
Improving care at the end of life: How advance care planning can help

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ABSTRACT

Based on a comparison of studies of patient desires regarding end-of-life care and of the actual course of end-of-life care, this article concludes that there is a significant discrepancy in the United States between the kind of care most people want and the kind of care they in fact receive. The article offers a case example to illustrate one type of dilemma commonly encountered in end-of-life care. It then introduces and describes the practice of advance care planning. Use of advance care planning, it is argued, can prevent moral dilemmas and improve end-of-life care.

KEYWORDS: Advance care planning, Advance directives, Death and dying, End-of-life care, Moral dilemmas

INTRODUCTION

Controversies about health care choices for patients approaching the end of life have played a prominent role in the brief history of the discipline of bioethics. In the 1970s and 1980s, early debates in bioethics in the United States focused on the scope and limits of patient rights to refuse life-sustaining treatment (President's Commission, 1983). Two of the most widely discussed issues in bioethics in the 1990s, namely, the appeal to futility to limit access to life-sustaining treatment and the justifiability of euthanasia and physician-assisted suicide, also addressed treatment decisions at the end of life (Moskop, 1999). Prompted in part by these continuing controversies, medical researchers and professional groups have begun to pay increasing attention to the topic of end-of-life care. Their efforts include investigation of patient desires regarding care at the end of their lives and examination of patterns of end-of-life care.

Comparison of data about patient desires for end-of-life care and the actual course of end-of-life care suggests that there is a significant discrepancy in the United States between the kind of care that most people want and the kind of care that they in fact receive. Increasing dissatisfaction with current options for end-of-life care has prompted groups and individuals to propose a variety of strategies for improving care at the end of life. After a review of two studies of patient desires regarding end-of-life care and two studies of the actual course of end-of-life care, this article will examine one important strategy for improving care at the end of life, namely, advance care planning, a recently developed approach to preparing for end-of-life care choices. The article will describe the basic components of the advance care planning process and cite results from a community-wide advance-care planning program in LaCrosse, Wisconsin, to illustrate the benefits of this approach.

WHAT KIND OF END-OF-LIFE CARE DO MOST PATIENTS WANT?

Based on an analysis of interviews with 126 patients, including dialysis patients, persons with

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human immunodeficiency virus (HIV) infection, and residents of a long-term care facility, Singer et al. (1999) found five frequently identified areas of concern about end-of-life care. The five areas these patients most often identified were:

1. receiving adequate pain and symptom management;
2. avoiding inappropriate prolongation of dying;
3. retaining control over their end-of-life decisions;
4. relieving burdens that their dying would impose on loved ones; and
5. strengthening relationships with their loved ones.

Singer et al. conclude that research and practice in end-of-life care should focus on these five patient-identified desires.

Partial confirmation of the importance for patients of the above set of desires can be found in a second study of important factors at the end of life. Steinhauser et al. (2000) administered a survey about attributes of a good death to a national sample of 340 seriously ill patients in the U.S. Veterans Affairs (VA) health care system. Attributes rated as important by at least 80% of the patient-respondents included a number of factors related to pain and symptom management and to avoiding prolongation of dying (being kept clean, being free of pain, being free of shortness of breath, being free of anxiety, and maintaining one's dignity), other factors relating to control over decision making (naming a decision maker, knowing what to expect about one's physical condition, knowing that one's physician is comfortable talking about death and dying, feeling prepared to die, and having treatment preferences in writing), and still other factors relating to relieving burdens and strengthening relationships with loved ones (having financial affairs in order, saying goodbye to important people, resolving unfinished business with family or friends, sharing time with close friends, believing family is prepared for one's death, and having family present).

These reports offer at least a provisional account, subject to modification by future studies, of North American patients' most important desires for care at the end of life. How do they compare to the end-of-life care commonly provided in the United States?

WHAT KIND OF END-OF-LIFE CARE DO MOST PATIENTS RECEIVE?

The most comprehensive data on end-of-life care in the United States come from SUPPORT, the Study

to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (The SUPPORT Principal Investigators, 1995). SUPPORT was a five-year, multicenter study, in two phases, of treatment decisions and outcomes for 9105 adult patients hospitalized with life-threatening illnesses; 47% of the patients died within 6 months of enrollment in the study.

