

ENTERPRISE RISK MANAGEMENT

Perspectives on advance directives

By the 2006 Monographs Task Force of the American Society for Healthcare Risk Management

INTRODUCTION

Terri Schindler Schiavo died in 2005 after her feeding tube was removed. Her death came nearly 15 years after she suffered cardiac and respiratory arrest and followed an ugly court battle between her parents and her husband. Essentially, the argument was over what the patient would have wanted and the spouse's right as guardian to make that decision for her, and became more complicated when her parents challenged the diagnosis of persistent vegetative state. (1)

In spite of wide media interest in the Schiavo case, a 2005 CBS News Poll found that 82 percent of the public believed it was a private matter and inappropriate for Congress to be involved. When asked if the actions of Congress made intervention easier in the future, 68 percent replied yes, and that they were concerned about it. Eighty-two percent stated that if in a coma, they'd prefer to have the feeding tube removed and be allowed to die.

Despite these statements (a similar CBS News Poll in 1990 yielded similar results), only one in three Americans had completed advance directives – legal documents that either appoint a proxy to be the decision maker or communicate a patient's preference regarding life-sustaining treatments in the event they are incapacitated. (2)

As in the Schiavo case, any situation has the potential to increase in complexity if family members disagree amongst themselves as to what constitutes appropriate treatment, especially if that disagreement involves the withdrawal of life-sustaining support.

The Schiavo case arose 15 years after passage of the Patient Self-Determination Act, a federal statute providing patients with the right to accept or refuse life-sustaining treatment and the means to communicate these preferences should they be unable to speak for themselves. Health care providers continue to review the impact of the PSDA on today's health care delivery system to evaluate whether its intended benefits have been realized. With the multitude of delivery systems of care, coupled with the efforts of community groups and greater awareness, it is time to examine whether patients have been fully engaged in the process of planning their end-of-life care.

It also is time to examine the success and failures of advance directives, the legal ramifications, barriers and strategies for improvement. In the quest for patient autonomy, it is imperative that health care providers understand what has worked and what has not.

Risk management implications

The federal Patient Self-Determination Act of 1990 and individual states' laws govern advance directives. Therefore, health care risk managers must be aware of compliance considerations to ensure that the facility's policies meet current legal requirements. Moreover, to ensure that expectations of patients and residents and their families are met, risk managers must see that these policies are properly communicated to everyone involved – care receivers as well as care givers.

Put It in Writing

The American Hospital Association, with support from ASHRM, is promoting a national education campaign to encourage Americans to document their end-of-life preference while they are still young and healthy enough to do so.

The AHA campaign includes a Web site, www.putitinwriting.org, with step-by-step instructions on how to complete advance directives, including links to resources in every state, and a downloadable wallet card to alert health care providers.

Forms of declaration

As stated earlier, the federal Patient Self-Determination Act sets forth requirements for providers of health care, including hospitals, skilled nursing facilities, nursing facilities and home health agencies, and makes Medicare/Medicaid participation conditional on compliance with these standards. Briefly, these requirements include:

1. maintaining written policies and procedures that address advance directives, including a clear and concise statement of any limitations if the provider cannot implement an advance directive on the basis of conscience;
2. providing written information to all adult individuals receiving medical care by or through the provider;
3. documenting in the medical record whether the individual has executed an advance directive;
4. providing education for staff, and
5. providing community education.

The act does not prescribe a federal format for an advance directive. Rather it is defined as "a written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the State),

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relating to the provision of health care when the individual is incapacitated.”

State laws vary concerning the appropriate documents to cover these situations. All states permit individuals to express their wishes as to medical treatment situations involving terminal illness or injury, and to appoint someone to speak for them in the event that they cannot do so themselves.

Depending on the state, these advance health care directives may be known as “living wills” or “health care proxies.”

