The Values History

The Evaluation of the Patient's Values and Advance Directives

David J. Doukas, MD, and Laurence B. McCullough, PhD

Ann Arbor, Michigan, and Houston, Texas

Autonomous decision making by patients can be enhanced by a variety of advance directives. These directives, the living will and the durable power of attorney, have an ethical and legal basis on which the patient can prospectively make decisions about life-sustaining therapies. The strength of these directives can be enhanced by the use of the Values History, serving as an adjunct

to them. The Values History can also be used as a clinical tool to elicit the values of the patient as they pertain to chronic as well as critical medical care. Documentation of the patient's values will give the health care team a fuller understanding of the patient's preferences and directions. *J Fam Pract 1991*; 32:145-153.

Complex ethical dilemmas in the care of debilitated patients in hospitals and long-term care facilities happen with increasing frequency. One response has been the development and use of advance directives as a means of respecting the autonomy of those patients who may later become incompetent. ^{1–4} Legal instruments, primarily the living will and the durable power of attorney, have been developed to direct physicians and institutions to discontinue life supports. ⁵ These legal instruments, however, focus little attention on the patient's underlying values and beliefs regarding such directives. To remedy this shortcoming, the authors propose a more systematic evaluation of advance health care decision making by the competent patient: the "Values History."

The validity of the Values History is based on a basic ethical consideration: the Values History enhances the autonomy of the patient in a way that present advance directives do not, by clarifying for the health care team the patient's expressed values underlying decisions to be carried out when decision making by the patient is no longer possible. One possible benefit of such an evaluation is to help physicians and institutions manage more reliably the uncertainties that surround advance directives.

Fundamental Advance Directives

The Living Will

Living wills are intended to document in advance patients' preferences concerning the administration of mechanical or artificial means of life support in the event of a terminal illness or condition. Typical statutes authorizing these directives, now in effect in 41 states and the District of Columbia, provide that a living will becomes effective when the patient has no reasonable hope of recovery and is unable to participate in decisions regarding his or her care. Until that time, the patient can revoke or change the living will at any time. Executed in accordance with statutory requirements, a living will is binding on health care providers.

A major shortcoming of living wills is that they only vaguely define which medical procedures the patient has rejected. Their language is general and imprecise, leaving them open to subjective interpretation. In some states they must be reexecuted periodically. Most important, they do not obligate the physician and the patient to work together prospectively, in anticipation of possible hospitalization or admission to a critical care unit, to identify the patient's beliefs and values concerning terminal care, quality of life, aggressive treatment to sustain life, interests of family members, and other issues. An equally important process of this physician-patient collaboration would be the imparting of information by the physician, permitting the patient to make informed choices among the various possible treatment options.

Submitted, revised, August 1, 1990.

From the Department of Family Practice, University of Michigan, Ann Arbor, and the Center for Ethics, Medicine, and Public Issues, Baylor College of Medicine, Houston, Texas. Requests for reprints should be addressed to David J. Doukas, MD, University of Michigan Medical Center, Department of Family Practice, 1018 Fuller St, Bax 0708, Ann Arbor, MI 48109.

© 1991 Appleton & Lange

ISSN 0094-3509

The Durable Power of Attorney

The durable power of attorney is the legal empowerment of a person other than the patient to make decisions for the patient when the patient is incompetent. The word durable is important, because a (simple) power of attorney becomes ineffective immediately upon the patient's incapacity. The durable power of attorney allows the assignment of a legally enforceable surrogate decision maker for the incompetent patient. All states as well as the District of Columbia have durable power of attorney statutes, and several of them (including DC) specifically define this authority for health-related decisions. The responsibility of the person holding durable power of attorney is to consider the medical choices available to the incompetent patient and choose the option that most closely adheres to the earlier spoken or written wishes and values of the patient. If no living will has been signed, the durable power of attorney permits transferral of the patient's decisional authority to his or her agent. The complete responsibility for treatment decision making will not rest as heavily on the shoulders of the agent if the patient has signed a living will or prior discussions on medical directives between patient and agent have taken place. Yet the durable power of attorney alone may constitute a better approach than a living will alone because it provides the greater flexibility of the two documents.

