



ADVANCE DIRECTIVE UTILIZATION IN THE ICU: ETHICS, LAW, AND PRACTICE

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ABSTRACT

One in five Americans dies during hospitalization in the ICU. Over 90% of ICU deaths result from a decision to withhold or withdraw life sustaining treatment. In an effort to preserve individual autonomy and decision making capacity during end-of-life decisions, the idea of an advance directive was developed in the 1970s. Once written, advance directives are supposed to aid physicians and surrogate decision makers in fulfilling the wishes of the patient. Although advance directives are in place to preserve patient autonomy, they are typically vague in nature and difficult to apply to complex situations. Additionally, a lack of laws requiring physicians, hospitals, and families to follow advance directives during end-of-life decision making has resulted in ethical dilemmas, increased spending, and reduced quality of care. In a society where the majority of deaths follow a barrage of life-extending and life-saving treatments, documenting patient preferences has become increasingly important. Although the importance of advance directives has been emphasized through the passage of public health laws such as the Patient Self Determination Act, the majority of Americans do not have an advance directive. This presentation is intended to offer both legal and lay audience a descriptive analysis of the current laws, ethical dilemmas, and practical barriers to utilization of advance directives in the ICU. Furthermore, this presentation will inform both lay and legal audiences about benefits and drawbacks of advance directives, as well as give recommendations for how advance directives can be utilized to deliver higher quality, more cost effective care in the ICU.

BACKGROUND

Decisions to withhold, withdraw, or utilize life support and other medical technologies that have the ability to keep individuals alive who would otherwise die naturally are referred to as end-of-life decisions (Baggs, Norton et al. 2007). Traditionally, end-of-life care decisions were made by health care providers (Wikinson, Wenger et al. June 2007). However, in the 1960s, patient and consumer rights movements began to shift the implementation of medical treatments to an autonomy based system where patients have the right to refuse medical treatment (Wikinson, Wenger et al. June 2007).

Although patients began demanding the right of autonomy in the 1960s, patients were not granted the right to withdraw or refuse life sustaining treatments until the New Jersey Supreme Court Case involving Karen Quinlan set the standard in 1976 (Heubel and Biller-Andorno 2005). Furthermore, the decision to become a DNR or "do not resuscitate" was not legalized until the mid-1970s (Santonocito, Ristagno et al. 2012). In the United States, individuals have come to expect autonomy – the ability to govern one's self – when engaging in end-of-life decisions (Szasz June 1969). In order for individuals to maintain autonomy and decision making capacity during end-of-life decisions, advance directives were developed (Bowden June 2009).

The advance directive is a legal document that allows a competent individual to exercise autonomy during end-of-life decisions by specifying the health care one would like in the event that he or she is unable to make a decision in the future (McNaughton and Rawling 2007). Advance directives typically address the refusal or desire to be given several medical interventions including: 1) cardiopulmonary resuscitation (CPR); 2) nutrition; 3) intravenous medications; 4) antibiotics; 5) mechanical ventilation; 6) do not resuscitate orders (DNR); and 7) blood products (O'Neill 2007; Luce and White 2009). Once written, advance directives are supposed to be used by surrogate decision makers to fulfill the wishes of the patient in the event that the patient can no longer speak for himself (Wikinson, Wenger et al. June 2007).

CURRENT LAWS

In 1976, California was the first state to pass a law allowing advance directives to be considered during end-of-life decision making (Wikinson, Wenger et al. June 2007). Today, forty-seven states and the District of Columbia have laws that give allow the consideration of advance directives during end-of-life decision making (Massachusetts, Michigan, and New York do not have laws which explicitly allow advance directives to be considered legal documents) (Freeman Autumn, 1994).

In 1990, Congress enacted the Patient-Self Determination Act (PSDA) which requires health care facilities receiving Medicare and Medicaid funding to ask patients whether they have an advance directive and, if not, whether they would like to speak to someone about making one. Although the PSDA requires hospitals to ask whether a patient has an advance directive, there is no federal law requiring hospitals and family members to follow advance directives that are in place.

Although advance directives are in place to preserve patient autonomy, the lack of laws requiring hospitals and family members to consider advance directives during end-of-life decision making has resulted in ethical dilemmas for surrogate decision makers. Even when an advance directive is in place, surrogate decision makers are not legally obligated to follow the advance directive.

ETHICAL DILEMMAS

Imagine a patient that has no hope of regaining cognitive awareness, yet is able to breathe with the aid of a ventilator. Remove the ventilator and the patient will die naturally, maintain the ventilator and the patient will live the remainder of his life lying in bed with no conscious awareness of the world around him. Advances in medical technology have blurred the boundaries between life and death, leaving patients and families to make decisions such as this one every day. Many ethical dilemmas result when surrogate decision makers, which are typically family members, desire more care than warranted by the advance directive (Wikinson, Wenger et al. June 2007). In addition to the extent of care a patient receives, advance directives are often difficult to interpret or too vague to apply to the complex situations that arise in the ICU, resulting in ethical dilemmas (Kass-Bartelmes and Hughes 2003).