In the first phase of SUPPORT, investigators observed the care provided to 4301 patients. Notable among the reported observations are the following: (1) 50% of the conscious patients who died in the hospital experienced moderate or severe pain during most of their last 3 days of life; (2) 50% of all the patients who died in the hospital spent 8 or more days in an ICU, on mechanical ventilation, or in coma before their deaths; and (3) 31% of all patients did not want cardiopulmonary resuscitation (CPR); of these patients, 49% did not have a do not resuscitate (DNR) order written during their hospitalization.

In phase 2 of SUPPORT, nurses were assigned to specific patient groups to facilitate communication among patients, families, and physicians about patient prognosis and treatment preferences. Despite this intervention, however, phase 2 results showed no improvement in study outcomes for the intervention groups over the control groups or over phase 1 results. A large number of the study patients still experienced significant pain prior to death and spent many days in an ICU, on mechanical ventilation, or in a coma before death. As in phase 1, patients' wishes regarding resuscitation were often not known by their physicians.

A more recent national study of the dying experience strongly suggests that the deficiencies in end-of-life care identified by the SUPPORT investigators have not disappeared. Teno et al. (2004) conducted a mortality follow-back study of deaths in the United States in 2000, interviewing family members or other knowledgeable informants regarding the last few weeks of life of 1578 decedents. Nearly one-fourth of the respondents reported that the patient did not receive any or enough help with pain or dyspnea, and half reported that the patient did not receive enough emotional support. Some 30.1% of the respondents wanted, but did not have, contact with the patient's physician, and an additional 23.9% had concerns about the physician's communication about medical decision making. One-third of the respondents also expressed concerns about emotional support for the patient's family. In nearly all areas examined, significantly higher rates of concern were reported when the patient's last place of care before death was a nursing home or hospital.

A DISCREPANCY BETWEEN DESIRES AND REALITY IN END-OF-LIFE CARE

The studies outlined above suggest a significant discrepancy between the kind of end-of-life care most patients desire and the kind of care they are likely to receive. Patients desire freedom from pain, but many experience moderate or severe pain in the days before death. Patients do not want their lives prolonged inappropriately, but many are kept alive for days or weeks before death by intensive care or mechanical ventilation. Patients desire control over end-of-life treatment decisions, but physicians are often unavailable to patients and families or unaware of their patients' treatment preferences. Patients desire to ease the burden of their dying on their loved ones, but prolonging the dying process through aggressive medical treatment will likely increase the emotional and financial burden on the family. Finally, patients desire to strengthen their relationships with their loved ones, but intensive care isolates patients and makes communication with family and friends difficult.

Why do the above differences between patient desires and the reality of end-of-life care persist? Many factors, cultural, personal, professional, and social, are likely contributors to this situation. Culturally, Americans tend to place a high value on youth, productivity, and independence, and to fear and avoid problems of aging, dependence, and death (Becker, 1973). Thus, many patients and their families may be ignorant about their options for end-of-life care (Silveira et al., 2000), and may have unrealistic expectations about the power of medicine to prolong their lives (Murphy, 1988). Medical education, until very recently, has emphasized a responsibility to fight aggressively to prolong life and has portrayed the death of a patient as a failure for the physician (Cassel, 1996). Medical curricula have typically not included formal training in pain and symptom management or in communicating with patients about terminal illness and about end-of-life care. For example, only 4 of 126 U.S. medical schools taught a separate required course on care of the dying, according to a 1997–1998 American Medical Association (AMA) survey (AMA, 1999). Social and structural barriers to quality end-of-life care also persist, including limited availability of hospice and palliative care programs and limited funding for these programs (Committee on Care at the End of Life, 1997).

In recent years, problems in end-of-life care have attracted increasing attention. As noted above, ongoing debate in the United States about the issue of legalizing physician-assisted suicide has called significant public attention to deficiencies in end-of-

life care like those identified in the SUPPORT study. Professional and public organizations have proposed and implemented a variety of efforts to remedy these deficiencies, including public education campaigns about end-of-life care options, new professional specialties in hospice and palliative care, and public policy initiatives to support institutional and individual caregivers. The rest of this article will describe and recommend one of these efforts, namely, advance care planning.

