

Making Difficult Choices at the End of Life

A Personal Challenge for All Participants

by David A. Fleming, MD

There are increasingly more people with chronic conditions and society is aging rapidly, creating perhaps a subtle expectation that death can be defeated, or at least postponed indefinitely.



David A. Fleming, MD, FACP, is Associate Professor of Medicine and Director, Center for Health Ethics, Department of Health Management and Informatics, University of Missouri-Columbia School of Medicine.

Abstract

With the modern ability to sustain life well beyond its natural limits questions about restricting treatment, identifying patient preferences, and the expectation that psychological as well as physical needs be addressed are part of the challenge. Physician beliefs and values should be considered when treatment goals are discussed with patients nearing the end of life. This allows the physician to balance them with those of the patient and to place them in the context of professional obligations even when beliefs conflict. Sharing beliefs with patients may strengthen the relationships and minimize conflict, but this should be done cautiously and in context of the patients' needs and the clinical circumstances. Care should therefore be taken to respect the moral sensitivities of all participants when difficult choices are to be made at the end of life.

Introduction

Identifying goals of treatment and expressing preferences through advance planning and documentation is increasingly important for patients with advanced disease, but accomplishing this

is often difficult. This is particularly true for patients and caregivers of advanced age who often resist participation in discussions about treatment options when they become ill.¹ Considering limitations in treatment for patients with advanced illness is also anathema in a medical culture that strongly promotes patient autonomy and encourages intervention, even when death seems imminent. Almost 60% of deaths in this country occur in the hospital, and of these 74% occur after decisions have been made to forgo life-prolonging treatment.² Eighty-five percent of all patients with cancer admitted to the ICU die there.³

Deciding when and how to stop treatment is not easy because there are many unknowns. Prognosis of death is notoriously inaccurate.⁴ In addition, patients are frequently ambivalent about wanting or not wanting treatment at the end of life.⁵ Thirdly, expressions of belief and value may not occur at a time when they can be articulated or understood by the family, physician, or others involved in the care of the patient, or before the ravages of illness and suffering begin to influence their decisions.

If possible, physicians should encourage discussion with patients about end of life care at a time when they and their loved ones are not acutely ill, and

when they have the time and capacity to participate effectively. The best time to do this is typically in the outpatient setting during routine follow-up rather than in the hospital during acute illness.

Caregivers are crucial to the care of patients with chronic illness and become important participants in the discussions about end of life care because patients often defer to them.⁶ Family members and significant others typically assume the caregiver role while representing the patient to the health care team and participating in the coordination of care. Caregivers' awareness of treatment preferences and what is important to the patient may be unclear if timely discussions have not occurred prior to the loss of decision-making capacity in the patient.

Caregivers who are conflicted or unsure may become frustrated and distressed when decisions must be made for their patient. Even when written or verbal healthcare directives exist, they are often difficult to interpret and may not pertain to the clinical circumstances. This often leads to further confusion and ambivalence for caregivers and providers who must ultimately decide for the patient. Family discussions when the patient has sound health and decision making capacity will encourage clarity in directives about treatment goals and the conditions of living that are acceptable or unacceptable to patients as they near death.

Physicians also have conscientious beliefs that cannot be avoided and should not be abandoned. Respect for patient autonomy obligates the physician to prioritize the preferences and welfare of the patient, but not if that requires violating personal moral dictates. Medical training encourages objectivism and a prudent level of

detachment to encourage unbiased clinical judgment, but physicians cannot totally buffer themselves from personal feelings while in the midst of an ethical dilemma.⁷ A successful, and ethically grounded physician-patient relationship is bolstered by good communication and shared decision-making that requires careful balancing of the values and beliefs of both parties.

This paper reflects on three broad domains of end of life care that may challenge the autonomy and beliefs of physicians as well as patients, and at times place them in conflict. First, I will discuss the challenge of using health care directives in identifying patient preferences; second, whether futility is a useful concept in the modern paradigm of health care; and third, the importance of spirituality in the realm of health care. In each domain the sometimes-subtle impact of personal belief is often unavoidable for physicians and may influence the way information is conveyed and how care is provided.