Living will: The living will is the patient’s declaration of how he/she wants to be treated in certain medical conditions. Again, depending on state law, the document may permit the patient to express whether he or she wishes to be given life-sustaining treatment. Most states also allow patients to express preferences as to treatment when medical conditions render them permanently unconscious, without detectable brain activity.

Health care proxy: This document is also sometimes referred to as a “health care surrogate” or a “durable medical power of attorney.” It appoints a person to make medical decisions for the patient in the event that he or she is unable to do so.

Some states have standardized documents, while others leave the language up to lawyers and their clients.

Nutrition and hydration provisions: Some states permit a patient to decide in advance whether he or she wishes to be provided artificial nutrition and hydration. Such provisions are a source of controversy surrounding advance directives, since the ethical issue as to whether nutrition and hydration constitute palliative care or extraordinary care remains hotly debated.

Portable do not resuscitate (DNR) order: Some states have adopted a type of advance directive called a “portable DNR order” or “comfort care order.” This is a physician’s order that is written in advance of cardiac or respiratory arrest, and requested and/or consented to by the patient. The order typically follows the patient from facility to facility. It is typically indicated for persons who are at the end of life, by virtue of their age and medical condition.

Organ and tissue donation: In many states, persons may include in advance directives their preference to become an organ or tissue donor at the time of death. While many states maintain this registry at the department of motor vehicles, many have standardized forms that they now include in their advance directives forms as well.

Reciprocity and procedural/statutory provisions: Most states provide that they will recognize the documents created in other states, so long as they meet the host state’s statutory and procedural requirements. The rules for witnessing vary. For instance, some states require only a notarized signature for the declaration to be valid; others require that it be witnessed and notarized.

LEGAL PERSPECTIVES

The law regarding advanced directives attempts to measure several state interests against every “person’s right to be left alone.” (3) In determining the outcome of cases involving the effectuation of advanced directives, the courts generally apply a balancing test.

Supreme Court weighs in

In 1990, the United States Supreme Court found that a state has a legitimate interest in the protection and preservation of human life and is not required to remain neutral in the face of an informed and voluntary decision by a physically able adult. Ruling on *Cruzan v. Director, Missouri Dept. of Health* 497 U.S. 261, the Court upheld the Missouri law that required clear and convincing evidence when the formalities of the living will statute were not met. (4) The Court found that a state has a legitimate interest in safeguarding an individual’s choice between life and death. The Court noted that this was a deeply personal decision, “of obvious and overwhelming finality.” (5)

The “due process clause” protects an interest in life as well as an interest in refusing life-sustaining medical treatment. (6) Not all incompetent patients will have family members to serve as decision makers and, unfortunately, there will be those situations where family members will not act to protect the patient. (7) The Supreme Court held that Missouri could protect this choice though the imposition of heightened evidentiary requirements. (8)

State courts continue to face issue

Since the Supreme Court’s decision in *Cruzan*, many state courts have dealt with the issue of the right to refuse treatment. In 1997, the Wisconsin Supreme Court held that a guardian could only direct a physician to withdraw treatment, including artificial hydration and nutrition, if the ward was in a persistent vegetative state and the surrogate made the decision that was in the best interests of the ward. (9) In addition, the court held that when a person is not in a persistent vegetative state, it is not within in the ward’s best interest to have medical treatment withdrawn, and without an advance directive or clear statement of intent the surrogate cannot have treatment withdrawn. (10) According to the Wisconsin Supreme Court, the issue was whether a surrogate could decide to withhold or withdraw life sustaining treatment from an incompetent person who was not in a persistent vegetative state. (11)

All states have enacted legislation setting standards on what constitutes a valid advance directive (one type of which is a living will) and what is required to execute one. Texas, for example, has enacted a statute that allows physicians to disregard a patient’s treatment decisions if the physicians believe that the caring for the patient would be futile.