IMPROVING END-OF-LIFE CARE THROUGH ADVANCE CARE PLANNING: A CASE EXAMPLE

How can advance care planning contribute to better end-of-life care? To answer this question, let us first consider the following case example.

Mr. Smith is a 75-year-old man with multiple illnesses, including chronic obstructive pulmonary disease and congestive heart failure. He lives at home with his wife, who is his primary caregiver. When he suddenly stops breathing one evening, his wife calls the local emergency telephone number. The rescue squad arrives promptly, resuscitates Mr. Smith, and transports him to the Emergency Department (ED) of the local hospital. In the ED, he is intubated and then he is admitted to the medical intensive care unit (MICU).

One week later, Mr. Smith is still in the MICU. He is on ventilator support and has not regained consciousness. A consulting neurologist reports that he has suffered anoxic brain damage and may never regain consciousness. He has also developed aspiration pneumonia and will soon require a tracheostomy for long-term ventilator support. Given the patient's multiple problems, Dr. Johnson, Mr. Smith's attending physician, estimates his chances of leaving the ICU alive are no better than 20%.

Dr. Johnson explains the situation to Mr. Smith's wife and his adult son and daughter and asks what kind of care they believe Mr. Smith would want. In response, Mrs. Smith insists that Dr. Johnson not discontinue any life-sustaining measures and do whatever he can to keep her husband alive. Mr. Smith's son disagrees, however. He tells the physician that his father informed him that he would not want to be kept alive on machines and gives the physician a copy of a living will, signed by Mr. Smith, stating in general terms a desire not to be kept alive by "extraordinary means" in a "hopeless condition." Mrs. Smith acknowledges that Mr. Smith prepared a living will many years ago, but she doesn't believe he meant it to apply to the current situation. Mr. Smith's daughter is unsure what kind of care her father would want, but says she will

support her mother in this difficult situation. How should Dr. Johnson proceed?

Though this is a hypothetical case, many physicians and nurses in the United States will be familiar with similar difficult situations. The case poses an apparent moral dilemma for Dr. Johnson. There are two obvious alternatives, to continue life support or to withdraw life support and allow Mr. Smith to die. Plausible reasons can be offered for each alternative. Continuing life support honors Mrs. Smith's explicit instructions, and it may preserve Mr. Smith's life, at least for a time. Withdrawing life support may be what Mr. Smith would want, given the limited prospect for survival or for a good quality of life. There are unavoidable uncertainties about the consequences of treatment and about Mr. Smith's wishes. A decision is necessary, but there is no obvious "right answer," that is, no answer that all will accept or that will prevent recriminations and hard feelings.

Much effort could be devoted to analyzing this case (and others like it), attempting to determine what Dr. Johnson should do. Another fruitful approach to such cases, however, is to ask whether the moral dilemmas they pose can be prevented. In the rest of this article, I will argue that engaging in a process of advance care planning can forestall many end-of-life treatment dilemmas.

WHAT IS ADVANCE CARE PLANNING?

Advance care planning is the name most often used for an approach to preparing for end-of-life care that has attracted increasing attention in the United States during the past decade. One recent guide defines advance care planning as "an organized approach to initiating discussion, reflection, and understanding regarding an individual's current state of health, goals, values, and preferences for future treatment decisions" (Hammes & Briggs, 2000). The concept of advance care planning grew out of previous efforts to encourage the use of advance directives, documents designed to guide health care decisions for a person after he or she has lost the mental ability to participate directly in making such decisions (Moskop, 1989). Though one type of advance directive, the living will, has been available in the United States for about 25 years, most Americans have not prepared an advance directive for themselves. Limited use of advance directives is likely due to a variety of factors, including the previously mentioned reluctance to think about death, the fact that most people require assistance in understanding and completing these documents, and fear that completing an advance directive may adversely affect one's treatment (Orentlicher, 1994).

Advance care planning is a strategy that involves the use of advance directives, but is designed to overcome the limitations of too narrow a focus on the directives themselves (Singer et al., 1998). In advance care planning, expressing one's plan for end-of-life care in an advance directive is only one step, albeit an important step, in a larger and ongoing process that includes education, reflection, communication, and review. Advance care planning advocates argue that each step in this process can contribute to improved care at the end of life.

