’t supposed to die, because she wasn’t made a dictated this sort of a situation and I don’t know if this acknowledged the bruises on her body from bumping into things in the nursing home where she had lived a long time. The nurse said, “She has had Alzheimer’s disease for a long time and has been incontinent for a long time. She came in with advanced pneumonia, which means that in the nursing home, they weren’t treating it, which was wise, but she wasn’t supposed to die, because she wasn’t made a ‘No Code.”’

The following day I spoke with the son, an educated banker, at his mother’s bedside. He said, “She was clear that she didn’t want her dying prolonged, yet this is tough because she couldn’t have predicted this sort of a situation and I don’t know if this is prolonging her life.” He went on, saying, “She’s stable, not any worse than two days ago.” And he added, “But she’s hardly responsive.” He told me that the doctors in the emergency room needed to know from him if they should intubate her because without mechanical ventilation she would have died immediately. With tears in his eyes he reported that he had said, “yes, go ahead,” because he wanted her to live, was hopeful she would stabilize, and could not possibly be singled out to be responsible for her death at that moment. Although he made that decision quickly, he agonized over it. He told me, “It isn’t her time yet.” He noted that she had been hospitalized a year before, that “she was tough,” and that she had “come back” from other health care crises. He said he would not want her to live indefinitely on a ventilator and neither would she. He only wanted her to have the opportunity to get better, to get off the ventilator. Regarding the DNR decision, he told me he made his mother a “No Code.” He said, “Some families might think making a ‘no code’ decision is participating in killing the patient, but I don’t think so.” He did not mention what I was told by the medical and nursing staff, that he had to be talked into making that decision.

On the afternoon of Mrs. A’s eighth day in the ICU, a nurse called me to the bedside and said, “Look at this.” She had been trying to turn the patient and was having a great deal of difficulty. Mrs. A’s limbs were so contracted, her legs so tightly wrapped around one another, that the nurse could not disentangle them. She pulled the sheet off the patient for my benefit to reveal intertwined, emaciated legs. The skin was hanging directly on the bones.

Ten days after admission, Mrs. A’s son continued to want “aggressive” care, that is, continued mechanical ventilation and treatment for the recalcitrant pneumonia, so the medical staff tried a different antibiotic. I went to Mrs. A’s bedside with a health worker who was going to draw her blood. He spoke to her in a loud voice, close to her face, and she turned to face him. I came close to the bed and reintroduced myself to him, “How would you handle this situation?” he replied that he would never have put her on a ventilator and neither would she. He only wanted her to have the opportunity to get better, to get off the ventilator. He was “very concerned” and wanted “everything done.” The nurse assigned to Mrs. A for the day told me, “If this were my mother, I’d let her go. I don’t know why the son is doing this—guilt? need? If she doesn’t get better, the doctors will begin to talk to the son about taking her off the ventilator and letting go, but not until she doesn’t start to get better.” Two days later I was told that, after lengthy conversations with the medical and nursing staff about what would happen if his mother needed CPR, the son was convinced, though reluctant, “to make his mother DNR” (Do Not Resuscitate in the event of cardiac arrest). But she was still receiving mechanical ventilation and intravenous medication and nutrition. Several nurses told me that she had come from the nursing home extremely malnourished, weighing 75 pounds, and looked like “she arrived from Auschwitz.”

Three days postadmission, there was no improvement and Mrs. A was not responsive. Her son made the decision to continue antibiotics for another 24 hours, to “see what happens” and then consider withdrawing supportive care. A nurse said to me, “Why is the son hanging on? The patient should never have been put on a ventilator in the emergency room. She should have had a naso canula, and then she would have eventually died, peacefully.” A second nurse reported that the son kept saying his mother was strong, yet he acknowledged the bruises on her body from bumping into things in the nursing home where she had lived a long time. The nurse said, “She has had Alzheimer’s disease for a long time and has been incontinent for a long time. She came in with advanced pneumonia, which means that in the nursing home, they weren’t treating it, which was wise, but she wasn’t supposed to die, because she wasn’t made a ‘No Code.”