Health Care Directives

An advance directive is a written document that tells what a person wants or does not want if he or she is unable to speak for them self. The most common form of written advance directive used in health care is the "living will".⁸ When the advance directive identifies another person to represent the patient, the designated person becomes the durable power of attorney (DPOA) for that patient. The durability component limits the authority of the DPOA to only speak for the patient when he or she is incapacitated—a detail that sometimes becomes blurred when the patient becomes ill but is still competent to represent them self.

Advance directives are legally designed to provide "clear and convincing evidence" of a person's

wishes.⁹ Unfortunately they are often difficult to apply and may contain vague language. Many physicians also become frustrated by not having access to directives when needed or when patients and families are reluctant to discuss end of life issues when decisions must be made. Some have argued that the living will concept has failed as a realistic application for health care in this country because of these concerns and others.¹⁰ This argument tends to discount several decades of ethical concern for patient autonomy and rights of refusal, but is not without some merit when examining the data.¹¹

In spite of laws, policies, and public campaigns that have encouraged written health care directives (HCD) over the years, only about 20% of adult patients actually have one.^{12,13}

This low rate of response has been attributed to many reasons; some patients feel that they don't need a HCD and others suspect that having one will not change the treatment they will receive.¹⁴ As health care choices have become more complex and medical information more difficult to interpret few people know or can articulate what they would want in times of severe illness. Even if patients have documented their wishes surrogates and providers often do not interpret what is often a long and complicated document accurately, if at all.

Physicians may resist complying with certain components of the HCD when, in their belief, life can be saved by reasonable and technically feasible intervention, such as intubation or inserting a feeding tube. Physicians often struggle with not following standard protocols of treatment, even if doing so is contrary to the patient's wishes. Fear of litigation and demands by the family often encourage intervention as well. SUPPORT found

that physicians were aware of patients' preferences to avoid CPR less than half the time, and structured attempts to inform physicians about prognosis and patient preferences failed to modify behavior.¹⁵

Resuscitation is frequently misunderstood by many patients or avoided as a topic of discussion. Patients tend to overestimate the effectiveness of cardiopulmonary resuscitation (CPR) and tend to want it, but for the most part have only a vague awareness about what it will do to them or the chances of survival.¹⁶ This may be because physicians typically don't explain it very well.¹⁷ Preferences about CPR tend to be influenced by the patient's desires for success and how the physician conveys details about the procedure and probable outcomes.

Whether they have a health care directive or not, elderly patients tend to opt for CPR when it is presented positively by the physician but they choose nonintervention when it is presented negatively.^{18,19} When details of CPR and probability of survival are included in the discussion the majority of elderly patients decide that they would not want to have it.²⁰ Walker R et al. Living Wills and Resuscitation in an Elderly Population.

Patients with end stage disease may also change their minds frequently when considering quality of life and desire for resuscitation.²²

The location and clinical relevancy of the HCD is a frequent impediment to compliance. A written HCD may not be readily available, or it may have been written many years ago and at a time when the patient's values or beliefs were different. Not infrequently the DPOA does not agree with the living will and decides contrary to its dictates. It is very difficult for family members to refrain from imposing personal values when decisions they

make affect the life and welfare of a loved one. As a result, when advance planning is not done as a family and preferences are not clearly elucidated, unwanted treatment and suffering frequently occur.²³

To avoid these conflicts Lynn offers a reasonable strategy to improve care of patients with eventually fatal chronic illness:²⁴

·Universality: enrolling in or leaving any system of care (hospital, nursing home, home care, etc) should lead to reviewing or documenting advance care plans in every patient. Compliance should be a part of the quality assurance program of all health care institutions.

·Continuity: attempts should be made to maintain the same health care team in all clinical settings: acute, ambulatory, chronic, and home.

·Transparency: documentation should be available across all settings and to all providers. The use of electronic medical records with universal provider access can facilitate this.