The main drawback to the durable power of attorney concept is the limit to which one person can fully understand the health care preferences of another unless there have been comprehensive discussions between them.⁸ It is questionable whether a surrogate decision maker can foresee the patient's responses in all circumstances when critical decisions must be made. Indeed, there is evidence that communication between the competent patient and the patient's appointed agent has not always taken place,⁹ with the possibility that the person holding the durable power of attorney may fail to follow precisely the patient's prior autonomous directives.

In summary, while living wills and durable powers of attorney protect decision-making authority (either directly or indirectly), they do not always enhance autonomy. The enhancement of autonomy is more than mere decision-making authority; it is the exercise of such authority in the particular, concrete context of a patient's values and beliefs. The Values History supplements advance directives by protecting and promoting patient autonomy. Advance directives also tend to take an "either-or" approach to intervention, a view that overlooks the clinical reality that severely ill patients could possibly benefit from a trial intervention, ¹⁰ which may be needed only temporarily and can be withdrawn, returning the

patient to a preintervention status. Whether mechanical ventilation or administration of antibiotics can benefit a particular patient often cannot be reliably determined in advance. If the patient so chooses, a trial of intervention could be stopped either after a specified time has elapsed or when reasonable medical judgment shows that the intervention will not be beneficial, ie, it will only prolong the patient's dying process. This more nuanced approach reflects the emerging concept of levels of intervention as an important concern of critical care, replacing the now fading all-or-nothing approach.¹¹

The Values History

The Values History has two parts: (1) an explicit identification of values, and (2) the articulation of advance directives based on the patient's values. Almost all jurisdictions allow specific directives to be appended to the living will if the intent is in concordance with the living will statute. The Values History can therefore address the vagueness of "withholding heroic means" by allowing the patient to detail those health care measures that are wanted (and to what degree) and those that are not wanted. The Values History is proposed as an ethically justified, clinically applicable supplement to the living will for acute and chronic medical care.

The first section of the Values History invites the patient to identify those values and beliefs associated with terminal care that are most important to him or her. This section offers an advantage over the "medical directive" that was proposed by the Emanuels in 1989 in that it asks the patient to focus fully on clarifying his or her values-related reasons for specific treatment choices. The goal is not to assess the validity of the patient's values and beliefs according to the perspective of the physician, other health care professionals, or institutions. To judge the validity of another person's values is a gross and wholly unacceptable form of medical paternalism.¹² On the other hand, the physician may be valuable to the patient in facilitating the exposition of the patient's values.13 As the patient articulates his or her values, the physician can enhance the patient's autonomy by assisting in the removal of "physical, cognitive, psychological, and social constraints" that could impede the informed consent process.¹³ The goal of this process is twofold: (1) to help the patient to become clear about what he or she wants and does not want and why, and (2) to help health care professionals and institutions to understand, respect, and implement the cluster of value-based decisions that result from using the Values History in the clinical setting. As a result, doubt about health decisions at risk for being too vague, too general, or only loosely connected

to the patient's values are reduced. Further, such values clarification would be valuable in enhancing physicianpatient communication during the discussion concerning terminal care when compared with Emanuels' medical directive.

The second section of the Values History begins with acute care designations: consent for or refusal of cardiopulmonary resuscitation, use of a respirator, and placement of an endotracheal tube. The chronic care designations then follow and include decisions for administering intravenous fluids, enteral feeding tubes, and total parenteral nutrition for nutritional support, use of medication, and use of dialysis. For directives 2 through 8, the patient is afforded these options: intervention, trial of intervention (limited by time or medical judgment), or nonintervention. This section of the Values History also offers directives not found in living wills or the Emanuels' document, such as admission to the hospital but without specific services (eg, admission to general medical floor only, forbidding admission to critical care), and "Do not call 911" for patients in long-term care facilities. 14 The Values History concludes with the assignment designations, and the assignment or exclusion of a named decision maker for the patient, consent for autopsy, and consent for organ donation. The Values History in a format updated from earlier versions1,2,15 can be seen in the Appendix to this article.

In summary, after the patient has signed a living will, the patient would discuss his or her values and advance directives of the Values History with the physician. First, the physician would engage the patient in discussion(s) on perspectives on the quality of life vs length of life (ie, the Values Section of the Values History). When the values section is completed, the physician would begin the patient education and disclosure process that would lead to discussion and possible signing of the Directives Section of the Values History.