Stories of Intensive Care Death

Case Study #1

At ICU rounds, I learned of Mrs. A, age 79, who had arrived the night before from a local nursing home with a diagnosis of advanced Alzheimer’s disease, advanced bilateral pneumonia, and respiratory failure. Paramedics were called when she was observed to be in respiratory distress; she was brought by ambulance with high-flow oxygen to the hospital emergency room and intubated (put on a mechanical ventilator). I was informed by ICU staff that her son was with her when she arrived on the unit. He was “very concerned” and wanted “everything done.” The nurse assigned to Mrs. A for the day told me, “If this were my mother, I’d let her go. I don’t know why the son is doing this—guilt? need? If she doesn’t get better, the doctors will begin to talk to the son about taking her off the ventilator and letting go, but not until she doesn’t start to get better.” Two days later I was told that, after lengthy conversations with the medical and nursing staff about what would happen if his mother needed CPR, the son was convinced, though reluctant, “to make his mother DNR” (Do Not Resuscitate in the event of cardiac arrest). But she was still receiving mechanical ventilation and intravenous medication and nutrition. Several nurses told me that she had come from the nursing home extremely malnourished, weighing 75 pounds, and looked like “she arrived from Auschwitz.”

Three days postadmission, there was no improvement and Mrs. A was not responsive. Her son made the decision to continue antibiotics for another 24 hours, to “see what happens” and then consider withdrawing supportive care. A nurse said to me, “Why is the son hanging on? The patient should never have been put on a ventilator in the emergency room. She should have had a naso canula, and then she would have eventually died, peacefully.” A second nurse reported that the son kept saying his mother was strong, yet he acknowledged the bruises on her body from bumping into things in the nursing home where she had lived a long time. The nurse said, “She has had Alzheimer’s disease for a long time and has been incontinent for a long time. She came in with advanced pneumonia, which means that in the nursing home, they weren’t treating it, which was wise, but she wasn’t supposed to die, because she wasn’t made a ‘No Code.”

The following day I spoke with the son, an educated banker, at his mother’s bedside. He said, “She was clear that she didn’t want her dying prolonged, yet this is tough because she couldn’t have predicted this sort of a situation and I don’t know if this is prolonging her life.” He went on, saying, “She’s stable, not any worse than two days ago.” And he added, “But she’s hardly responsive.” He told me that
Case Study #2

I was made aware of Mr. B, age 89, nine days after he had arrived at the nursing home with a diagnosis of myocardial infarction and aspiration pneumonia. According to what the nurses knew, the patient was designated DNR when he arrived, that is, his wishes were for no resuscitation should he stop. He was intubated in the emergency room (and would not have survived had he not been) where the treating physician convinced his wife to make him a “full code,” that is, in the event of cardiac arrest resuscitation would be attempted.

On the ninth day of his stay, the social worker invited me to attend a team conference with the patient’s wife. The medical staff was attempting to “wean” Mr. B from the ventilator by first lowering the amount and pressure of oxygen and then by withdrawing the tube from his throat and lungs so he would breathe on his own. They were unsure how to proceed if he needed to be reintubated sometime later in order to survive. Would the patient want to be reintubated? Did his wife know his wishes? The team wanted to meet with Mr. B’s wife. We learned from her that she and her husband had been married 56 years, that she had supported his career, that she had cared for him since his stroke 30 years before, and that “he’s the only thing I have and I want to hold onto him as long as I can. The last thing he said to me was, ‘I want to live.’” We did not learn her husband’s wishes about life prolongation. Two physicians, a social worker, a chaplain, and I were present during the meeting with Mr. B’s wife. We learned from her that she and her husband had been married 56 years, that she had supported his career, that she had cared for him since his stroke 30 years before, and that “he’s the only thing I have and I want to hold onto him as long as I can. The last thing he said to me was, ‘I want to live.’” We did not learn her husband’s wishes about life prolongation in this context (being intubated in the ICU).