·Consistency: emergency providers should routinely ask about advance care plans when serving patients who might reasonably be expected to have a poor prognosis or be at high risk of death.

These guidelines may not be applicable across all systems, but the goal should be to provide optimum conduits for communicating patient preferences and goals of treatment within and across systems that incorporate the activities of multiple providers.

For the individual provider it is important to simply ask the right question at the right time and with the right information. Patients tend to be responsive to end of life questions and the advisability of completing a HCD when they have a solid and trusting relationship with their physician.²⁵

Given the opportunity it is also important to encourage discussions about values and preferences in the presence of family, especially the designated DPOA. When all participants hear the same thing confusion may be avoided at a later date. Revisiting the discussion from time to time will also encourage clarity.

Advance directives can be a useful means of opening the door to meaningful discussions about dying. Rather than a prescription for action (or inaction), HCDs may be the first step in encouraging useful discussions about values and what kind of life patients want to live at the end of life.

Futility as a Valid Concept

Distinguishing between "ordinary" and extraordinary" treatments and the notion of medical futility has been conceptually recognized for over three centuries. Pellegrino argues that futility is not a moral principle, but an appraisal of probable clinical outcome, benefit, and burden in the care of patients.²⁶ Medical futility is a clinical judgment that, in the patient's current clinical circumstance, it is not physiologically possible for an intervention to achieve its intended and predictable biomedical goal.

Futility is a relatively new concept that was unrecognized in the medical literature until 1987. Prior to the 1980s the ability to sustain life in the face of serious illness was much more limited. Subsequently rapidly advancing developments in medical technology and the sophistication of intensive care units has provided the capability of keeping patients alive almost indefinitely. In the wake of the technology movement patients and physicians began voicing concern that many patients were being kept alive well beyond a reasonable quality of life. Out of the bioethics movement of

the 1970s and 1980s a demand for greater patient autonomy in health care represented a desire to protect and empower patients to refuse unwanted treatment especially when it was felt to be futile.²⁷

With time, however, the ability to identify medical futility has blurred. In 1995 134 articles were published in the medical literature dealing with futility, but by 1999 this number had dwindled to only 31. Many have argued that the concept of futility is indefinable and no longer pertained in modern health care. This argument is difficult to refute because there is no agreement in the medical community as to the underlying principles that determine futility. In a more practical sense, it is difficult to claim futility when medical science has the ability to effectively replace multiple organ systems that have failed.

Another difficulty with futility is that there are conflicting opinions as to suffering and the value of life. Personal value judgments are unavoidable, including by physicians, and may influence decisions in a direction not necessarily consistent with the patient's stated preferences, even if a HCD or valid surrogate is available. The difficulty lies in determining which values are important in the futility calculus.

Pellegrino offers a morally appropriate use of futility in the clinical setting which can be useful in the ethical considerations of withholding or withdrawing treatment.²⁸ The Pellegrino model is a prudential guide incorporating both subjective and objective criteria that can be used in the joint determination of futility by physicians and patients, or their surrogates. Unlike medical futility alone, Pellegrino's futility calculus is a proportionality equation that strikes a balance between three criteria: *effectiveness*, *benefit*, and *burden*:

Clinical effectiveness is an objective determinant by the physician and is evidence based. *Effectiveness* takes into consideration prognosis and the probability of attaining an intended measurable clinical outcome that will make a difference in morbidity, mortality, or functionality.

Benefit refers to what the patient perceives as valuable and is directly related to their personal treatment goals. Benefit centers on the patient's assessment of "good", which is to say those goals and values that relate to whether further treatment is worthwhile or not. The patient's surrogate, in order to be valid as a surrogate, should also represent these values and goals of treatment when the patient can no longer do so. In most circumstances the emotionality of the moment makes it very difficult for surrogates, typically family members, to remain objective and selectively represent the patient, especially when they do not agree with the patient's expressed wishes. Personal opinions and beliefs not infrequently come into conflict.