ABOUT THE AUTHOR

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Making the decision to withhold, withdraw, or utilize life support and other medical technologies that have the ability to keep individuals alive who would otherwise die naturally

Advance Directive

If I am unable to make my own medical decisions, the following represents my wishes:

Life-sustaining treatments

I do not want life-sustaining treatment, including CPR. If life-sustaining treatments are started, I want them stopped.

I want the life-sustaining treatments that my doctors think are best for me.

Other wishes _____

Artificial nutrition and hydration

I do not want artificial nutrition and hydration if they would be the main treatments keeping me alive. If artificial nutrition and hydration are started, I want them stopped.

I want artificial nutrition and hydration even if they are the main treatments keeping me alive.

Other wishes _____

Comfort care

I want to be kept as comfortable and free of pain as possible, even if such care prolongs my dying or shortens my life.

Other wishes I want to be kept comfortable, but not if it is going to prolong my death substantially.

THE COMPLEXITY OF ADVANCE DIRECTIVES: YOU ARE THE DECISION MAKER

Imagine you are the appointed health care representative for a family member or close friend. Although you knew you were the appointed health care representative, you and your loved one did not talk about health care decisions because you did not expect that you would actually be in the position where you would have to decide their medical treatment. The Advance Directive above is presented to you at the hospital and you are told that you need to tell the doctors how to proceed. Utilizing the Advance Directive provided above, make the appropriate health care decision for your loved one based on the hypotheticals presented.

Hypothetical 1:

Your 60 year old father who has been receiving dialysis over the past year for renal failure tells you that his stomach is really hurting and asks you to take him to the hospital. At the hospital, he hands you his Advance Directive (see Advance Directive above) and health care power of attorney form which appoints you to make his medical decisions in the case that he cannot. He says he is sorry he did not tell you sooner, but "after mom passed away he didn't want to talk about death anymore". At this point, he starts screaming in pain and is taken back to emergency surgery for a bowel obstruction. Once your father is opened on the operating table, the physicians see that he has a necrotic (dead) bowel and there is nothing more they can do. His abdomen is closed and he is sent back to the ICU. His physicians approach you and explain that they can keep your father alive for several more weeks using life-sustaining treatments such as ventilation and TPN (nutrition through an IV); however, due to his necrotic bowel, he will not survive and his death will come most likely from sepsis (infection throughout his body) if life-sustaining care is continued. Your father is unable to speak, and you are not sure if he is able to respond to you when you touch him. What decision are you going to make for your father?

Hypothetical 2:

Your 47 year old best friend experiences a massive stroke on a Sunday evening in his home. He is divorced, does not have any children, and is an only child himself. Four years ago, after both of his parents passed away, he asked you to be his designated health care representative because he did not have anyone else. At the time, he asked you to be his health care representative. He joked that you "better not just pull the plug on me", but that he also "never wanted to be kept alive if he could not enjoy life". You receive a phone call from a neighbor who found him down in his kitchen on Monday morning nearly 15 hours after he had suffered a stroke. You rush to the hospital and are told by his doctors that they are not sure if he will ever wake up. After a long night of sitting by your friend's bed, you wake up the next morning to find that he is awake. After an assessment by his physicians, you are told that your friend is paralyzed on his left side and that he will never be able to say more than a few words. Additionally, he is no longer able to swallow and will require a PEG in order to receive food for the rest of his life. He is able to breath on his own; however, due to his stroke, he is not aware enough to make his own medical decisions. The physician hands you his advance directive (see advance directive above) and asks you whether he should insert the PEG tube and discharge your friend to a nursing home, or if you would like to refuse the feeding tube on his behalf. The physician explains that refusing the feeding tube does not mean that your friend will be in pain because he will be given medications to be kept comfortable. What decision are you going to make for your friend?