One of the physicians said to Mrs. B, “We have a little bit of a dilemma. He’s not an optimal candidate to completely remove the tube right now. Sometimes it’s hard to decide when to pull the tube out, but he could die if we do it. We’re close to the time to do it though, and we need to know what to do. Would he want to die if he can’t breathe on his own?” The wife replied, “I’ll leave it to God’s will. I want to keep him going as long as I can. I’m going day by day.” Then she said, “The last thing he said to me in the nursing home was that he wants a haircut. Please, that was his last request. Do I pay for it?” She went on to talk about the importance of his haircut request as symbol of his character as well as her hospital visiting schedule. When the physicians rose to leave, Mrs. B thanked everyone for saving her husband’s life. Following the conference, one of the physicians wrote in the chart: “Progress stalled by multiple factors. Intrinsic: age, old stroke, general weakness; Extrinsic: infection, fluid excess. Likelihood of recovery in question as time evolves.” During the next week, Mr. B continued to deteriorate. He had been moved out of the ICU to a medical ward. A month after he was admitted to the hospital, he had a new, different strain of pneumonia, was minimally responsive, and was not breathing on his own. The chart note reads: “Condition is even worse now and any measures (even noninvasive ventilation) are not going to alter outcome. Recommend comfort measures only.” His wife, I was told by one of the physicians, “had decompensated completely, had a psychotic break, had a nervous breakdown.” She was also in the hospital, on the psychiatric unit, and apparently thought her husband had already died. The physician was attempting to locate a distant relative so that he could discuss with some family member the possible withdrawal of antibiotics, parenteral nutrition, and nasal canula oxygen that the patient was receiving. He told me that withdrawing those things would hasten the patient’s death “somewhat.” He also reported that he had favored no intubation when the patient arrived, stating that Mr. B would have died shortly thereafter and would not have had to go through “this entire month” in the hospital. But, he said, another doctor insisted on intubation and took Mr. B to the ICU. Later it emerged that a relative had arrived in town, located the patient’s papers, and found a document that stated that Mr. B did not want to be intubated and
did not want his life prolonged by technological means. When the physicians were informed about this, they discontinued lab work, diagnostic work, and treatments. Mr. B died several days later while his wife was still hospitalized.

**Case Study #3**

Mrs. C, age 81, had been living independently at home, caring for her frail and somewhat forgetful husband. She was admitted to the hospital with severe coronary artery disease, and the plan was to treat her medically, not surgically, because of her age. She began to improve and the staff members were planning to send her to a nursing home for a convalescent period before she returned home. They sent her to the cardiac catheterization lab for some diagnostic tests where “she crumped” according to the ICU nurses who subsequently treated her. That is, she would have died without heroic measures to sustain life. Two days later, she had a massive heart attack.

Nine days following admission, her husband gave consent over the telephone for surgery—to do a mitral valve repair and coronary artery bypass graft. The husband gave consent because, at the time, Mrs. C was on a ventilator and could not communicate her wishes. Mr. C was told that she would die without surgery; there was a chance that she would live with the surgery. A nurse emphasized to me that nobody told him that if she did survive, she would be confined to a nursing home afterwards as a “cardiac cripple.”

The husband only came to the hospital once, to watch his wife being taken out of the ICU and into surgery. He was brought there by a friend. He had his own medical problems and had been hospitalized for pneumonia the week before his wife was admitted. He told the staff that he had a fever, was too infirm to come visit, had no transportation, and that it agitated his wife when he was there. As Mrs. C was being wheeled out of the ICU and toward the operating room, her husband and friend asked, “Will she survive the surgery?” Afterward, Mr. C called the unit daily, spoke with the nurse on duty, and always stated that his wife had not wanted surgery and had not wanted to live like this, an insulin-dependent diabetic. “I shouldn’t have signed for the surgery,” he repeated on the phone often.

Four days after the surgery, the husband spoke with one of his wife’s physicians and told him that if anything happened to her, he did not want her to be resuscitated. He reiterated that she did not want the surgery in the first place; she would not want resuscitation. A nurse informed me that she had listened in on the phone conversation for legal reasons, to verify that “code status” discussion. Yet Mrs. C remained a “full code” because the physician in charge of the case noted that the husband was “somewhat demented” and that relatives in another state “were of another mind.”

Over the next 10-day period, Mrs. C had two more surgical procedures: the first to close the chest incision because her chest was too swollen after the initial surgery; the second to clean the surgical wound. Both procedures were necessary to ensure her survival. I learned from the physicians and nurses caring for her that once a decision to go ahead with surgery is made, a path of action is chosen. One cannot deviate from ensuring survival during postsurgical care. The three ICU nurses who cared for her most during this period each said to me, “We’re torturing her,” and “I wouldn’t want my loved one coded if she crashed in this condition.” One of them said that Mrs. C was never given an informed choice to make: “Nobody said to her, ‘If this goes wrong, we may be able to get you to a nursing home level. Shall we do it?’”

