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Advance Care Planning

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Abstract (Summary)

All 50 states and the District of Columbia have passed legislation on advance directives, reinforcing the fact that adherence to such directives is mandatory rather than optional. However, the majority of states place restrictions on proxy decision making. Consonant with the [Cruzan] decision, New York requires "clear and convincing evidence" of a patient's wishes in order to withdraw or withhold artificial nutrition and hydration.

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One hundred years ago, the odds that a visit to the doctor would result in a measurable improvement in a patient's condition were slim. But the mere fact that modern physicians are far more likely to be able to influence the course of illness in a particular way does not mean that patients necessarily want them to do so. Patients who are near the end of life often prefer treatment that is focused exclusively on comfort; frail elderly patients may choose to trade longevity for quality of life. Although patients have long been able to refuse burdensome treatment, the U.S. Supreme Court first explicitly stated that patients may accept or reject any proposed treatment, regardless of their underlying medical condition, in the 1990 decision in Cruzan v. Director, Missouri Department of Health. In that case, the Court addressed the question of whether artificial nutrition could be withdrawn from a young woman who was in a persistent vegetative state; this is precisely the situation of Terri Schiavo in Florida, whose feeding tube was recently withdrawn at the request of her husband and then reinserted at the order of Governor Jeb Bush, after the Florida legislature granted him the necessary authority.

In Cruzan, while upholding the prerogative of individual states to establish standards for the type of evidence required for the limitation of treatment, the Court supported the right of patients to self-determination. In the words of Justice Sandra Day O'Connor, "The liberty guaranteed [by the Fourteenth Amendment] must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water."1 The implications are far-reaching: only if patients know the benefits and burdens of treatment alternatives can they effectively exercise their autonomy, and only if patients engage in advance care planning can they hope to maintain their autonomy, should they become incapable of making decisions.

Advance directives are widely viewed as the cornerstone of advance planning. They encompass both instructions about what kind of care should be provided (living wills) and who should make the decisions if the patient cannot do so (proxy designations). Though helpful as a means of expressing a general philosophy of end-of-life care, living wills are often vague, using phrases such as "heroic measures," and most apply only to "terminally ill" patients facing "imminent death." Some living wills provide concrete instructions for care in a variety of clinical situations, such as the use of feeding tubes or ventilators in the event of permanent unconsciousness. Even detailed instructional directives, however, cannot describe all

the situations in which patients may find themselves. Their precision also makes them inflexible: whether or not a given procedure is acceptable may depend on what the intervention is expected to achieve and on what alternatives are available.

Another strategy for advance care planning is to focus on who will make the decisions rather than on what those decisions should be. The naming of a friend or family member to serve as a health care proxy (also referred to as assigning a durable power of attorney for health care) gives physicians someone to talk to who can apply the patient's preferences to the existing clinical situation. Surrogates are expected to make decisions on the basis of "substituted judgment," or what the patient would want. If the patient's views are unknown, surrogates must resort to best interests, or what most people in the same situation would want. Combination directives clarify both who should make decisions and what they should decide, as well as the values on which the decision should be based.

All 50 states and the District of Columbia have passed legislation on advance directives, reinforcing the fact that adherence to such directives is mandatory rather than optional. However, the majority of states place restrictions on proxy decision making. Consonant with the Cruzan decision, New York requires "clear and convincing evidence" of a patient's wishes in order to withdraw or withhold artificial nutrition and hydration. Another 12 states permit proxies to make decisions about artificial nutrition only if the patient expressly authorized them to do so. Seven states similarly restrict the ability of a proxy to decide about any life-sustaining treatment unless the patient specifically delegated that authority (see Table).2 In 37 jurisdictions, laws regarding health care surrogates specify a hierarchy of persons who are empowered to act on behalf of an incompetent patient who has not named a proxy. However, default surrogates are typically limited both in the types of decisions they may make and in the clinical circumstances in which they may make them. In Florida, for instance, where the Schiavo case has been unfolding, the patient's spouse is the default surrogate. His decision-making authority is constrained by the need to demonstrate clear and convincing evidence that Terri would not have wanted to receive artificial nutrition while in a persistent vegetative state.

Table. Limitations of State Laws Regarding Advance Directives.*

Like other types of preventive medicine, advance directives are underutilized even though they are cheap, low-tech, and potentially highly effective. Despite the federal Patient Self-Determination Act of 1990 (requiring facilities that participate in Medicare or Medicaid to offer patients information about advance directives), state laws regarding advance directives, and the publicity generated by the Cruzan case, only 15 to 20 percent of adults have a written directive. The best approach to boosting utilization is an initiative such as the "Respecting Choices" program in La Crosse, Wisconsin, combining grassroots education, a uniform system of documentation, and coordination among sites of care.3 The program's success shows that advance care planning involves more than naming a health care proxy or filling out a form. It is a process that begins with physicians helping their patients to articulate and prioritize their goals of care. For patients in the throes of acute illness, choosing among several treatments, each with its own probability of success and mix of potential side effects, is easier if it takes place within the context of a previous discussion of the goals of treatment. Such discussions provide a framework for all decision making, in addition to protecting the patient in the event of incompetence.

If physicians take seriously their obligation to engage patients in decisions about their health care, they will initiate discussions of goals and preferences before a crisis develops. Once they begin the conversation, advising patients to appoint a health care proxy and determining the scope of that person's authority will follow naturally. And that is all that physicians need to do - the idiosyncrasies of state law notwithstanding - to enable their patients to be treated in accordance with their wishes.4

[Footnote]

1. Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990).
2. Sabatino C. Health care power of attorney and combined advance directive legislation. Chicago: American Bar Association, January 1, 2002. (Accessed December 2, 2003, at http://www.abanet.org.)
3. Hammes B. Update on respecting choices four years on. Innovations in End-of-Life Care 2003;5. (Accessed

December 8, 2003, at http://www.edc.org/lastacts.)
4. Annas GJ. The health care proxy and the living will. N Engl J Med 1991;324:1210-3.

[Author Affiliation]
Muriel R. Gillick, M.D.

[Author Affiliation]
From Harvard Vanguard Medical Associates and the Department of Ambulatory Care and Prevention, Harvard Medical School both in Boston.