Hypothetical 3:

Your 55 year old mother presents at her primary care doctor because her skin is turning yellow. She is not in any pain; however, her physician recognizes right away that she has jaundice and orders an ultrasound of the pancreas to determine the cause. The ultrasound reveals that your mother has a mass in her pancreas blocking her biliary duct which is causing her jaundice, or "yellow skin". Your mother undergoes a surgery to remove the mass in her pancreas. At the time that your mother consents to the surgery, both her and her physicians do not believe that she will experience any remarkable side-effects and so end-of-life decisions are not discussed. Following the surgery, it becomes clear to her physicians that she is having respiratory failure and they are unable to extubate her. Additionally, the physicians are unable to wake her from sedation and they believe that she has sustained substantial injury to her brain due to lack of oxygen (anoxic brain injury). They really do not know whether she will ever wake up. One week later, your mother remains intubated, and her physicians still do not believe she will be able to live without the assistance of the ventilator. The physicians ask you if you would like to continue with life-prolonging interventions that would include tracheostomy and sending her to a nursing home, or if you want to extubate her now. They explain that extubating her now means she will die shortly after extubation from respiratory failure. What decision are you going to make for your mother?

BENEFITS OF ADVANCE DIRECTIVES

In a society where the majority of deaths follow a barrage of life-extending and life-saving treatments, having a document which outlines patient preferences is important in order to maintain individual autonomy (Tilden and Thompson 2009). Proponents advocate that advance directives are imperative in order to ensure that the patient's wishes are followed. Advocates point out the numerous situations where family members of the patient want more aggressive treatment than the patient desired. In these situations, an advance directive would offer the legal solution ensuring that the patient's wishes were followed regardless of what the family members want (Sviri, Garb et al. 2009).

In addition to ensuring that the patient is able to exercise autonomy during end-of-life decision making, advance directives also encourage communication about end-of-life care to take place. Furthermore, studies show that communication about end-of-life decisions has been associated with less aggressive care and reduction in use of unsuccessful life sustaining treatments (Curtis and Vincent 2010).

Advocates for advance directives assert that regardless of the limitations of advance directives, use should be increased in order to insure that the patient's wishes are followed and to decrease the burden on the patient's family (Tilden and Thompson 2009). Furthermore, advocates will cite studies which conclude that prior failures of advance directives are attributable to faulty implementation, not to the underlying concept (Halpern 2012).

DRAWBACKS OF ADVANCE DIRECTIVES

Advance directives have been found to have issues along every step of the process. The most basic issue with advance directives is accessing the document when it is needed (Bradley, Brasel et al. 2010). A more complex issue is the ability of the surrogate decision maker to understand and abide by the advance directive (Kuniavsky, Ganz et al. 2012). One study showed that while surrogate decision makers indicated the desired to follow their loved one's wishes, adherence to the patient's wishes was difficult when the patient's wishes did not match the families emotional needs (Schenker, Crowley-Matoka et al. 2012).

One of the more complex issues with advance directives is the patient's ability to understand the brevity of the treatment options they are refusing or requesting (Johnson, Zhao et al. 2012). When faced with the issue of deciding what end-of-life treatments a person will want in the future, many people do not know enough about the options they are selecting from. In one study of 201 elderly patients, 70% of subjects changed their minds about end-of-life care treatment options when given the same scenario but with a different description of the intervention (Fagerlin and Schneider 2004). Furthermore, wishes expressed in an advance directive may not remain consistent over time (Siegel 2009). As one author noted, "advance directives . . . are largely viewed as a failed mechanism to improve end-of-life care because they are static in the face of dynamic illness, promise more control over the future than is possible, and often only address ill-defined situations." (Cooke and Curtis 2012).

PRACTICAL BARRIERS TO UTILIZATION IN THE ICU

Despite a federal law requiring all hospitals that receive Medicaid and Medicare reimbursements to ask their patients if they have an advance directive, the literature indicates that advance directives are not often utilized in making end-of-life decisions in the ICU (Daniels 1981). Furthermore, even with a federal law in place, the documented presence of an advance directive upon patient admission to a hospital is only between 3 and 14%, with the overwhelming majority of these people being over the age of 65 (Gordy and Klein 2011).

In a report completed by the Agency for Healthcare Research and Quality (AHRQ) in 2003, sixteen AHRQ funded research projects on end-of-life care were reviewed in order to determine the role of advance directives in advance care planning (Kass-Bartelmes and Hughes 2003). The studies revealed that advance directives only played a role in making end-of-life decisions in less than half of the cases where a directive existed and were only applicable when the patient was incapacitated and "absolutely, hopelessly ill" (Kass-Bartelmes and Hughes 2003). In essence, when an advance directive is present, it is extremely difficult to determine if it was followed.

The report also noted the lack of presence of surrogate decision makers, and when present, the tendency for surrogate decision makers to make prediction errors of overtreatment. Additionally, the report found that advance directives were not utilized because "providers and patient surrogates had difficulty knowing when to stop treatment, often waiting until the patient had crossed over the threshold to actively dying before the advance directive was invoked" (Kass-Bartelmes and Hughes 2003). Despite society's demand of autonomy when faced with medical decisions, the current end-of-life decision making process is failing to uphold the individual autonomy of patients.

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