Between the 13th and the 23rd day of hospitalization (the day Mrs. C died), Mr. C telephoned daily, spoke with the nurse on duty at the time, and asked each time, “Will she die?” He was always told what procedures were being done and what was being tried to keep her alive. Two nurses told me during that period that the patient would die anyway, regardless of what was done. A third nurse told me there was a chance she might recover. During this period Mrs. C was alert and following commands. Whenever I asked the nurses if they could actually know the patient’s pain subsequent to surgery, they told me they could not, but that they tried to assess it and hoped the medication she was receiving was treating the pain adequately.

The day before the patient’s death, one of the intensive care specialists informed me that Mrs. C was dying and referred to her kidney and liver function tests. She had multiple system organ failure. He said, “We’ll wait a couple of days and watch the numbers, but it looks bad.” On the evening of the following day, he called the husband and the (out-of-state) relative, told them the patient was dying, and asked permission to withdraw ventilator and medication support, which they gave without hesitation. Mr. C was asked if he wanted to come to hospital to see his wife again. He declined. The nurse on duty at the moment of death informed me, “It was one of the most peaceful things I have ever seen.” She told me in some detail how the staff gave Mrs. C medication to “make her comfortable,” turned the ventilator support down, gave more medication, and finally, turned the ventilator off. The whole process went very smoothly in her opinion and took an hour and a half. Two physicians were at the bedside the entire time. “It was really peaceful, really good,” she said. When it was all over, one of the physicians telephoned the husband and the other relative. A few days later, during a follow-up call by a social worker, they both expressed regret about giving consent for the surgery. They kept repeating that she had not wanted the surgery.

**Sources of the Problem of Death in America**

ICU deaths that follow life-prolongation efforts must be distinguished from other hospital deaths of frail elderly patients, many of which occur without conflict and are expected. Although some deaths on non-ICU wards certainly involve troubled decision making...
about the value and use of potentially life-extending treatments—for example, antibiotics, parenteral nutrition, and nasal oxygen—those non-ICU deaths are not so dramatically postponed. In the ICU setting, in contrast, the “problem” of death is most apparent. Commitment to the full range of curative and restorative therapies is paramount. Technological, surgical, and pharmaceutical interventions to prolong even frail and precarious lives are pursued exhaustively. Death is challenged with the full armamentarium of clinical medicine. These three cases exemplify the contemporary problem of death that derives from (at least) three sources: medicine as cultural knowledge, the goals of medicine, and the incommensurability of lay and medical worlds.

**Medicine as Cultural Knowledge**

Medicine, as institution, system of knowledge, and practice, has become an extremely powerful force in shaping knowledge in late 20th-century life (Lindenbaum & Lock, 1993; Lock & Gordon, 1988). As the location of death has shifted from the home to the hospital, especially in the United States, biomedicine has come to provide the fundamental framework for understanding death and the process of dying (Arney & Bergen, 1984). Health professionals have the assumed responsibility, once held by the family and community, for the care of persons at the end of life and they now widely influence how that care is understood and delivered. Most importantly, physicians have become the gatekeepers of the dying transition in the United States. They, rather than the dying person, define when the dying process has begun. This is most obvious in the ICU, where the inevitability of death frequently is not acknowledged until the end is very near, and the discontinuation of life-sustaining treatments often signifies the “beginning” of the dying process. Moreover, in the ICU, medical staff members orchestrate and control the timing of death (Slomka, 1992).

In addition, medicine has become the dominant framework for confronting and understanding the problem of old age in America (Estes & Binney, 1989; Kaufman, 1994). The “biomedicalization of aging” (Estes & Binney, 1989), the most recent characterization of medicine’s power to define aging, is thought to result from the dominance of scientific models for understanding the life course and the use of proliferating biomedical technologies for solving the problems of disease associated with old age. Indeed, Cole (1992, p. xxi) suggests that medicine, together with science, has replaced religion and possibly the family and community as the most powerful meaning system for conceiving the capabilities and limitations of the aged in the Western world. When an old and frail person is in distress, the immediate cultural understanding of the situation is through a medical lens, and the cultural response is to exert control through the tools of medicine. Thus, individuals who are approaching the end of their “natural” life spans (Callahan, 1987, 1993) are potentially subject to the rigors of advanced technologies for sustaining life. The “problem” of dying emerges because families, health care workers, and institutional policies can so easily ensure that a critically ill patient, even a very old one, is brought back from the brink of death to a critical condition unless someone intervenes to stop the process of heroic intervention before it starts.

