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#### **End-of-Life Care and Organ Donation Decisions:**

**A Doctor's Perspective**

**By Michael A. Williams, MD**

In the intensive care unit (ICU), physicians participate in critical decisions in two common sets of circumstances: end-of-life decisions, when withdrawal of life-sustaining therapies is considered; and brain death determinations, when organ and tissue donation is discussed.

End-of-life decisions are ubiquitous in the ICU, and yet they continue to be a disquieting process for patients, families, physicians and nurses. These decisions are rife with tensions—ethical, emotional, cognitive and even physical. Living wills, advance directives and durable powers of attorney for medical decisions have not had the intended effect of making these decisions easier for families in all situations. This article reviews the knowledge base, skills, conventions and controversies for end-of-life decisions, explains why best laid plans sometimes go awry, and offers practical advice for lawyers and their clients—all from a physician's perspective.

#### **End-of-Life Decisions**

The goal of end-of-life decision-making is matching a patient's values and preferences for treatment with the treatment actually received. Regrettably, this goal is not achieved as often as it should be. But the failure of health professionals to match the treatments they render to their patients' values and preferences is rarely deliberate. It is usually born of (1) inadequate opportunity or efforts to explore relevant issues with patients and their families and (2) insufficient knowledge of basic ethical and legal principles.

Many physicians and nurses need improved skills in communication and negotiation to address end-of-life decisions with patients and their families. Most health professionals strive to be ethical, yet many possess misconceptions about basic ethical principles and beliefs that are widely shared in the bioethics literature and promoted by national professional organizations. Such misperceptions can contribute to poor decision-making in end-of-life situations. Poor decision-making and poor communication skills combine to produce family dissatisfaction and feelings of anxiety by health professionals that can escalate into dilemmas and conflicts.

There is evidence that the knowledge, skills and attitudes necessary for ICU physicians and nurses to conduct good end-of-life decision-making are widely variable. Despite widespread educational efforts aimed at health professionals and the public, and despite implementation of the Patient Self-Determination Act in 1990 by Congress to promote the use of advance

directives (see §§ 4206 and 4571, Omnibus Reconciliation Act of 1990, P.L. 101-508), several studies have demonstrated that physicians and nurses often are unaware of patients' values and preferences for critical medical decision-making. As a result, they may act in disregard of patients' wishes.

The potential to be unaware of patient preferences is greater in the ICU. Fragmentation and discontinuity of care within the health care system usually mean that the ICU staff members have had no relationship with a patient before that critical illness. Consequently, the ICU staff almost never has an opportunity to discuss end-of-life preferences with patients before the ICU admission. As a result, staff members often discuss, assess and implement end-of-life decisions with patients and families in very short periods of time with little preparation and under intense emotional and physiological stress.

When a patient is unconscious, as is often the case in the ICU, it is even more difficult to make medical decisions consistent with the patient's preferences, because those preferences may be uncertain or unknown. In these circumstances, families or surrogates (terms that will be used interchangeably) must make medical decisions with the health care team on behalf of the patient. These decisions have personal, financial and social effects on the patient and family that can complicate matters for the surrogates who must participate in the medical decision-making process while in the midst of crisis.

Tension between the health care team and the surrogate frequently exists because they may have differing perspectives on the goals of saving or prolonging life (curative medicine) versus relieving suffering (palliative medicine) when the patient's outcome is still uncertain. In contrast to the uncertainty of the patient's response and eventual recovery, the urgency of medical treatment adds more tension for the health care team and surrogates as they strive to make decisions consistent with the patient's preferences. Sometimes the knowledge needed to make medical decisions appears only after waiting for the patient's response to treatment.

The purpose of end-of-life decision-making is not to advocate either the prolongation or the withdrawal of therapies. It should be a process for effective communication and decision-making on behalf of patients. The decision negotiation process is a way to create a shared understanding of the medical issues and the patient's preferences (or best interests, if the preferences are unknown) or to identify areas of uncertainty or disagreement. Shared decision-making with a family reflects respect for the autonomy of the patient and encourages treatment decisions that lead to outcomes consistent with the patient's preferences.

End-of-life decision-making is usually not a single event. It is a process requiring numerous meetings of the health care team and the surrogates to consider not only the patient's condition and preferences but also the ethical aspects of the treatment options. Such a process may seem insurmountable and time-consuming to all involved. But a well organized approach can result in effective communication, medical decisions and care that are consistent with the patient's preferences.

The basic steps of end-of-life decision-making and care involve assessing the patient, making decisions with the surrogate, and modifying the care plan—steps that should be repeated as often as necessary until a final decision and outcome are achieved. This iterative approach is supported by several key elements: facilitating the communication process, determining the patient's preferences and dealing with uncertainty.

