Living Wills are Overrated

In the mid-1980s, the state of Florida passed a law entitled, "The Life-Prolonging Act of Florida," which was the most enlightened living will law that I can imagine. Definitions were clear, terminal conditions were defined, guardianship was provided if necessary, and the living will forms were simple. This law is still in effect. In late 1991, the federal government enacted the Patient Self-Determination Act, which ensured that every patient was made aware at the time of admission to the hospital of their option to file a living will. One would think that these legislative actions would make decisions about death and dying easier for patients, families, and physicians.

I have been an attending physician for many years in a medical intensive care unit in a tertiary referral hospital. In this setting, I have been pleased with the effect of the Florida law since it clearly defines the responsibilities of the patient, the family or guardian, and the physician.

On the other hand, I have seen little effect of the Patient Self-Determination Act since its implementation. There is literature on the subject that appears to validate my observation. In 1991, prior to the implementation of the act, of those outpatients who wanted to issue some form of advanced directive, only 15 to 18 percent had actually done so.\(^1\) In 1993, each patient, on admission to a hospital, was asked about a living will, given a brochure, and offered the help of a social worker or chaplain. Only 4 percent of these patients actually executed a living will during studied hospitalizations.\(^2\) Thirty-two percent of the patients did not recall being counseled or receiving the brochure.

Even if the living will has been executed, it is often not available when acute care is needed. Emergency medical technicians, emergency room physicians, and intensive care unit physicians know that the document is often (1) in the lawyer's office, (2) in the safe-deposit box, (3) in the offspring's home, (4) in an unknown location, etc, when critical decisions about resuscitation must be made. Abiding by the wishes of the patient as written in the living will requires that the document be present and available at the time of emergency care. The lay public appears to be unaware of this fact.

It is clear that decisions about death and dying for patients with chronic illnesses may be facilitated by the existence of a living will, but the literature would imply that such patients are unlikely to have executed such a document. At least, in the nonemergency situation, the physician does have the time to discuss the issue with the patient and family and acquire a living will, if so desired.

In addition, the patient and the family may not be able to anticipate the nature of the terminal illness. They have not attended medical school, and they cannot be fully informed as to all the possibilities that could conceivably occur. I remember one woman with metastatic breast cancer who had signed a living will that specifically prohibited intubation and ventilation. She entered the hospital with bilateral malignant pleural effusions, and during a thoracentesis, developed a pneumothorax. A chest tube was inserted emergently, and because she appeared about to die from a complication of a procedure (and the living will was at home), she was intubated and ventilated. She did well, was alert, and the family brought in the living will several days later. Since it was not dated and not present at the time of emergency intubation, I was relieved that we had made the decision to resuscitate her. Luckily, she did well, and after repeated thoracenteses and diuresis, she could be extubated. I asked her what she would have wanted us to do had we had time to make such decisions during the emergency. She stated that she had no idea when she signed the living will that she might be alert, oriented, and awake and still be intubated and ventilated. If she had been aware of this possibility, she would have definitely wanted to be resuscitated. How could she anticipate this situation and her eventual extubation? This is not an isolated occurrence. The decision to sign a living will is more complex than the general public is led to believe, and I think this complexity accounts for the reluctance of patients to execute such documents.

Are there any solutions to these problems? The situation would be helped if physicians talked about living wills in advance of terminal illness. One could encourage specific documents which might better anticipate the terminal problem. Doctors should be given a copy of all living wills. Finally, patients should be encouraged to designate a healthcare surrogate who can make decisions if the patient is not competent. All of these measures make sense, have been advocated by ethicists, but are avoided by patients, families, and physicians.\(^3\) Because of the distasteful nature of these types of discussions, I do not expect a radical improvement in the acquisition and use of living wills.

I am in favor of living wills. In the care of patients
With chronic illnesses, living wills are useful if present. When caring for patients who are acutely and emergently ill, living wills are overrated.

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REFERENCES

Withholding and Withdrawing Nutrition and Hydration: Surrogates Can Make This Decision for Incompetent Patients

Deaths, or the anticipation of it, provokes strong emotions in physicians. Preventing premature deaths is a common reason many physicians choose a career in medicine. It is not surprising, therefore, that ethical issues surrounding death and dying stimulate impassioned and sometimes conflicting sentiments. In this issue of Chest (see page 1892), Dr. Rosner argues that nutrition and hydration should be considered basic supportive care for all patients, and he states there is no time “when general supportive measures can be abandoned, thereby hastening the patient's demise, unless the patient specifically requests such withholding or withdrawal because of severe pain and/or suffering.” Dr. Rosner apparently believes that families or surrogates do not have the right to request withholding or withdrawal of nutrition or hydration when patients are incompetent and have not left a clear record of their wishes.

We do not share Dr. Rosner's opinion that incompetent patients should receive nutrition and hydration because it can be labeled only as supportive care. We present our reasoning for withholding artificially supplied food and water from certain patients, when families or surrogates believe it is what the patient would have wanted.

When the body is ill, many distinctions between natural and artificial become blurred. It is natural, and almost without effort, that each of us breathes over 15,000 times a day. During that time, again with little effort, we eat three (or more) meals. Should we develop an illness whereby we cannot maintain adequate gas exchange (we have air hunger), mechanical or artificial ventilation is available. Similarly, should we develop a condition which prevents us from maintaining adequate nutrition or hydration, artificial means are available to provide these as well. Mechanical ventilation and artificial feeding may differ in their costs, invasiveness, and skill required for use, but both require trained medical personnel and are, in fact, medical interventions. A similar conclusion was reached by the Superior Court of California in Barber v Superior Court, in which two physicians faced murder charges for withdrawing nutrition and hydration from a patient with severe brain damage.

Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration. Their benefits and burdens ought to be evaluated in the same manner as any other medical procedure.

Situations in which tube feeding may be withheld fall under four general categories. The first group includes those patients for whom tube feedings cannot restore normal nutrition or hydration. For example, certain patients with extensive and severe burns will not survive, despite often arriving at the hospital alert. Patients with the most extensive burns can deteriorate quickly as a result of massive fluid loss; and there may come a point at which replacing fluid losses enterally or parenterally is futile. The second group consists of competent patients who refuse artificial nutrition and hydration. The third group of patients are the permanently unconscious. Although rare, there are a number of patients who have no reasonable chance of regaining consciousness and whose desires about tube feedings are not known. In these situations, physicians rely upon family or surrogates to speculate about what the patient would have wanted in the present situation. Is life prolongation in these circumstances a benefit or a burden to the patient? That question is best answered jointly by the patient’s physician and his or her family or surrogate. When a decision to withhold feedings is made, there is an emerging legal consensus allowing physicians and hospitals to carry out the decision.

The Massachusetts Supreme Judicial Court in Brophy v New England Sinai Hospital supported the withdrawing of nutrition and hydration from a patient in a chronic, persistent vegetative state:

In certain, thankfully rare circumstances, the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve. The law recognizes the individual's right to preserve his humanity even if to preserve his humanity to allow processes of a disease or affliction to bring about a death with dignity.

A fourth, and arguably most difficult, group of patients for whom tube feedings may be withheld are those for whom this treatment provides more burden than benefit. The demented elderly who can no longer feed themselves is one such group. There are significant risks associated with tube feeding. Indwelling