

Reversing the Code Status of Advance Directives?

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Twenty years ago, Congress passed the Patient Self-Determination Act, hoping to improve end-of-life care through the use of advance directives. The statute stimulated the development of a cornucopia of planning documents. Patients can sign a living will that states that they do not want their lives prolonged if they are terminally ill. They can complete an instructional directive that specifies, for each of several clinical scenarios, which listed medical interventions they would want. They can fill out a values history, describing what they care most about, or they can designate a surrogate decision maker to speak on their behalf if they lose the capacity to do so. All 50 states and the District of Columbia now recognize the assignment of a durable power of attorney for health care, and the vast majority of jurisdictions provide state-specific living wills to allow patients to express preferences for care near the end of life.¹ Despite the prodigious effort devoted to designing, legislating, and studying advance directives, the consensus of medical ethicists, researchers in health care services, and palliative care physicians is that the directives have been a resounding failure.^{2,3}

Advance directives are seldom completed — a national survey conducted in 2005 showed that only 29% of U.S. adults have a living will⁴ — and they are often not available when needed. The ability of surrogates to represent patients' preferences is poor, and the requests made in the documents are frequently overridden. At a more fundamental level, the selection of medical interventions for an imagined future health state is problematic, since preferences change in the face of real rather than theoretical conditions.⁵ The validity of directives that spell out preferences for specific interventions has also been questioned, because patients cannot make informed choices unless they know the benefits and burdens of the proposed treatments. In the face of so much skepticism, the conclusion in the article by Silveira et al. in this issue of the *Journal*⁶ that “advance directives are important tools for providing care in keeping with patients' wishes” is new and surprising.

Silveira et al. based their conclusions on the national Health and Retirement Study, a longitudinal survey of a cohort of adult Americans. They clear-

ly established that the loss of decision-making capacity near the end of life is an important concern: among the 3746 persons 60 years of age or older who died between 2000 and 2006, 42.5% faced choices about treatment and 70.3% of those persons lacked the ability to choose. Most striking was the finding that 67.6% of patients who needed to have a decision made about medical care had completed an advance directive. Among the 999 decedents who both needed decisions and lacked capacity, 6.8% had a living will only, 21.4% had a durable power of attorney for health care only, and 39.4% had both.

The key additional finding of the study is that concordance was high between patient preferences for care, as expressed in a living will, and the care actually received before death. In addition, the person chosen to serve as the health care proxy was usually the person who actually made the decisions. However, these observations were based on interviews with family members or knowledgeable informants, conducted an average of 13 months after the patient's death, in which the interviewer asked whether the advance directive called for comfort care, all possible care, or some limits on care and then asked what kind of treatment was provided. Verification of the specifics of the directive and of the actual treatment administered was not possible. Given that physicians find living wills inadequate to guide treatment decisions, it is crucial to know what was actually stated in the living wills that surrogates found helpful. Moreover, what we really would like to know — whether the preferences of patients were any more likely to be honored if they had a living will than if they did not — cannot be determined from this study. Finally, the study addressed only decisions made in the last days of life; impaired cognition often precludes patients' involvement in decision making for months or even years. Whether advance directives shape the many decisions affecting how patients live during the final stage of life is perhaps more important than whether they influence their final hours.

In light of the weight of evidence indicating that living wills are of limited efficacy, the findings of Silveira et al., while tantalizing, are insufficiently compelling to reverse the code status

of legalistic advance-directive documents. Nevertheless, they do demonstrate that talking about the goals of medical care has become acceptable to a large majority of those Americans who need it most — persons who are at high risk for incapacity at a critical juncture in their lives.

The ongoing challenge is to transform advance care planning from the act of signing a form to a process that begins by clarifying the patient's current health status, moves to elicitation of the goals of care, and then designates a proxy to work with clinicians in interpreting and implementing those goals.⁷ The Physician Orders for Life-Sustaining Treatment program is one attempt to do this.⁸ Adopted in a dozen states and being introduced in many others, this approach starts with a discussion between a patient and a clinician about goals and then translates those goals into a series of medical orders governing the use of interventions such as cardiopulmonary resuscitation and artificial nutrition. Its power depends on the strength of the underlying patient–doctor communication and on the establishment of a statewide system for communicating and honoring those orders.

A second approach is to use videos showing clinical situations to help patients define their goals of care and understand how they would be translated into practice in the event of a life-threatening illness. Videos have facilitated advance care planning for healthy older persons preparing for the possibility of dementia⁹ and are being piloted for patients with advanced cancer or severe heart failure. These strategies offer the possibility of truly promoting autonomy by allow-

ing patients at risk for losing capacity near the end of life the same enhanced quality of life that accrues to competent patients with advanced illness who discuss end-of-life care with their physicians.¹⁰

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1. Health care power of attorney and combined advance directive legislation. Washington, DC: American Bar Association, Commission on Law and Aging, December 2009. (Accessed March 11, 2010, at <http://new.abanet.org/aging/PublicDocuments/HCPA-CHT%2009.pdf>.)
2. Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med* 2007;147:51-7.
3. Fagerlin A, Schneider CE. Enough: the failure of the living will. *Hastings Cent Rep* 2004;34(2):30-42.
4. More Americans discussing and planning end-of-life treatment. Washington, DC: Pew Research Center for the People and the Press, 2006. (Accessed March 11, 2010, at <http://people-press.org/reports/pdf/266.pdf>.)
5. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. *Health Psychol* 2005;24:Suppl:S57-S62.
6. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211-8.
7. Lo B, Steinbrook R. Resuscitating advance directives. *Arch Intern Med* 2004;164:1501-6.
8. Hickman SE, Hammes BJ, Moss AH, Tolle SW. Hope for the future: achieving the original intent of advance directives. *Hastings Cent Rep* 2005;35:Spec No:S26-S30.
9. Volandes AE, Paasche-Orlow MK, Barry MJ, et al. Video decision support tool for advance care planning in dementia: randomized controlled trial. *BMJ* 2009;338:b2159.
10. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussion, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665-73.

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