COMPONENTS OF ADVANCE CARE PLANNING

As noted above, advance care planning is a multi-stage process of recognition, education, reflection, decision making, communication, and review regarding one's preferences for end-of-life care. Let us consider each of these components of the advance care planning process in turn.

Recognition

To engage in advance care planning, people must first recognize that they have different options or choices in end-of-life care and that they can plan ahead for their end-of-life care by identifying and communicating their preferences in advance. Some may participate in end-of-life treatment decisions as they care for their own parents or other loved ones at the end of life, but may not realize that advance planning is possible. An effective way to initiate advance care planning is for health care professionals to introduce this topic to their patients or clients as a routine part of good health care. Routine introduction of this topic by health professionals may help to overcome the initial reluctance of many patients to talk about death and dying, and it can prevent patients from jumping to the mistaken conclusion that any discussion of these issues must mean that the patient has a life-threatening illness. If the patient does in fact already have a serious illness, introduction of the topic of advance care planning may be a valuable way to encourage the patient to confront the situation directly and to examine options for responding to it.

One way to motivate initial patient interest in advance care planning is to characterize it as a kind of gift to the patient's loved ones. Advance care planning is a gift to loved ones because it gives them a clear idea of the patient's desires for care and so relieves them of the burden of deciding, without knowing the patient's wishes, what kind of care the patient should receive. As noted above,

many people express a desire for control over treatment decisions as they approach the end of life. Advance care planning can also be introduced as a way to give people greater control over these decisions.

An obvious requirement for engaging in advance care planning is that the person have sufficient mental capacity to understand his or her medical condition and options for care in the future. Professionals must, therefore, consider the patient's mental capacity in their decision about introducing the topic. After presenting the topic of advance care planning, professionals should also be guided by the patient's willingness to pursue it.

Education

Once people recognize the availability of advance care planning, they need several kinds of information in order to pursue it effectively. First, they need to understand their health condition, and, if they have a chronic or progressive illness, how their condition may change. Second, they need information about different options for care in response to possible or anticipated medical events, such as the significant worsening of a progressive disease. This information should include a description of the treatments themselves and of their major anticipated benefits and risks. Finally, they need to know what mechanisms are available for expressing and communicating their desires about future treatment options.

This educational component of advance care planning offers health care professionals an excellent opportunity to assess and to enhance their patients' knowledge in all of the above areas. Advance care planning training programs assist professionals in educating patients by providing them with various methods and materials, including checklists of important information for different types of patients and informational brochures and worksheets for preparing advance directives to share with patients and families (Emanuel et al., 1999; Hammes & Briggs, 2000).

A concern about advance care planning commonly expressed by physicians is that time constraints in the clinical setting will not allow them to engage in the process of educating patients about future treatment options and helping them to develop a plan. This is a genuine concern, but several responses can be offered. First, advance care planning need not occur "all at once" in a lengthy meeting. It can, instead, be pursued in a series of briefer discussions, perhaps including one to introduce the concept and provide educational materials, a second to answer patients' questions, and a third to

complete a written plan. Second, the advance care planning process can involve a team of professionals, not only the physician and patient. If, for example, a patient expresses interest in advance care planning in an initial discussion with her physician, the physician may arrange for the patient to meet with a professional colleague, often a nurse or medical social worker, who is trained to facilitate the planning process. The colleague can guide the patient through the process and inform the physician about the results. The physician can then review the patient's wishes and plans with her at a later appointment.

Reflection

Armed with adequate knowledge about their health condition and potential treatment options, patients can reflect on what options they do in fact prefer. Professionals can encourage this reflection by asking patients to think about what it means for them to live well at the present time and what kind of life they would desire if their medical condition were to change significantly. Because people differ greatly in their basic values and goals, they are also likely to differ in their desires for end-of-life care. Thus, one cannot assume that patients' preferences will be the same as those of their caregivers or even of their relatives. Patients can, however, be encouraged to discuss these issues with both caregivers and loved ones in order to test, refine, and communicate their reasoning and their choices. One value of engaging in a process of deliberation and reflection, then, is that it can help patients to select the treatment options that best embody their values and achieve their goals.