The Texas Advance Directives Statute provides a mechanism whereby physicians can refuse to honor a patient’s or his representative’s (collectively referred to as the “patient”) treatment decisions. (12) If a physician refuses to honor a treatment decision, the refusal shall be reviewed by an ethics or medical committee of which the

affected physician is not a member.(13) The patient shall be informed of the review process not less than 48 hours before the meeting and shall also, at that time, be provided with a copy of the statement set out in §166.052, together with a copy of the “registry list of health care providers and referral groups that have volunteered their readiness to consider accepting transfer or to assist in locating a provider willing to accept transfer.”(14) The patient is entitled to attend the meeting and to receive a written explanation of the decision reached during the review process.(15)

If the patient disagrees with the decision reached during the committee’s review, the physician shall make a reasonable effort to transfer the patient to a physician who is willing to comply and, if the patient is a patient in a health care facility, the facility’s personnel shall assist the physician in arranging transfer to another physician, another facility or an alternative care setting within the facility.(16) Treatment shall be continued pending transfer. The physician and the health care facility, however, are not obligated to continue to provide that treatment after the 10th day after the written decision is communicated to the patient, unless ordered to do so by an appropriate court. The constitutionality of this statute has not been challenged.

CARE GIVER & PATIENT PERSPECTIVES

Patient-physician discussions of advance directives are likely to occur in the following settings.(17)

- new patient office visit;
- periodic physician examination;
- office visit prior to an elective procedure; or a
- routine office visit.

With the exception of office-based surgery, it is unlikely that an advance directive would provide guidance for patient care in the physician office practice setting itself. More likely, the advance directive itself would address care in a surgicenter, a hospital or a nursing home setting.

The best place to have such “informed consent” discussions is in the outpatient setting so that the patient may draft the directive in a calm, unhurried environment.(18) This would allow a more thorough examination of patient preferences for treatment of certain conditions and for end-of-life care.(17) In addition, it would allow the physician an opportunity to explain to the patient as well as to his/her health care proxy possible treatments or medical interventions than would likely occur if the patient were incapacitated.(17, 19, 20)

How advance directives can be beneficial

Patients, as well as their families and counselors (lawyer, clergy person or trusted friend) on the one hand and physicians on the other hand, will be more likely to be satisfied with the outcome of the care provided when a patient is temporarily or permanently unable to participate in health care decision-making if the caregivers have access to the patient’s preference through an advance directive.(20)

The physician knows the patient’s preferences in advance. Correspondingly, the patient knows how the physician feels about these preferences. Thus, the physician-patient relationship is enhanced and likely strengthened.(20, 21)

From a risk management perspective, an advance directive provides the best legal evidence of a patient’s preferences for the type and the mode of administration of life-sustaining treatment.(22)

Ideally, the patient’s health care proxy should be included in the discussions leading up to the preparation of a final document. This should facilitate physician-proxy cooperation should the patient be unable to communicate his/her treatment preferences. In addition, the existence of an advance directive provides a framework in which both physician and proxy may be able to respond with informed but measured flexibility if unforeseen complications arise in the course of treatment.(20)

The preparation of the directive allows the physician to impart his or her own experience with death and dying so that patient may formulate a more informed directive that could potentially reduce areas of controversy between proxy and caregiver, should the patient be incapacitated and the advance directive need to be consulted.(20)

The patient’s primary care physician can serve as a resource to specialists to explain how a patient’s advance directive might apply in a given situation, based on his or her prior discussions with the patient in formulating document.(17, 22)

By consulting the advance directive, caregivers may be able to avoid either overtreating or undertreating the incapacitated patient. By preparing the directive in advance, the patient provides not only caregivers but also family and/or significant others with notice of treatment preferences, thereby potentially reducing both the emotional and financial burden on all parties.(20)

How advance directives can be problematic

Physicians often fear that their execution could be perceived as jeopardizing medically appropriate care that is consistent with agreed-upon limits, and that following a directive could lead to sanctions by reviewing bodies (professional organizations, governmental administrative regulatory bodies or the courts).(23)

