

Advance Directives: Know What You Want, Get What You Need

Ongoing progress in the delivery of health care makes the need to clarify patient wishes more critical than ever. This is particularly true for intensive care medicine and palliative care. We can extend life using technologically sophisticated devices that may or may not reverse disease or ensure a quality of life that is compatible with patients' wishes.

Our clinical capabilities have continued to expand, and we are now seeing the personal, social, economic, and other implications of these changes. At the same time, patient choice and autonomy are essential components of clinical decision making. Understanding the goals and expectations of each patient is crucial for making the right decisions, offering the right therapies, and providing care that is consistent with those objectives. During the past few years, several systems and regulatory requirements have been instituted to ensure that physicians and health care systems have information about patients' preferences. Each hospital is required to document whether patients have an advance directive and, if so, to have a copy of the document in the medical record. If patients have no advance directive, they must be offered an opportunity to execute one.

Many recent studies have demonstrated that, despite all our attempts to obtain advance directives from patients and to educate them about their rights and responsibilities, we have had limited success.¹⁻⁴ This issue of *Mayo Clinic Proceedings* includes 2 interesting and thought-provoking articles that address some of the challenges associated with ascertaining patients' wishes, communicating them to those who are able to make health care decisions, and guiding physicians who must decide what care to administer and when to withdraw or withhold care.^{5,6} These studies identify some important barriers that prevent us from obtaining advance directives and from understanding patients' expectations.

The study by Nishimura et al⁵ of Mayo Clinic Rochester provides an interesting overview of the advance directives, their contents, and the implications for patients and physicians. Although the primary purpose of the study was to describe health care preferences that patients expressed in advance directives, it also identified various important issues related to advance directives that, as the

authors acknowledge, raise as many questions as the study answered.

First, the authors found many ambiguities in the definition of an advance directive for health care. Many patients had documents in their medical records that were described as advance directives but, in fact, had no implications for clinical management. Whether patients thought they had specified a process for making end-of-life decisions that in fact they did not have is unclear. If so, not only were the documents of limited value to clinicians or the family but also they were not fulfilling patients' expectations.

Second, documents that did address health care issues took many forms and had many different elements. In some cases, multiple documents were available for a single patient and occasionally had differing implications for clinical decision making and end-of-life management decisions. The study was not designed to evaluate whether patients were aware of the potential for documents to be conflicting or of implications for clinical management. However, this potential inconsistency either in designating a surrogate decision maker or in describing personal wishes could be important for patients, their families, and health care professionals.

Patients change their wishes and preferences for various reasons, including the influence of others.⁷ Identification of the "right" designated surrogate is critical; if multiple documents specify different surrogates or have conflicting directions about a patient's wishes, health care could be adversely affected, and relationships among surrogate decision makers, family members, and friends can be compromised.

Third, the study evaluated the contents of advance directives in the abstract; that is, no decisions were being made and clinical care was not influenced by the study itself. Implications of the study's findings for actual decision making require further analysis. Would preferences expressed in the documents that were reviewed for the study still be the preferences of patients when they are critically ill?⁸ If not, how does the context affect the decision made by patients or their surrogates?

Finally, nearly all patients in this study by Nishimura et al were white and Christian. The authors recognize this limitation of the study and acknowledge that their findings cannot necessarily be extrapolated to a more diverse population.^{9,10} Are the conclusions drawn from this study relevant to other populations? Another important consideration is this study's completion at Mayo Clinic; most

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Address correspondence to Neal H. Cohen, MD, MPH, MS, Department of Anesthesia and Perioperative Care, University of California, San Francisco, 513 Parnassus, S211, San Francisco, CA 94143-0410 (CohenN@medsch.ucsf.edu).

patients included in the study were receiving ongoing care at Mayo Clinic. This “continuity of care” provided the opportunity for ongoing discussions about patient wishes and documentation. Would the findings be the same for another population receiving primary and specialty care from health care professionals working in different institutions? These and several other questions warrant further investigation.