### **Communication**

A good communication process incorporates timeliness, coordination, clarity, reiteration and empathy. Timeliness is important because in the ICU the patient's potential to respond to therapy is time-dependent. Coordination means identifying the patient's surrogates and health care team members who will participate in the decision-making. Clarity requires language that can be understood by all decision-makers. Even with clear, simple

explanations, a surrogate's emotional response and the complexity of medical information can impair understanding, especially when bad news is shared first. The health care team often needs to reiterate parts of the discussions. Reiteration involves more than mere repetition; it also includes the establishment of the expectation and a time to meet with the surrogate again. If this occurs at an important point in the patient's therapy, then the meeting is an opportunity to reassess the patient's response to therapy as an important criterion for decision-making. Empathy is the ability of health care professionals to identify with the situation of patient and family. An empathic communication approach to patients, surrogates and families can create trust and decrease anxiety. Although not strictly synonymous, empathy is often equated with a good bedside manner.

### **Preferences**

In the United States, there is a strong tradition and legal precedent for respecting individual autonomy with respect to end-of-life decisions. The preferred basis for surrogate medical decision-making is to understand the patient's preferences as much as possible and to keep them in mind when considering medical decisions. The preferences can be identified from advance directives or living wills, documented discussions with physicians or other health care professionals, specific conversations about the types of decisions the patient would make in similar circumstances, and general conversations about the patient's preferences. Some patients desire to delegate to their surrogates the power to make those decisions that need to be made. Most end-of-life decisions will incorporate information from several of these sources.

In a nation as diverse as the United States, the role of personal autonomy for end-of-life decisions is not universally accepted. In some cultures, the family is responsible for such decisions. If there is an opportunity, the roles of the individual and family in decision-making can be clarified by asking the patient, "If there is ever a need to discuss bad news or the possibility of dying, how would you like to proceed?" Patients can then choose either to be part of the process or to defer to family members according to preferences and customs. Either decision is an expression of patient autonomy.

Advance directives have their limitations in determining a patient's preferences. For example, in the setting of brain injury or illness, a persistent vegetative state—which is often cited as a reason to withdraw life-sustaining therapies—cannot be confirmed until three to six months after the acute injury. In addition, advance directives rarely indicate whether patients are willing to go through lengthy recovery and rehabilitation to achieve the desired outcome. Nevertheless, advance directives provide useful insight into the patient's values and outcome goals, and they can be a starting point for unanticipated situations. The value of an advance directive is enhanced when a patient has discussed its contents with family members. Surrogate decisions are easier when patients have spoken their wishes in addition to writing them. A written document without a voice may seem less authentic in times of stress, regardless of its legal validity.

### **Uncertainty**

The more uncertainty there is about the patient's preferences, the more the surrogates and the health care team must use the "substituted judgment" or "best interest" standard for surrogate decision-making. The best interest standard involves making a decision for the patient by analyzing the benefits and burdens ostensibly on the basis of either generalized criteria (e.g., values held by a "reasonable" or "average" person) or medically "objective" criteria (e.g., likelihood of pain and suffering, awareness of others, degree of disability). From a medical perspective, the difficulty is that few criteria, if any, are generalized or objective. Depending on the familial, ethnic, cultural, legal and religious backgrounds of the individuals interpreting the best interest standard, decisions as disparate as withdrawing or continuing life-sustaining therapy could be made in the patient's best interests.

The presence of uncertainty goes beyond patient preferences. It includes the uncertainties of the clinical evaluation, the therapeutic plan and the prognosis of the illness. It is unwise

and unfair to foist the entire decision-making process on a surrogate who has no medical understanding of the illness. Physicians can help surrogates and families make informed decisions by making specific treatment recommendations based on an integration of

- an understanding of the patient's preferences,
- a professional assessment of the likelihood that treatment will lead to an outcome consistent with the preferences and
- a projection of whether further time or treatment may affect the degree of uncertainty in the decision negotiation process.

A surrogate should listen carefully to be sure a physician's recommendation is based on the patient's values and not solely on the values of the health care professionals involved.

End-of-life decision-making with the family of patients in the ICU is a challenging process occurring under stressful circumstances. There are many opportunities for the decision negotiation process to go awry. Careful planning, with attention to the needs and responses of the family and with the aim of making decisions consistent with the patient's preferences, is vital to the success of the decision negotiation process—enabling the family and the health care team to make the wisest decisions possible.

### **Brain Death Determinations and Organ or Tissue Donations**

Discussing severe brain injury, brain death and organ donation with families is a special form of end-of-life decision-making in the ICU. In the United States, the organ donor must be dead if vital organs are to be procured (the "dead donor" rule). The prevailing practice for organ donation to occur is to determine the patient's wishes about organ donation and to obtain family consent, which necessarily entails discussions at the end of the patient's life. The major challenge in this process (above and beyond those for end-of-life decision-making) is the short time interval between telling a family that a patient is dead and presenting the option of organ donation. If the health care team is sensitive to the family's grieving process, then the requests can result in donation.