Moreover, some physicians may feel uncomfortable initiating the discussion about advance directives.(24) They may also be concerned that these discussions will take up too much time for which they do not expect to be adequately reimbursed.(17, 19)

Ultimately, physicians need to allow patients to control their health care. That right brings some responsibility. If physician and patient encounter a conflict of values as a result of their review of a proposed directive, then the physician might expect the patient to take one of the following steps:

- modify the directive to conform to the physician’s position;
- propose a third alternative that neither party initially expressed(25);

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- modify the directive to note that under certain circumstances where the physician did not concur with the patient's treatment preference, care would be transferred to a physician who would honor the patient's preferences (26);
- terminate the physician-patient relationship and seek future care from a physician whose values would accommodate the patient's position that was troubling to the initial physician.

Physicians should counsel their patients to discuss their wishes for specific types of treatment and end-of-life care with their health care proxy – a family member or another person whose opinions they might value regarding treatment issues (trusted friend, lawyer, clergy, social worker, etc.). Physicians should also encourage them to do so promptly. (27)

Physicians could encourage patients and their health care proxies to review information issued by reputable health care, medical, legal and community service organizations (see, for example, the AHA Web site www.putitinwriting.org). Although the use of state statutory/regulatory model forms may carry additional validity from a legal perspective, from a caregiving perspective, the major purpose of the advance directive is to provide the caregiver with guidance in providing preferred treatment to a patient who “has lost his or her decision-making capacity.” (22) Thus, even if a particular declaration does not follow the exact wording of a particular state's statutory/regulatory model, it “still provides the best evidence of patient's treatment wishes or choice of surrogate decision maker” (i.e., health care proxy) to the caregiver. (22)

If a customized directive form differs markedly from a statutory/regulatory form, a patient may want to consider having a lawyer draft an introductory paragraph or preface to the document expressing the patient's intent that the caregiver be relieved of liability for following the instructions of the advance directive in the same way as if the patient had used the statutory form. (28)

Fortunately, education programs exist to facilitate physician discussions of advance directives with patients. These programs can enable physicians to carefully but respectfully broach the subject of preparation and planning of the appropriate declaration within the context of health maintenance and general patient well being. (17, 24)

Knowledge of patient preferences before patients are incapacitated could prove to be less costly than not taking steps to implement such directive before a health catastrophe occurs. (17) Such discussions may be considered to be a “counseling session” and billed as such. (19)

PERSPECTIVES ON BARRIERS

In decades past, physicians often withheld information from their patients regarding terminal illnesses. (29) This paternalistic view was seen as the way to care for patients. Today, patients expect to be partners in their health care experiences; having physicians and other health care providers withhold information is no longer generally acceptable. (29)

Facing end-of-life decisions

Nevertheless, discussions about end-of-life decisions still fall into an area that few in health care are comfortable in discussing. Medical science is usually directed at finding cures or improving life while death is seen as a failure of those efforts. One needs to only consider the regularly used euphemism of “losing a patient” to understand how death may be seen by clinicians.

Conversations about death between physicians, clinicians and patients rarely occur. (29) The clinicians' negative feelings relating to death inhibit meaningful discussions. Moreover, insurance and reimbursement structures may affect the time that is spent discussing the disease process.

While the patient-physician relationship provides numerous opportunities to discuss advance directives, these discussions should be considered sooner rather than later. A recent survey indicated that patients felt end-of-life discussions should take place at an earlier time, prior to any life-threatening disease and that it was up to the physician to initiate that discussion. (30)

When these discussions were observed, it was noted that conversations averaged 5.6 minutes, with physicians speaking two-thirds of the time. Physicians did not explore the rationale for a patient's preference and most often presented worst-case scenarios rather than discussing the possibility of uncertain outcomes or reversible conditions. (31) Physicians used vague language or highly technical terms and didn't provide enough substantive information for the patient to make an informed decision.