In our judgment, a Values History can be completed on a patient within five visits or 1 year. The patient should be encouraged to share the Values History with family members of the patient's choice and with the person, if any, chosen to hold the durable power of attorney. The physician can serve as a facilitator of this process if that is the patient's preference. Early involvement of the family in discussing the patient's values and advance directives on terminal care helps avoid the difficulties of substitute decision making when the patient becomes incompetent. Also, this exchange within the family helps clarify the patient's health care goals so that relatives with conflicting health care goals will better understand and respect the patient's reasoning. Hence, the purpose of this exchange is to enhance patient autonomy through the informed consent to health care decisions (as discussed with the family), and to negate future attempts of family members to interfere with physician compliance with the patient's preferences. The completed Values History should be reviewed with the patient periodically, especially if there is a significant deterioration in the patient's health status.

The Values Section

The first choice in the Values Section of the Values History is basic: the question of length of life vs quality of life. Next, the patient is asked to identify which values relevant to terminal care (eg, based on dignity, comfort, or personal philosophy) are important. These values-based statements have been found in pilot testing with patients to be those that express commonly held values in patient health care decision making. Obviously these values may be supplemented to reflect the values of an individual patient. Alternatively, the patient may add other value-based statements to the list. The list provided is a useful starting point.

The Directives Section

The first three directives in this section, dealing with acute care situations, are crucial to do-not-resuscitate order decision making. An early and direct approach to cardiopulmonary resuscitation is necessary to reduce ambiguity. To detail explicitly that the patient has autonomously decided against cardiopulmonary resuscitation would help more precisely to clarify the code status of the patient.

The directives that follow include the choice of trial of intervention. The patient can choose either a predetermined time to attempt an intervention that, if fruitless, should be discontinued, or can have this attempt continued as long as there appears to be, in the physician's best judgment, medical benefit for the patient. The former choice is structurally more concrete by mandating termination at a specific time and is more explicit about the patient's autonomous preferences by setting definitive boundaries. The latter choice allows some variation when to discontinue the therapy only if no benefit is evident, but does not easily allow paternalistic intervention because it does not condone therapy that will prolong the dying process. The choice of time vs benefit trials more accurately reflects the needs of patients when consenting to trials of intervention than do those solely based on medical benefit as in the Emanuels' document. The utility of including the trial-of-intervention options becomes apparent with the following directives. The next acute care directive, the option of consenting to respirator

acceptance, is important, especially for patients with chronic pulmonary disease. Endotracheal tube placement is integral to the implementation of the first two directives and may help clarify the first two directives.

The chronic care designations cover those directives that might apply to long-term patient care. The directives begin with total parenteral nutrition. The patient should be fully informed about how total parenteral nutrition is used and how it differs from intravenous fluids. Intravenous hydration and medication also need to be discussed as directives in the context of long-term care. Further, a separate directive should explore the medications necessary for the treatment of illness by other routes (eg, by mouth or by intramuscular injection). The patient should be assured that the administration of intravenous medicines and fluids would never be withheld if requested by the patient for comfort care or pain relief. Directives addressing enteral feeding tubes and dialysis should be undertaken in the context of long-term recuperative or vegetative care.

The assignment designations are the last part of the Directives Section, which is composed of several directives detailing autopsy, paramedic or intensive care unit care, proxy negation, organ donation, and appointment of a durable power of attorney. The patient's directive regarding autopsy can be a highly charged personal decision.

The next directives allow the patient to decide on admission to an intensive care unit or to receive paramedic care. Following these directives is an option to add consent, refusal, or trials of intervention to other specific directives not otherwise addressed (eg, specific types of surgery).

All the above 10 directives are initialed by the patient and dated as they are decided over time. Each of these directives requests that the patient explain the reasons for his or her decision in terms of the values earlier identified. The importance of this information is to understand the patient's motivations, to examine and discuss possible inconsistent values, and to expose and reverse possible psychological factors that may hinder the patient from participating in the informed consent process.