Burden is also a subjective assessment made by the patient and may refer to physical, emotional, fiscal, or social costs imposed by treatment. Burden and benefit are not readily quantifiable because of the subjective as well as objective nature of the determination and the outcomes that may or may not be acceptable to the patient. Though the physician may help to inform *burden* and *benefit* with objective facts and prognosis, it is the patient, or her surrogate, who makes the final assessment. The ultimate calculus takes into account the proportional relationship of these variables.

Futility is therefore not a singular mathematical calculation of facts or an assessment of technological effectiveness. The Pellegrino model

offers a means of viewing medical intervention as proportionate to the needs and desires of the patient, but this calculus should be made cautiously. Applied too rigorously, a futility determination may ignore the obligation to help the patient live the last days of his or her life as serenely and dignified as possible, even if long-term survival is not possible.²⁹ The fulfillment to the patient and family of sharing one last family gathering may be well worth the discomfort of one more day on the ventilator.

Families may also demand, "everything be done", even when the treatment demanded is no longer medically effective. Ethically, such a demand cannot be supported because it would force physicians to practice irrational medicine. Respect for patient autonomy dictates that the patient has the right to request and refuse treatment, but this is not an absolute right. Patient autonomy cannot override a physician's conscious moral objection or professional responsibilities to practice evidence based medicine and uphold standards of care. In Pellegrino's words, "Beneficence and autonomy must be mutually re-enforcing if the patient's good is to be served, if the physician's ability to serve that good is not to be compromised, and if the physician's moral claim to autonomy and the integrity of the whole enterprise of medical ethics are to be respected."³⁰

Patients are not ethically justified in expecting physicians to provide treatments proven to be medically ineffective, or to do something that the physician believes is morally reprehensible. Physicians as persons are also entitled to respect. The nature of the physician-patient relationship, which is the moral grounding of medicine, requires that neither physician nor patient be ethically empowered to impose their will on

the other. Ultimately, a parting of ways may be necessary if conflict is irreconcilable. When professional and moral commitments become mutually incompatible a respectful separation by safely transferring care of the patient to another provider or health care facility may be necessary.³¹

Spirituality and End of Life Care

Increasingly important to patients is the spiritual dimension of healing, which patients are often drawn to near the end of life.³² Most patients welcome an opportunity to discuss faith and religious belief with their physician.³³ However, there continues to be disagreement as to the extent to which physicians should engage in discussions about religion and faith at the bedside. Many physicians are uncomfortable doing this and some clerics feel that these issues should be left to the experts.^{34, 35}

Physicians may be uncomfortable dealing with spiritual issues for several reasons. Medical training tends to encourage professional detachment for the sake of objectivity. As a result physicians tend to suppress personal feelings and beliefs in the interest of unencumbered clarity in clinical judgment. Respect for patient autonomy also requires the physician to allow for and foster uncoerced patient choice, which might be threatened should the physician's personal feelings or beliefs become known. Personal beliefs incur personal bias, which may unfairly influence the physician's ability to think clearly and objectively when considering clinical evidence. If a carefully constructed professional facade is breached, physicians may feel uncomfortably "humanized" by being confronted with personal finitude and realize that they too are vulnerable.

Being untrained in dealing with

the spiritual realm of healing, physicians may also feel unable to meet the primary needs of patients when medical science has reached its limit. In the modern paradigm of health care the good of the patient tends to be defined in biomedical terms, and when these goals are no longer achievable, there is often a sense of frustration and even anger felt by the provider. The physician may tend to withdraw psychologically and emotionally when "nothing further can be done" for the patient.

At these times the physician *qua human being* must come to grips with the reality of personal limitation and the inevitability of death. She may ask, "Why me" and "what else can I do for this patient?" The loneliness and desperation of losing a patient, with whom they have a long relationship, can likewise cause the physician to question their own spirituality.³⁶

Clinical studies are beginning to clarify how spirituality and religion contribute to the coping strategies of patients with severe, chronic, and terminal conditions. Chechinov discovered that a positive mindset and a supported sense of "self" tend to have a positive impact on clinical outcomes for patients approaching the end of life.³⁷ Now there is indication that spirituality may promote longevity, protect against cardiovascular disease, and improve recovery from acute illness.