The forms and tools currently available are sometimes confusing and misleading. One study found that 77 percent of the subjects changed their minds when given a different scenario with the same interventions. (32)

Other issues that may arise in prohibiting frank discussions of death and dying on the practitioner end include fear and personal issues. Chances are highly likely that nurses, physicians or social workers have experienced death in their own lives. A patient's experience may bring those memories and feelings back for the caregiver. Also, the clinician may be dealing with his or her own mortality, which may further inhibit the ability to have open communication. (33)

Communication challenges in various settings

Too, each health care setting presents unique challenges to effective communication regarding end-of-life decision-making.

Physician offices: Studies have shown that physicians are more likely to have conversations about end-of-life care with their patients when clinical conditions dictate. (34) Some physicians believe that these discussions are not necessary unless a patient has a specific terminal disease. In general even these conversations rarely occur despite the clinical condition of the patient. Barriers to these discussions include a lack of knowledge and comfort level of the individual physician. (34)

Community hospitals: Depending on the size of the facility and the community served, other problems may arise in conjunction with end-of-life planning through advance directives. (35) There are very few texts used in nursing programs that deal with end-of-life issues. Some studies have shown that nurses and other clinicians feel that they should have such discussions with patients, but feel that they are not qualified to initiate them. (35) Another challenge may arise because an individual clinician may have a relationship with the patient outside of the confines of the hospital making the conversations much more delicate. (35)

Intensive care units: Many times, patients enter the ICU setting because of a sudden acute process. Clinicians in ICU settings have little history with these patients. The physicians may have been brought in only for the acute process and may not have long-term physician-patient relationships with such patients. (36) The patients and their family may have never discussed end-of-life planning. In these circumstances, conflicts may arise between family members as to what their loved one would want. (36)

Unlike discussions about end-of-life care in outpatient settings, the decisions in the ICU setting are less abstract. (36) Instead of thinking in terms of possibilities, the thinking is along the here and now. Families and health care providers may both be trying to find answers to the questions surrounding the patient's wishes. If the patient has a signed advance directive, it may not solve conflicts among family members; however, it may provide a valuable piece of information indicating what the patient would want to have happen if he or she were able to communicate.

Preoperative settings: Increasingly, surgeries are performed in outpatient hospital or ambulatory surgery settings. (37) While these areas may provide one of the few opportunities for interactions between an otherwise healthy individual and health care practitioners, (37, 38) clinicians may feel an increased discomfort with discussing end-of-life care with people who are getting ready for routine outpatient surgery. (37)

Nevertheless, benefits may result from having end-of-life discussions in these situations. People who may not have otherwise thought about their preferences can consider advance directives, which can result in thoughtful conversations with their families and loved ones to share their preferences. Others in the family may be prompted to consider their own preferences when the topic is discussed.

Emergency services: First responders and first receivers are trained to provide care in crises. Life-sustaining treatments are among the repertoire of these providers. When someone activates emergency services, that person asks for immediate help. (38) As discussed previously, some states have portable DNR orders that can dictate the care and efforts provided by these caregivers.

STRATEGIES FOR SUCCESS

Clinicians can draw from policies to facilitate open discussions with patients and families and identify available resources. A clinical pathway will support staff members who may need to speak to patients and families about the need to plan for death because such policies are familiar and detailed. (39) Policies also provide details that need to be covered that one may forget during the conversation. (39) Clinicians can turn to these to rehearse the various aspects that need to be covered and the paperwork that is needed for the medical record.

Educational opportunities comprising various scenarios should not be overlooked. (39) Clinician courses should focus on communication, understanding their own beliefs and common themes that patients and families experience. (40) Other educational courses on legal topics of power-of-attorney for health care, living wills, portable DNRs should also be covered. (39) When caregivers have more information at their disposal, conversations with patients and families will be that much easier.