Throughout this consent process, the operating assumption is that the patient is competent to make these decisions unless reliably shown to be incompetent to do so. The burden of proof is upon the clinician to establish and thoroughly document in the chart a clinical judgment regarding the patient's competence. If the patient possesses questionable ability to evidence a health care choice, understand information relevant to making that decision, or appreciate the importance or risks and benefits of the decision, then the physician needs to reeval-

uate the patient's informed consent capabilities. ¹⁶ When disclosure attempts have been repeated exhaustively, rendering informed consent untenable, the physician must attempt to reverse those treatable processes so that the patient can make his or her own health care decisions. ¹⁶ Failing such measures, the physician would turn to identify alternative substitute decision makers.

The proxy negation directive allows the patient to name a person or persons to be excluded from decision making if the patient should become incompetent, thereby preventing later ethical crises regarding the standing of these individuals to make decisions for the patient. This directive may be useful to exclude a family member with a differing philosophy toward life and medical care, or if the patient suspects some conflict of interest or ill will.

The organ donation directive is the Uniform Donor Card in the form permitted by the patient's state to allow the advance designation for the use of organs in transplantation, medical therapy, medical research, or education

The last major directive is durable power of attorney, again as allowed by the local jurisdiction, preferably in the form of a durable power of attorney for health care. The limits of the durable power of attorney for health care can then be framed to reflect the preferences of the patient as voiced in the Values and Directives sections. Further, the person holding durable power of attorney can serve as the patient's agent to decide on any treatment measures not specified in the Directives Section. It should be understood, however, that the patient should make his or her own decisions, rather than leave a relative or friend to identify, perhaps mistakenly, the patient's wishes.

Barriers to the Use of the Values History

The physician, the patient, the patient's family, and the law can all act as barriers to the successful use of the Values History. The physician may have difficulty with accepting the concept of spending time in the outpatient setting discussing advance directives, much less values, with their patients. Educational efforts (in the medical and lay literature) directed at both physicians and patients could enhance the interchange necessary to elicit the Values History. Particular appeal could be made to physicians that such an intervention would obviate the far more difficult crisis management needed when the patient becomes critically ill. The benefits of such a "prophylactic bioethics" measure more than offset the burden of time invested.

The physician may perceive that discussing the possibility of death with the patient as a harmful act, contrary to the physician's beneficence-based role. The physician could also feel constrained by discomfort in disclosing the eventuality of death or by a paternalistic desire to wait until the "right time." If the physician is not the health provider who elicited the Values History, when the patient becomes hospitalized the physician may refuse to honor it and insist on transferring the patient's care. These examples illustrate how paternalistic desires to protect or benefit the patient could be used to overrule autonomy claims of the patient. Such attempts to strip patient decision-making capabilities are, therefore, ethically suspect.

The patient's condition, especially an incompetent mental status, can be a barrier to implementing the Values History. ¹⁷ No autonomous advance directives can be obtained if the patient lacks comprehension or decision-making capabilities. Certain barriers to competence may be reversible; such barriers should be evaluated, and when possible, treated. An indecisive, competent patient or a patient who refuses to discuss the prospect of dying can also impair efforts to elicit a Values History. In both circumstances, sensitive educational efforts should be the first response. If these efforts fail, the physician should consider recommending that the patient choose a durable power of attorney who is knowledgeable about the patient's values and previously stated preferences.

The family of the patient may also act as a barrier to the implementation of the Values History. A family member may try to ignore the patient's advance directives to withhold or withdraw certain therapies, challenging the patient's decisions and the physician's duty to carry them out. Educating such a family member on the patient's right to refuse specific interventions can help here. Discussing the patient's Values History when it is completed (with the patient's permission) can help prevent the family from becoming a barrier to its implementation.

Finally, the possibility of legal barriers to the Values History must be considered. While most states now have living will statutes, nine states do not. Lack of the living will statute would not eliminate the usefulness of both instruments, however, since both would help the medical team by clarifying the patient's prior competent values and preferences. Within the Values History, the durable power of attorney and organ donation statutes vary by jurisdiction; therefore, the wording specified by statute should be used for that section of the Values History. The durable power of attorney is commonly available from hospital counsel and health care attorneys, while the organ donor card is readily available from local departments of motor vehicles.