In my year of observation at one hospital, I learned, for example, that if a person arrives in the emergency room needing mechanical ventilation to survive, that person will be intubated regardless of age. The goal of emergency medicine is to stabilize conditions and save lives; negotiations about how long to prolong life and questions about the quality of that life are set aside for future deliberation. It is somewhat ironic to note that although emergency room policies and practices regarding life prolongation can be considered truly age-blind, they are one important source of the problem of death in America. The use of advanced technologies to artificially prolong life begins for many in the hospital emergency room (Singal, Hedges, & Rosseau, 1992). Moreover, hospital policy across the United States dictates CPR use for cardiac arrest on all patients unless the patient or a surrogate strongly advocates otherwise, even though the poor outcome of CPR on elderly adults is well known among health professionals (Schecter, 1994; Taffet, Teasdale, & Luchi, 1988).

**Action and the Goals of Medicine**

As medicine has become the dominant framework for understanding what to think about illness and old age and how to act as the end of life approaches, responsibility in medicine has been conceived through action, through continued treatment to the point of cure, stability of the condition, or death of the patient (Muller & Koenig, 1988). That stance is held not only by health care practitioners—it is widely shared by the public and, I want to suggest, has been challenged primarily in the past decade by the discourse on death as problematic. As more technological and clinical innovations become available, there is more that can be done to postpone death. Only when outcomes of specific treatments are repeatedly negative and the patient has an obviously downward course (as illustrated in these three case studies) does the option of stopping emerge as viable. Yet even then family members, patients, or health professionals may want or feel obligated to continue aggressive treatment. The technological imperative in medicine—to order ever more diagnostic tests, to perform procedures, and especially in the context of these three stories, to intervene with ventilators, medications, and surgery in order to prolong life or stave off death whenever there is an opportunity to do so—is the most important variable in contemporary medical practice. The notion of palliative care is gaining support and acceptance among health care practitioners and the public, but the press to control and conquer end-stage disease still strongly influences medical thought and action. Appropriate courses of intervention are determined by the immediacy of solving particular problems in specific situations with the best tools available (Kaufman, 1993).
The technological imperative shapes the field of actual practice for all players in the hospital arena even though death without high-technology intervention is valued, by many, in principle. In one study, for example, approximately half of physicians and nurses interviewed stated they had acted contrary to their own values by providing overly aggressive treatment (Solomon et al., 1993). Thus decisions to stop procedures or to withdraw treatments are conceived as a struggle, as difficult, and as ethically problematic because they occur within this very powerful framework. The power of technology is so pervasive, shaping institutional policies as well as individuals' actions, medical practitioners sometimes feel caught in clinically dissatisfying and ethically troublesome situations that they cannot resolve through their own behaviors. Other than one survey of clinicians conducted at five hospitals (Solomon et al., 1993) there are no detailed studies, to my knowledge, of how the disjunction between institutionalized technology use and deep concern about overtreatment affects clinicians' emotional well-being and ability to practice intensive care medicine on frail, dying elderly patients. Such ethical dissonance will continue to exist, for practitioners and health care consumers, as long as complex health care delivery systems foster the technological imperative and thwart the ability of individuals to conscientiously discontinue procedures that prolong dying.

Although responsibility in medicine is largely conceived through action, there remains a fundamental lack of clarity about medical goals at the end of life (Brody, 1992; Callahan, 1990, 1993), a sense of not knowing what is good for the patient (Mattingly 1993; Smith & Churchill, 1986) and indeed, an uneasiness about not knowing what is good in the science and practice of medicine (Smith & Churchill, 1986). The common questions of how aggressive to be and how to reconcile “comfort” and “treatment” point to the often murky relationship between everyday dilemmas and the goals of medicine. An individual practitioner may have clear-cut treatment goals and know what is right and good for a particular patient, only to have those goals derailed or reinterpreted by others within the health care system who are committed to using advanced technology or by patients and families who demand that “everything” or “nothing” be done. Or, competing goals may vie for dominance in a specific situation, as in cases of whether to hospitalize or intubate a patient, perform surgery, and label the patient “full code” or “DNR.” Conflicting goals between medical specialists, on the one hand, who want to offer more treatment options to ameliorate specific disease processes or reverse specific declining functions and, on the other hand, generalist physicians and nurses who want to alleviate suffering with palliative measures when death appears inevitable are well known. Sometimes there are no well-defined goals, especially about justification for prolonging a very frail life. Yet even then, some practitioners are hesitant to stop life-prolonging interventions. The relationship between goals and individual practitioner responsibility is often fraught with ambiguity and, at times, with anguish and frustration.

