



## Ethical and Legal Issues at the End of Life

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End-of-life issues often present conflicts between and among the medical team, patients and patient families. During these times of patient and family fear, grief and possible prognostic uncertainty, differing value systems can lead to opposing assessments of risks and benefits with respect to continued aggressive treatment, feeding and hydration, pain control, and overall decision-making. Many of these issues can be resolved at the bedside with good communication between the stakeholders. On occasion, however, third-party involvement, such as ethics consultation, is necessary. Further complicating such interactions are fears of litigation if a physician chooses an action against the wishes of some family members. This article will present frequently encountered areas of conflict and the legal underpinnings of current ethical thinking that can be applied to educate and inform decisions for patients,

families and the medical team.

### Surrogate Decision-Making

When a patient is unable to make his or her wishes known, a proxy source must be used to inform decision-making. These sources can be living wills or other advance directives, an agent acting under a durable power of attorney for health care (DPOAHC), or in the absence of these, family members or friends. In these situations, two questions are raised: who makes medical decisions for the patient, and how should medical decisions be made?

In 1975, Karen Quinlan was being maintained on a ventilator in a persistent vegetative state (PVS). Her parents obtained guardianship in order to discontinue the ventilator, an action which was reported to be consistent with her previously stated beliefs. The treating physician

wished to continue treatment on the basis of conforming to medical standards and traditions. Eventually, the New Jersey Supreme Court agreed with the family's position of their right to be proxy decision-makers for their daughter and, thus, gave them surrogate decision-making authority.<sup>1</sup> Today, the choice of medical decision-maker when the patient has not designated one is generally determined by state statute. In South Dakota, the hierarchy determining the order of surrogate decision-makers can be seen in Figure 1.

**Figure 1.**  
**South Dakota Statute of Proxy Health Decision Makers<sup>2</sup>**

- If a DPOAHC or appointed guardian is not available,
1. The spouse, if not legally separated
  2. An adult child
  3. A parent
  4. An adult sibling
  5. A grandparent or an adult grandchild
  6. An adult aunt or uncle, adult cousin, or an adult niece or nephew
  7. Close friend

A legally executed DPOAHC trumps all others, including spouses. If one is not available, then health care providers progress down the list until an appropriate person is found.

If two or more people exist in a single category, such as siblings, they generally share decision-making responsibility. Recently, the law has been revised to allow close friends of the patient who are familiar with the patient's health and belief system to also be eligible.<sup>3</sup>

Once the identity of the surrogate decision-maker is determined, one of two standards is applied to make proxy decisions for the patient. The first is generally known as "substituted judgment."<sup>4</sup> These decisions apply information from the patient that indicates what he or she would want in a given situation. This evidence can range from living wills at one end of the spectrum to previously stated preferences or known values of the patient at the other. It must be stressed that the decision of the surrogate in this situation is not to be the decision that the surrogate would make for himself or herself but that which the patient would make if they were able to at that moment. Living wills and other advance directives, if available, can provide great insight into the patient's wishes. Indeed, in South Dakota, the law states that the proxy decision-maker must "consider the recommendation of the attending physician, the decision the incapacitated person would have made if the incapacitated person then had decisional capacity, if known, and the decision that would be in the best interest of the incapacitated person."<sup>5</sup>

If there are no known preferences of the patient, one must then apply another standard for decision-making. That standard is referred to as the "best interest" (of the patient) standard. With this standard, the burdens and benefits of any intervention must be considered with the goal of minimizing the burdens, such as pain and suffering. The decision must be one that a reasonable person in the same situation might choose for him- or herself.<sup>4</sup>

Once a surrogate decision-maker has been identified and the standard for those decisions has been defined, emotionally challenging decisions sometimes need to be made. One of the most difficult is the decision to withhold or withdraw life-sustaining medical treatment (LSMT). This may include mechanical ventilation, antibiotics, transfusions, dialysis, pressors, and intravenous or enteral fluids and nutrition. Once started, LSMT can appear to some as more difficult to discontinue than not starting it at all. Legally and ethically, there is no difference between withholding and withdrawing LSMT.<sup>5,6</sup> That is not to say that they are not different psychologically for all involved parties, but from the decisional standpoint, they should be treated as equal.