In the second study, Go et al⁶ from Gundersen Lutheran Health System in La Crosse, WI, address barriers for health care professionals (physicians, nurses, and other support staff) in executing their own advance directives. The authors found that even professionals who care for patients with cancer execute their own advance directives very infrequently. The study raises several critical issues about the value of advance directives that we as health care professionals need to address. The findings in this population and this community are more important than is obvious at first glance. In this community, a remarkable percentage of the population has advance directives: as many as 85% of patients who died had advance directives. This finding suggests that professionals are communicating the importance of advance directives to patients and their families. In contrast, health care professionals themselves often had no written documentation of their wishes about health care. They did indicate that they had discussed their wishes related to life-sustaining therapies and end-of-life care, although with whom is unclear. While the authors noted that the more experienced (ie, older) medical staff in particular were more likely to have advance directives, even in this group of professionals with a great deal of experience in caring for patients with cancer, more than 40% had no written advance directives. When advance directives had been executed, in about 30% of cases neither their own physician was aware of the directive nor was a copy of the advance directive available in the medical record. This lack of documentation is worrisome because it is in a cohesive and comprehensive health care system in which communications and coordination of care might be more effective than in many other communities or than for patients referred from one system to another.

Go et al made some interesting recommendations to improve the percentage of health care professionals who have written advance directives. The primary recommendation was to impose a workplace intervention program to encourage completion of written advance directives. Their recommendations are thought-provoking, although they might be inappropriate or inadequate to provide the kind of guidance needed to make health care decisions at critical times.

While time was described as a barrier to completing advance directives, the most important aspect of an ad-

vance directive is its reflection of ongoing discussion with patients and family members, friends, and health care professionals about personal goals, expectations, and outcomes of care. These discussions are time-consuming but cannot be scheduled or choreographed. They require ongoing conversations, theoretical constructs, and personal experiences over time. They also require an understanding of personal, family, religious, and economic implications of the decisions,^{9,10} as well as a context that is often theoretical, particularly when (as is suggested in this study) patients are young and healthy. Would they make the same decisions, or even have the same discussions, at a different point in their lives?

Despite some of the limitations of these studies, we should learn several lessons. The most important lesson could be that the current method for identifying patient wishes and ensuring that they are incorporated into the plan of care is not working. Neither patients nor health care workers have well-documented advance directives that are consistently available, nor do directives provide adequate guidance about decision making or consistently identify a surrogate who understands what patients will want at some future time. The goal of having the advance directive is admirable. Whether it is realistic to expect that we can fulfill the goal is unclear. However, on the basis of the findings from these studies, we should be considering alternative models for obtaining instructions, ensuring that directives accurately reflect patients' wishes, and communicating instructions to health care professionals. Simply requiring that the document be filed in the medical record is inadequate. Some have suggested that electronic personal health records that are updated regularly, with prompts reminding patients to do updates, will be helpful. Electronic records will never replace ongoing discussion of personal goals, quality-of-life concerns, and other issues among patients, their loved ones, and health care professionals. Another challenge these studies describe is dealing with these decisions in the abstract. Health care professionals included in the study reported by Go et al were generally young and healthy. Just as adolescents do not acknowledge their vulnerability, we, as health care professionals—even when we care for dying patients on a regular basis—do not consider ourselves “at risk.”

Until we are better able to engage in conversations about our own goals for care, quality-of-life issues, and vulnerability, it will continue to be difficult to ensure that advance directives are available when needed and that they accurately reflect the wishes of patients. Advance directives are invaluable resources to health care professionals and to families when they confront life-threatening situations or end-of-life care. These studies emphasize that, although we each have the opportunity to

provide input into the care we receive in the future, most of us have been unwilling or unable to take responsibility for determining our own fates. As health care professionals, we must devise better ways to encourage each of us to do so.

Neal H. Cohen, MD, MPH, MS
Department of Anesthesia and Perioperative Care
University of California, San Francisco

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