**Incommensurability of Lay and Medical Worlds**

It is important to note that although medicine has become the dominant lens through which to view the problems of old age and death, and though the technological imperative is widely shared by health professionals and health consumers alike, at least several areas of knowledge are not shared by medical practitioners and the lay public. For example, detailed knowledge about human physiology and disease processes, the way in which particular technologies actually work on the body, and hospital rules regarding the designation of resuscitation orders are not similarly understood by health care providers, patients, and families. While watching numerous case scenarios unfold in the ICU, I observed that family members (and many patients as well) are entirely unprepared for the kinds of active decision making that critical illness in the contemporary hospital context imposes. Faced with the prospect of intubation or its withdrawal, a decision about high-risk surgery, and an intensive care stay with an unknown outcome, families generally do not know what to want, other than the general recovery of their relative. They do not know what “life support” entails operationally. They sometimes do want the lives of their relatives extended indefinitely by artificial means, even if that means they will be permanently comatose. And they are not always concerned primarily with pain and suffering when they fear imminent death and hope for survival. Hospital expectations, especially those regarding the need to designate a code status, are usually outside their world of experience. Most families I observed had never conceptualized, let alone discussed with their relative, the idea of “code status” per se. They did not know what staff meant when they referred to it. In addition, very few families had discussed the possibility of or desire for resuscitation or intubation, specifically, with their relative before the hospitalization or indeed, before the critical illness. The point I wish to make is that the "choices" patients and families face in the ICU are created for them by institutional directives, late 20th-century hospital culture, and the technological imperative; they do not arise from patients’ worlds of experience. This incommensurability between medical and lay worlds of understanding is an additional source of the "problem" of death in America.

**Interpreting the Cases**

Conflicting goals and incommensurable knowledge were evident in the case of Mrs. A. Her pneumonia was left untreated, an act that seemed to ensure her death in the nursing home. Yet, in respiratory distress, she was rushed to the hospital. Mrs. A’s son arrived there thinking his mother could be cured of pneumonia and returned to her previous level of function, which he did not view as precocious. He did not see her extreme frailty, did not acknowledge pneumonia as her final illness, did not prepare for her death. He pressed for continued treatment and struggled deeply with the notion that she would not, could not
be “saved” if she had a cardiac arrest. Hospital pressure to clarify code status in the “best interest” of the patient created an existential crisis as the son grappled with what DNR meant for him. In contrast, the health care team faced the problem of how to organize and to provide what they considered a relatively “humane” death once this very frail woman was in the ICU receiving mechanical ventilation. They wanted to withdraw all support as soon as she arrived. But they could not reshape a common trajectory: the nursing home response to her respiratory distress facilitated her intubation in the first place; her son’s hope for recovery and demand for continued treatment obscured consideration of suffering or best possible death. In the end, hospital policy usually honors family members’ wishes, at least for a time, even if those wishes seem inappropriate to doctors and nurses.

Mr. B’s wife attempted to advocate for her husband as best she could while he was in the ICU by visiting him almost daily and trying to ensure that his requests were met. But she could not articulate for hospital staff what they needed to know, the patient’s wishes regarding life prolongation. She did not comprehend the subject of extubation and potential reintubation as a pressing medical concern. She was oblivious, first, to the big question facing the health care team in the ICU and, then, to the question of withdrawing treatments on the medical ward. Mr. B’s medical decline plunged his wife into a deep personal crisis. She was unable to consider rationally either the physician’s need to know whether to withdraw treatments or the type of death her husband wanted. The doctors, following institutional protocol, had to pursue family member approval regarding the withdrawal of treatment in order to facilitate what they considered to be the most appropriate and least prolonged death under the circumstances. Though most family members I observed do not require psychiatric treatment following the ICU hospitalization of a relative, they are, like Mrs. B, unprepared for the kinds of questions that require immediate and straightforward answers. Those questions, based on how technology is used, how the body works, and how the hospital is run, simply are not part of most families’ experience.