Drawing from professional affiliations

Professional organizations can be tapped for information and support. (41) For instance, the American Medical Association's Education for Physicians on End-of-life Care is one source for physicians. (42) The American Nurses Association Position Statement on Nursing Care and Do-Not-Resuscitate (DNR) Decisions provides recommendations to help resolve some dilemmas that clinicians may face in relation to DNRs. (42) The ANA statement can serve as a framework for hospitals beginning to develop courses for clinicians on dealing with the prospect of end-of-life care.

Additionally, ASHRM's "Risk Management Pearls for Long-Term Care & Skilled Nursing Facilities" booklet for staff education programs touches on end-of-life issues (available at www.ashrm.org, Resources section, ASHRM Store page.)

Tips for primary caregivers

Physicians should initiate discussions of advance directives. Studies have shown that patients prefer that they do so. (18, 19, 20) Physicians should share their concerns about medically inappropriate care with the patient in advance so the patient may decide if he or she could in good conscience modify the directive to accommodate such matters.

Continuing medical education programs relating to topics about end-of-life should be attended by the practitioners. Training in this area cannot be neglected in medical school, either. Physicians have resources within their professional organizations which are good sources for tools to conduct these discussions with patients.

Specific training in the state law regarding advance directives and their use in emergency services should be held. Withholding treatment or attempts at treatment that may be futile goes against the basic training of this specialty.

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Community-wide educational series on advance directives and end-of-life planning may be an important tool for providing education to friends and neighbors. Debriefing and support of the clinicians after a patient's death may have increased importance in community hospitals because of the relationships caregivers may have had with such patients outside of the clinical institution. (35)

Ambulatory clinics should evaluate their process for educating patients. How and when do physicians discuss end-of-life decisions with patients? How time-consuming is it and how is it addressed? Clinics should evaluate the number of touch-points a patient encounters while negotiating the system and how these opportunities could be optimized for education.

Education material should be included with the first primary care encounter or sent out in welcome packets. These packets often include information to assist patients in formulating advance directives.

Ambulatory center personnel should assess the patient's understanding, especially if their preference is contrary to what would be expected. If possible, they should include family members and document all advance-care planning in the medical record, including who was present, the decision made, and why. They should also revisit the discussion with each hospitalization and again evaluate the patient's goals and desired functionality. (43)

Before patients can successfully implement an advance directive, they must accurately understand the proposed treatment and clearly state their preferences. The directives must be made available to the physician, facility and the designated decision-maker, and be documented in the medical record.

Ambulatory care clinics possess prime opportunities in which to educate, encourage, and assist patients in formulating their end-of-life decisions. Conversations with patients about their treatment preferences should be a routine aspect of care. (30)

FUTURE PERSPECTIVE

The 21st century promises to an aging population a new era of healthy living and longevity. Improved lifestyles, effective advances in pharmaceuticals and technological advances in diagnosis and treatment are the future.

Accompanying these expectations are foreseeable conditions that may very well affect the realization of this potential. The extraordinary growth in elder populations is expected to stress an already stretched health care system. Financing and servicing this growing demand will require some hard public policy decision-making. Regulatory agencies may mandate strict compliance with physician-provided counseling on available patient choices dealing with advance directives, as well as other end of life and like procedures.

The growing prospect of an ever increasing hostile health care workplace; emerging infectious diseases, pandemics, lethal terrorist attacks, drug resistant pathogens and more robust natural disasters will add unknown variables to future legal and ethical life and death decisions.

In the face of these challenges, advance directives have the potential to provide useful guidance and direction to caregivers regarding patient preferences. Their execution may reduce the risk that either patient or caregivers will undergo needless stress from uninformed and controversial guesses regarding appropriate treatment that would likely be made in their absence. When potential patients and caregivers work together to formulate mutually acceptable advance directives, the chances are increased that patients will receive adequate and appropriate care that incorporates the timeless values of comfort and dignity.

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