Decision Making

The processes of education and reflection about end-of-life care reach their initial conclusion in decision making. Relying on their knowledge and reflection, people who engage in advance care planning can make informed decisions about what kinds of care they would and would not want in different situations. They can also make decisions about how their treatment preferences will be expressed and communicated to others, especially their loved ones and their health care providers. Basic choices here include whether to complete a written advance directive, which type of advance directive to use, whether to express one's preferences in very specific or more general terms, whether to designate a health care agent with authority to make treatment decisions on one's behalf, and if so, whom to designate as one's health care agent. Health care profes-

sionals should be prepared to offer advice and support to patients in making these decisions.

Communication

Once they have made basic decisions about their wishes for end-of-life care, individuals should be encouraged to communicate their decisions with loved ones and with their health care providers. Such communication is essential to respecting the person's wishes, because others cannot respect a patient's wishes unless they have been informed about them. If the person has chosen to appoint a health care agent to make decisions for him or her by means of a health care power of attorney, it is obviously extremely important that the person inform his or her agent about what the person's wishes are and ascertain the agent's willingness to carry out those wishes. If a person's plans have been recorded in an advance directive of any type, copies of that document can be given to family members and caregivers. Health care institutions, including hospitals, long-term care facilities, hospices, and home health agencies, are required by federal law in the United States to inquire of their patients or clients whether they have an advance directive. More institutions are now making advance directives a part of the patient's permanent medical record so that they can be easily retrieved and made available to caregivers when needed. Several private organizations and governmental agencies have established on-line advance directives registries that enable individuals to register and access their directives via the Internet (North Carolina Department of the Secretary of State, 2004; U.S. Living Will Registry, 2004).

Review

Completion and communication of one's plan for end-of-life care are important steps in the process of advance care planning, but they are not necessarily the final steps. Advance care plans often express preferences about treatment options that may be encountered many years in the future. In the intervening years, however, the person's goals, values, and preferences for care may undergo considerable change. The person's health condition, and the options available to treat a particular condition, may also change dramatically. The person one has chosen to act as one's health care agent may no longer be available or be willing to perform that role. For all of these reasons, it is advisable periodically to review and, if necessary, to update one's plans. Health care professionals who have a long-term relationship with their patients can raise this issue

at regular intervals to reaffirm or revise existing plans. Professionals assuming the care of new patients should inquire whether they have advance directives and, if they do, should confirm that the directives are up to date.

BENEFITS OF ADVANCE CARE PLANNING

The above description of the components of advance care planning suggests a number of significant benefits of this approach. Professionals who are able to offer persuasive reasons for engaging in advance care planning may find it easier to help patients overcome initial barriers of ignorance, fear, and avoidance of end-of-life issues. Once they overcome these barriers, many patients will recognize that advance care planning can help to satisfy their own desire to retain control over their care and also avoid imposing a potentially burdensome responsibility on their loved ones. Advance care planning gives patients a clear, socially recognized opportunity to record their wishes in advance directives and to communicate those wishes to family and caregivers. Patients' willingness to address these wishes directly gives their caregivers a clearer understanding of their treatment preferences and thus makes it easier for caregivers to respect those wishes.

Consider once again the case of Mr. Smith. Suppose that Mr. Smith had engaged in an ongoing process of advance care planning with health professionals and loved ones prior to his emergency hospital admission. Might this have prevented the dilemma that arose in his case? Mr. Smith had apparently expressed some previous interest in end-of-life care, since he had prepared a living will some years earlier. Continuing discussion about his medical condition, possible complications, and treatment options may have given him a better understanding of his situation and allowed him to express his treatment wishes more clearly and explicitly. Additional information about advance directives may have enabled him to choose a type of advance directive better suited to his situation, perhaps a health care power of attorney authorizing his son to act as his health care agent. Mr. Smith might also have been encouraged to discuss his wishes with his wife, children, and primary care physician; such discussions might have helped them to understand and accept his wishes. Periodic review of his plan with his physician and family could have reinforced their awareness of his wishes. If his advance directive had been made a part of his permanent medical record at the local hospital, it could have been retrieved and given to his physicians on admission,

so that they would have an earlier and fuller understanding of his wishes and, if Mr. Smith had appointed a health care agent, would know who was authorized to make treatment decisions on his behalf. These preparations might well have prevented the treatment dilemma that arose in their absence.