Mr. C was forced to make a choice between his wife’s imminent death and her potential, probable death at some unknown time in the future. His “decision” to proceed with surgery did not arise voluntarily. It was, of course, a life affirming decision and perhaps the only moral one available. But for him, the “choice” was untenable because he was clear that the patient had not wanted surgery. He regretted his decision for 23 days while he pondered his wife’s ICU ordeal and her quality of life. Once the surgery occurred, the medical team would only proceed with postsurgical, life-prolonging care. That pathway influenced all the activities preceding Mrs. C’s death, including her code status determination. In that case, knowledge of what was good for the patient, as well as the characterization of her death, varied enormously among players. The husband did not want his wife to suffer or live severely impaired. For him, the death could be characterized as occurring over 23 agonizing days. The medical team thought surgery might prolong her life. The aftercare—regardless of the transient suffering it caused—was necessary to enhance her chances for survival. The nurses felt their work was futile and inhumane, and that they were contributing to a “bad” death. Yet, at the very end, a nurse defined the moment of death as “good”—controlled, comfortable, and peaceful.

Mrs. A died 12 days following admission to the ICU. Mr B was hospitalized a month, half of it in the ICU. Mrs. C was in the ICU for 23 days. One might ask if better “communication” between medical staff and patient or between medical staff and family could have shortened these patients’ ICU stays, ameliorated family suffering, or made death easier to face. As the SUPPORT study indicates, the passing of information about prognoses and treatment wishes to physicians did not improve the quality of hospital deaths or reduce days spent in ICUs. Neither did nurse interventions to promote discussion of life-extending care (SUPPORT Principal Investigators, 1995). Various observers have noted that those particular activities do not actually improve or increase communication, that is, meaningful discussions between physicians and patients and the involvement of patients in decision making (Lo, 1995; Moskowitz & Nelson, 1995).

These three cases illustrate, additionally, that the passing of technical information from doctor to patient or family and staff requests for information about end-of-life wishes does not alter family ambivalence and anguish or reduce the fundamental incommensurability between lay and medical worlds of understanding. Thus, in the case of Mrs. A, much information about frailty and futility was passed from physicians and nurses to the patient’s son. Although that information was useful in directing the son to “choose” not to have his mother resuscitated in the event of cardiac arrest, it did not affect the son’s demand for aggressive, life-prolonging treatments over a 12-day period. Only when the patient was actively dying despite treatments could hospital staff convince him to withdraw support. In the case of Mr. B, medical staff questions to his wife regarding reintubation were not answered in what they considered to be a timely fashion despite ongoing talk. The wife, like many family members, was simply unable to enter a dialogue on their terms. The husband of Mrs. C was asked to choose between surgery and immediate death. Once that decision was made, hospital practices of postsurgical care overrode the importance of dialogue and, indeed, the value of ameliorating patient and family suffering. In some sense “communication” is a “black box” containing a variety of features, including: the passing of personal and medical information from the patient or family to the doctor; the passing of technical and institutional information from the hospital staff to the patient and family; the expression of anguish, hope, anger, and ambivalence about life-prolonging treatments by the patient and family; and finally, actual dialogue in which worlds of understanding are shared. The last feature, I suggest, is rare in the hospital practice of dying.
that can be solved through the courts, legislation, and the role of technology. It is about a pervasive cultural awareness of how to decide. Although social debate on the problem of death in America will depend on the complex ways in which work is conducted and rules are enacted in American hospitals at the end of the 20th century. It is about the diffuse power of litigation that is vitally important. And it is not merely about an abstract and theoretical conception of a "good death" but is about the actual situation is both much more muddled and far less rational than the cultural conversation suggests. The problem of death in America is about the extension of medicine's "gaze" (Arney & Bergen, 1984; Foucault, 1975) as a cultural phenomenon to advanced age and the very end of life. It is about the complex ways in which work is conducted and rules are enacted in American hospitals at the end of the 20th century. It is about the diffuse power of litigation that hangs over every hospital activity to problematize decision making, action, and acquiescence to patient surrogates. It is about the vast gulf between lay and professional understandings of human physiology and the role of technology. It is about a pervasive cultural confusion about the nature and end of the human life span. And it is about not knowing what to want, or how to decide. Although social debate on the problem is necessary and urgent as many observers of health care have noted, it is not the sort of dilemma that can be solved through the courts, legislation, and discrete hospital policies about resuscitation. Resolving the problem of death in America will depend on a broad reconsideration of medicine's dominant role in social life to reshape institutional practices and values and to reacknowledge a transition process from life to death, one that is highly variable from person to person.

References


Received March 10, 1998
Accepted September 23, 1998