Explicit advance instructions within the living will may create another legal barrier to the Values History. Although permissible in most living wills, such instructions are not addressed in some.7 The listing of directives can be complicated when living will statutes prohibit withholding certain medical therapies (eg, intravenous hydration and nutrition). 18 If there exists such a prohibition, patients could be informed that although withholding these therapies is not condoned by state statute, these statutes have been successfully challenged in the past.19 In such cases, consult hospital or office legal counsel about adding to the living will directives that are not condoned in the legislation. Alternatively, specific directives could be deleted from the Values History if the patient so consents. Despite such differences, it is hoped that the clinician will strive to implement the Values History by reconciling its ethical foundation with the legal stipulations of the jurisdiction involved.

Conclusions

The Values History is proposed as an ethically justified clinical tool intended to be used as an adjunct to legal advance directives. Although changes in sections 14 and 15 are necessary by jurisdiction, such alterations are easily adapted to this document. The durable power of attorney and organ donor legislation of the physician's jurisdiction should be inserted or substituted before using the Values History. By customizing the Values History in this way, the clinician will have a tool of considerable precision with which the value-based advance directives of patients can be clarified. We propose that the use of the Values History will enhance patient autonomy significantly by allowing the patient to identify health care decisions prospectively, to discuss them with family members, and to have the physician implement them.

References

- Doukas D, McCullough L. Assessing the values history of the elderly patient regarding critical and chronic care. In: Gallo J, Reichel W, Anderson L, eds. Handbook of geriatric assessment. Rockville, Md: Aspen, 1988:111–24.
- Doukas D, Lipson S, McCullough L. Value history. In: Reichel W, ed. Clinical aspects of aging. 3rd ed. Baltimore, Williams & Wilkins, 1989:615–6.
- Wanzer S, Federman D, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients—a second look. N Engl J Med 1989; 320:844–9.
- Emanuel L, Emanuel E. The medical directive; a new comprehensive advance care document. JAMA 1989; 261:3288–93.
- Kapp M, Pies H, Doudera A, eds. Legal and ethical aspects of health care for the elderly. Ann Arbor, Mich, Health Administration Press, 1985.
- Eisendrath S, Jonsen A. The living will—help or hindrance? JAMA 1983; 249:2054–8.
- 7. President's Commission for the Study of Ethical Problems in

- Medicine and Biomedical and Behavioral Research: Deciding to forego life-sustaining treatment. Washington, DC, Government Printing Office, 1983:310–2.
- Wanzer S, Adelstein J, Cranford R, et al. The physician's responsibility toward hopelessly ill patients. N Engl J Med 1984; 310:955–9.
- 9. Evans A, Brody B. The do-not-resuscitate order in teaching hospitals. JAMA 1985; 253:2236–9.
- Wear S. Anticipatory ethical decision-making: the role of the primary care physician. HMO Pract, Mar-Apr 1989; 3:41–6.
- 11. Civetta J, Taylor R, Kirby R, eds. Critical care. Philadelphia, JB Lippincott, 1988.
- 12. McCullough L, Lipson S. A framework for geriatric ethics. In Reichel W, ed. Clinical aspects of aging. 3rd ed. Baltimore, Williams & Wilkins, 1989:577–86.
- Ackerman T. Why doctors should intervene. Hastings Cent Rep August 1982:14–7.

- Stollerman G. Decisions to leave home [editorial]. J Am Geriatr Soc 1988; 36:375–6.
- Doukas D, McCullough L. Truthtelling and confidentiality in the aged patient. In Reichel W, ed. Clinical aspects of aging. 3rd ed. Baltimore, Williams & Wilkins, 1989:608–15.
- 16. Appelbaum P, Grisso T. Assessing patients' capacities to consent to treatment. New Engl J Med 1988; 319:25, 1635–8.
- McCullough L, Lipson S. Informed consent. In Reichel W, ed: Clinical aspects of aging. 3rd ed. Baltimore, Williams & Wilkins, 1989:587–96.
- 18. Society for the Right to Die. The physician and the hopelessly ill patient: legal, medical, and ethical guidelines. New York, Society for the Right to Die, 1985:32–3.
- Corbett v D'Allesandro, 487, So2d 368 (Fla App), rev denied, 492 So2d 1331 (Fla 1986).