There is little doubt that spirituality is important to patients. Many studies have shown that a strong faith has a positive impact on health and well being.³⁸ Sources quoted in *Newsweek* November 2003 indicate that people who attend church regularly tend to live longer, be less depressed, and lead a healthier lifestyle.³⁹ An extensive review of the literature by Post, Puchalski and Larson indicates

that patient expressions of spirituality and religious belief are important to health outcomes and that recognition of these expressions by physicians, with appropriate response, is important.⁴⁰ In a recent study geriatric patients who report greater spirituality, but not necessarily greater religiosity, are more likely to appraise their health status as good.^{41,41}

For physicians attitudes about incorporating spirituality into the more secular art of medicine and healing are mixed, and the debate is whether physicians should ever discuss spirituality or pray with their patients.⁴² A recent study revealed religious belief to be more prevalent among the general population than among physicians.⁴³ Those physicians who do report regularly addressing spiritual issues with patients do so because of the importance of spirituality in their own lives and because of the evidence supporting spirituality and health.⁴⁴ Others argue that "separation of church and medicine" should be maintained because of the broad pluralism of secular beliefs, values, and religions that exist in society and the danger of misunderstanding and offensiveness should physicians attempt to become spiritually involved with patients of a different belief system.⁴⁵

There is no easy answer. As always, when the clinical path is not clear, physicians must rely on their own considered judgment in finding a prudent course of action. Spiritual belief and need have always been at the bedside. Whether the physician is prepared and skilled to meet these needs, either directly and personally, or through referral to others skilled in spiritual healing, must be a product of the accommodations made within the healing relationship, grounded in trust and mutually reinforced by all participants.

Conclusion

End of life care is ethically challenging because of the moral diversity of individuals. Physicians are now able to keep patients alive well beyond natural limitations, blurring the ability to identify when the “end of life” actually begins in the trajectory of chronic illness. There are increasingly more people with chronic conditions and society is aging rapidly, creating perhaps a subtle expectation that death can be defeated, or at least postponed indefinitely.⁴⁶ In the midst of these unknowns questions about limiting treatment, identifying patient preferences, and addressing the nonphysical needs of patients are but a few of the challenges facing health care today.

Discussion and guidelines have been offered to address three specific domains of end of life care, but there are no easy answers. Like so many questions in health care the responses will be ethically framed but different for each patient. Ultimate solutions to end of life dilemmas can only be found at the bedside through relationships of mutual respect and recognition by patients, families, and physicians that personal beliefs and values must coexist by the nature of this relationship, and that differences and similarities must be balanced within that moral context.

I would offer a final note of caution. Discussing personal beliefs with patients and families may inspire confidence, but such discussions should be approached in light of the sometimes-delicate need for privacy, the clinical circumstances, and the ultimate goals of treatment. The physician’s personal feelings and beliefs deserve respect, but the need to be heard must be balanced in the context of those goals.