The number of organs procured for transplantation in the United States is insufficient to meet the needs for transplantation. One reason for the unrealized donor potential is that many families of eligible donors are not given the option of donation— either the eligible donors are not identified or their families are not approached about organ donation by the health care team. Another reason is that numerous families that are offered the donation option decline.

Hospital experiences affect family decisions to donate. Nondonor families are often those less satisfied with the quality of care received and with the donation *request* process. They report particular concerns about having insufficient time and privacy to make up their minds and that the person making the request was insensitive to their needs. Another factor affecting decisions is the belief held by most nondonor families that a brain-dead person can recover. In contrast, donor families were more satisfied with the patient's quality of care and the process requesting the organ donation.

Consequently, the structure, sequence, timing and coordination of the donation process are vital. Interviews with donor and non-donor families provide important insights. The most successful requests for donation

- are in a private setting,
- allow the family to comprehend death (brain death) before discussing organ donation (decoupling) and
- involve the transplantation coordinator.

Each of these elements enhances the organ donation consent rate. The decoupled process model for explaining grave prognosis, brain death and then organ donation significantly affects family satisfaction and increases the consent rate for donation. Decoupling, which involves separating the discussion of death from the request for organ donation, is not easy in the busy ICU environment and requires coordination between hospital staff and the transplantation staff.

The desire to increase organ donation consent rates can create conflicts of interest. If *consent* is the primary goal of the donation process, then a family's refusal can be seen as a "bad" outcome. If approached with this mindset, well-meaning efforts to increase donations may not consider the needs of families who are in shock. The most obvious conflict of interest is when organ donation is discussed with the family before brain death is pronounced, which may lead the family to question whether the team has the patient's best interests in mind.

Although increasing the consent rate and procuring more organs is desired, the more important goal is the implementation of a process that focuses on the families of potential donors. Within this framework, either decision is acceptable, simultaneously preserving and promoting the goals of caring for families and identifying possible organ donations.

### **Practical Advice**

No matter how well planned, end-of-life decision-making is always stressful. Poor planning makes it even more stressful. Although a person's death can never be made a "happy" experience, there is the potential to make it either a miserable experience or a memorable one for patients and families. Planning, process, patience and empathy are key ingredients to a memorable death.

The most important advice is for patients to summon the courage to discuss the possibility of dying, plus the kinds of outcomes that are acceptable or unacceptable (e.g., persistent vegetative state) long before they are seriously ill, if possible. Ideally, not only will the patient have an advance directive and a person to serve as his health care proxy, but also the patient will have discussed individual wishes with his or her family or health care proxy and with the physician. Those discussions improve the understanding of those who may have to make decisions on behalf of the patient. They provide an opportunity for anticipating the "what ifs" and helping all participants learn that no advance directive can possibly anticipate every situation or contingency. Patients with a chronic illness should reconsider their wishes periodically, as their experiences with illness and recovery can alter the preferences they expressed before they were ill. Some will want a more curative approach, others a more palliative approach.

Patients should give a copy of their advance directives to their physicians and to their health care proxies and should try to bring copies of their directives with them to the hospital, if possible. Accordingly, advance directives should be immediately accessible. A safe deposit box at a bank is not an immediately accessible place to keep an advance directive. A drawer or file cabinet at home is a better choice.

Patients who desire to donate organs should make their wishes known in writing and in person. Perhaps the most common approach is to make this indication on a driver's license. But unless that choice is accompanied by a discussion (even a brief one) with family members, it can be an additional shock to the family of a brain-dead patient when they are informed that the patient's license indicates an organ donation preference. Even better is to include the desire to donate organs in an advance directive. Not only should solid organs such as kidneys, heart and lungs be considered, but also tissues such as skin, bone and corneas should be considered.

Patients and families should be forewarned about the loss of control in the hospital environment, as well as the incredible emotional toll, especially if the patient is critically ill or dying. Yet within that environment there is help that can be sought. Nurses, social workers and clergy are available to discuss emotional or spiritual needs and can help arrange meetings with physicians. Scheduling meetings with physicians is understandably difficult, but firm, polite insistence usually yields results.

Lastly, patients, families, surrogates, physicians and nurses should take care not to interpret advance directives too simplistically. Directives cannot anticipate every situation, and many times the directive is several years old, and the patient's values or wishes may have

evolved over time. An advance directive should be seen as an invitation to a series of conversations about the patient's wishes. It provides the starting place for understanding the patient's wishes.

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