Advance care planning is a relatively new approach to improving end-of-life care. To be successful, it will require professionals who are willing and able both to assist their patients through the advance care planning process and to honor their patients' preferences at the appropriate time. It will also require health care institutions that are willing to support the planning process to retain plans, to make them available when decisions are needed, and to ensure that plans are honored. Results from one U.S. city, LaCrosse, Wisconsin, suggest that a vigorous community-wide advance care planning education program can enable large numbers of local residents to complete advance directives, and institutional policies can enable advance directives to be honored in the appropriate circumstances (Hammes & Rooney, 1998). Of 540 decedents studied during a 1-year period in La Crosse, 85% had written advance directives, and 95% of those with advance directives had the document in their medical record at the time of their death. Almost all of these advance directives requested that life-sustaining treatments be forgone as death neared, and treatment was forgone in 98% of the deaths.

Advance care planning is not a panacea; it cannot resolve all of the various problems that may arise as patients approach the end of life. It can, however, help patients to make their treatment preferences clearer and better known to their caregivers and loved ones. Greater clarity and understanding of patient desires regarding end-of-life care, along with formal recognition of the authority of advance directives, can, in turn, make it easier to achieve the worthy goal of honoring those directives.

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REFERENCES

- American Medical Association. (1999). *EPEC Participant's Handbook*. Chicago: American Medical Association, pp. 1–7.
- Becker, E. (1973). *The Denial of Death*. New York: Free Press.
- Cassel, C.K. (1996). Overview on attitudes of physicians toward caring for the dying patient. In *Caring for the Dying: Identification and Promotion of Physician Competency*. Educational Resource Document. Philadelphia: American Board of Internal Medicine, pp. 1–4.
- Committee on Care at the End of Life. (1997). Financial and economic issues in end-of-life care. In *Approaching Death: Improving Care at the End of Life*, Field, M.J. & Cassel, C.K. (eds.), pp. 154–187. Washington, DC: National Academy Press.
- Emanuel, L.L., von Gunten, C.F., & Ferris, F.D. (1999). *The Education for Physicians on End-of-Life Care (EPEC) Curriculum*. Chicago: American Medical Association.
- Hammes, B.J. & Briggs, L. (2000). *Respecting Choices: Advance Care Planning Facilitator's Manual*. La Crosse, WI: Gundersen Lutheran Medical Foundation, p. 2.1.
- Hammes, B.J. & Rooney, B.L. (1998). Death and end-of-life planning in one midwestern community. *Archives of Internal Medicine*, 158, 383–390.
- Moskop, J.C. (1989). Advance directives in medicine: Choosing among the alternatives. In *Advance Directives in Medicine*, Hackler, C., Moseley, R., & Vawter, D.E. (eds.), pp. 9–19. New York: Praeger.
- Moskop, J.C. (1999). Ethics controversies in a changing medical environment: Managed care, futility, and assisted death. *Annals of Behavioral Science and Medical Education*, 6, 41–48.
- Murphy, D.J. (1988). Do-not-resuscitate orders: Time for reappraisal in long-term-care institutions. *JAMA*, 260, 2098–2101.
- North Carolina Department of the Secretary of State. Advance health care directives registry. www.nclifelinks.org/ahcdr/. Accessed February 16, 2004.
- Orentlicher, D. (1994). The limitations of legislation. *Maryland Law Review*, 53, 1255–1305.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Deciding to Forego Life-Sustaining Treatment*. Washington, DC: Author.
- Silveira, M.J., DiPiero, A., Gerity, M.S., et al. (2000). Patients' knowledge of options at the end of life: Ignorance in the face of death. *JAMA*, 284, 2483–2488.
- Singer, P.A., Martin, D.K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *JAMA*, 281, 163–168.
- Singer, P.A., Martin, D.K., Lavery, J.V., et al. (1998). Reconceptualizing advance care planning from the patient's perspective. *Archives of Internal Medicine*, 158, 879–884.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., et al. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, 284, 2476–2482.
- The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*, 274, 1591–1598.
- Teno, J.M., Clarridge, B.R., Casey, V., et al. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, 291, 88–93.
- U.S. Living Will Registry. www.uslivingwillregistry.com. Accessed February 16, 2004.