References

1. High D. Why Are Elderly People Not Using Advance Directives. *J Aging and Health*. 1993; 54: 457-515.
2. Block S. Psychological Considerations, Growth, and Transcendence at the End of Life: The Art of the Possible. *JAMA*. 2001; 285: 2892-2905
3. Dowdy M, Robertson C, and Bander J. A Study of Proactive Ethics Consultation for Critically and Terminally Ill Patients with Extended Lengths of Stay. *Crit Care Med*. 1998; 26: 252-259
4. Annas GJ. Informed Consent, Cancer, and Truth in Prognosis. [see comment][erratum appears in *NEJM* 1994; 330(9): 651]. *NEJM*. 1994; 330(3): 223-5.
5. Chechinov H, et al. Will to Live in Terminally Ill. *The Lancet*. 1999;354:816-819
6. Fleming D. The Burden of Caregiving at the End of Life. *Missouri Medicine*. 2003; 100(1): 82-86
7. Sir William Osler. Aequanimitas. Valedictory Address, University of Pennsylvania, May 1, 1889.
8. Emanuel E and Emanuel L. Living Wills: Past, Present, and Future. *J Clin Ethics*. 1990; 1: 9-19
9. Cruzan v Director, Missouri Dept of Health, 110 S Ct 2841 (1990)
10. Fagerlin A and Schneider C. Enough. The Failure of the Living Will. The Hastings Center Report. 2004; 34(2): 30-41
11. Fleming D. A Global Perspective on Healthcare Decisions at the End of Life. *Reg Affairs Focus*. 2001. (October): 14-18
12. Emanuel L. Advance Directives for Medical Care; Reply. *NEJM*. 1991; 325:1256
14. See note 3
15. The SUPPORT Principal Investigators. A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. *JAMA*. 1995; 274: 1591-1598
16. Coppola M et al. Perceived Benefits and Burdens of Life-Sustaining Treatments: Differences Among Elderly Adults, Physicians, and Young Adults. *J Ethics Law and Aging*. 1998; 4(1): 3-13
17. See note 10
18. McNeil M et al. On the Elicitation of Preferences for Alternative Therapies. *NEJM*. 1982; 306: 1259-1262
19. See note 1
21. Murphy D. et al. The Influence of the probability of Survival on Patients’ Preferences Regarding Cardiopulmonary Resuscitation. *NEJM*. 1994; 330(8): 545-549
22. See note 5
23. Lynn J, Goldstein N. Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering. *Ann Int Med*. 2003; 138: 812-818
24. Ibid
25. Chaitin E et al. Physician-patient Relationship in the Intensive Care Unit: Erosion of the Sacred Trust? *Crit Care Med*. 2003; 31(5 Suppl): S367-372.
26. Pellegrino E. Decision at the End of Life: the Use and Abuse of the Concept of Futility. <http://www.uffl.org/vol10/pellegrino10.pdf>
28. Pellegrino E. Decisions at the End of Life: The Use and Abuse of the Concept of Futility.
29. Ibid
30. Pellegrino E. Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-patient Relationship. *J Cont Health Law & Policy*. 1994; 10: 47-68
31. See note 26
32. Campbell J and Fleming D. Separation Anxiety Between Religion and Medicine: Reclaiming the Sacred Dimension of Healing. RPP Journal Reports. <http://rpp-dev.missouri.edu/e-journal>. 2004
33. Ehman JW et al Do Patients Want Physicians to Inquire about Their Spiritual or Religious Beliefs if They Become Gravely Ill? *Arch Int Med*. 1999; 159: 1803-1806
34. Ellis M, et al. What do Family Physicians Think about Spirituality in Clinical Practice? *J Fam Practice*. 2002; 51(3): 249-254
35. See note 32. See Comments at: <http://rpp-dev.missouri.edu/e-journal/forum1.html>
36. Ibid
37. See note 5
38. Post S, et al. Physicians and Patient Spirituality: Professional Boundaries, Competency, and Ethics. *Ann Int Med*. 2000;132(7):578-583
39. Kalb C. Faith & Healing. *Newsweek*. November 10, 2003;44-56.
40. Post S, Puchalski C and Larson D. Physician and Patient Spirituality: Professional Boundaries, Competency and Ethics. *Ann Int Med* 2000; 132(7): 578-583
42. See note 39
43. Sulmasy D. The Healer’s Calling: Spirituality for Physicians and Other Health Care Professionals. New York: Paulist Press, 1997.
44. Ellis M, Campbell J, Detwiler-Breidenbach A, and Hubbard D. What do Family Physicians Think About Spirituality in Clinical Practice? *J Fam Practice*. 2002; 51(3): 249-254.
45. Scheurich N. Reconsidering Spirituality and Medicine. *Academic Medicine*. 2003; 78(4): 356-260
46. See note 1