Numerous legal cases have supported the surrogate's ability to advocate for withdrawal of the above LSMT. Some of the most widely known cases are the Quinlan case, the Cruzan case, the Bouvia case, and most recently, the Schiavo case. Like Karen Quinlan, Nancy Cruzan was diagnosed with PVS. She was not ventilator dependent but was being fed via a gastrostomy. After years, her parents wished to discontinue feeding that was, according to testimony, inconsistent with the patient's previously stated wishes. This was challenged by the state of Missouri, citing the state's interest in preserving life. The United States Supreme Court agreed that the state may require "clear and convincing evidence of the patient's wishes," but if available, the surrogate has a constitutional right of refusal of life-sustaining medical treatment for the patient.<sup>1</sup>

In 1986, Elizabeth Bouvia was a 28-year-old quadriplegic who had a feeding tube inserted against her will. She sought a court order to have the feeding tube removed. The trial court refused, siding with the medical community and citing concerns for the sanctity of life and fear of participating in suicide. The appellate court disagreed, stating in part "the right to refuse medical treatment is basic and fundamental. It is recognized as a part of the right of privacy protected by both the state and federal constitutions. Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion."<sup>7</sup> Thus, the court agreed with Ms. Bouvia, and the

feeding tube was removed. These cases and many others have established the constitutional right to refuse any treatment, including LSMT, either by the patient or by the surrogate. South Dakota statute states “Death resulting from the withdrawal or withholding of life-sustaining treatment in accordance with this chapter does not constitute, for any purpose ... a homicide on the part of the attending physician or other health care provider.”<sup>8</sup>

What about the opposite situation? How does a practitioner approach the scenario in which the surrogate demands that life-prolonging treatment be continued at the end of life? Another article in this issue addresses the concept of “futility,” so it will be discussed only briefly here. When LSMT appears to be burdensome or appears to not meet the goals of medicine yet the surrogate refuses the withholding or withdrawal of that treatment, several strategies are available. The most important is continued communication with honest assessments of the clinical situation, the goals of continued treatment, the inherent uncertainties and an appreciation of the difficult situation in which the surrogate or family finds itself. Time-limited trials of the discussed LSMT can be offered. Ethics consultation is available. Hospitals may have “futility policies” that can be applied. One state, Texas, has a futility statute.

In 1999, Texas adopted a wide-ranging law on advance directives. It is now codified as Chapter 166 of the Texas Health & Safety Code.<sup>9</sup> Health & Safety Code §166.046 applies when a physician refuses to honor a health care decision made by or on behalf of a patient. Subsection “e” specifically includes those situations in which the patient or the decision-maker requests life-sustaining treatment, which the physician has decided is inappropriate. Section 166.046 provides a multi-step process in these cases. First, the physician’s refusal is reviewed by an ethics or medical committee, of which the attending physician may not be a member. Life-sustaining treatment continues during the review.<sup>10</sup> The patient or surrogate is provided with a written description of the review process and of applicable policies and procedures of the health care facility.<sup>11</sup> The patient or surrogate is given at least a 48-hour notice of the committee meeting (which may be waived).<sup>12</sup> They are also provided with a specified written statement regarding the right to transfer to another facility and a list of health care providers and referral groups that have indicated willingness to consider accepting transfer or to assist in finding such a health care facility.<sup>13</sup> The patient or surrogate may attend the committee meeting and shall receive a written explanation of the decision the committee reaches.<sup>14</sup> If the physician, patient or surrogate does not accede to the

committee’s decision, there is a process for transferring the patient to another physician, another care setting within a health care facility or another health care facility.<sup>15</sup> Life-sustaining treatment must continue to be provided for 10 days after the written decision is delivered to the patient or surrogate.<sup>16</sup> The patient or surrogate may seek judicial intervention.<sup>17</sup> Before extending the 10-day period a court must find by a preponderance of the evidence (the usual burden of proof in civil matters) that if an extension is granted there is a “reasonable expectation” that a physician or health care facility which will accept the patient can be found.<sup>18</sup> In South Dakota, no such law exists at present; therefore, physicians must rely on hospital policies and ethics consultation for guidance and support.

At the end of life, pain, discomfort, shortness of breath and other symptoms are often present and can greatly diminish the dying person’s quality of life. The need for and practice of palliative care are growing within the country. Current practice encourages titrating doses of narcotics, such as morphine, to sufficient levels in order to alleviate pain. Many physicians remain concerned, however, that escalating doses of narcotics to treat these symptoms will cause the patient to die and, as a result, be considered murder, physician-assisted suicide or euthanasia. Certainly, death in these cases may be hastened. But within the ethics literature and in state law, using medicines appropriately to treat a symptom despite unintended but foreseeable side effects (e.g., respiratory depression) that may hasten death is both ethical and legal. The underlying presumption is that the treatment is offered to treat the symptoms, not to cause the death of the patient. This is often referred to as the Principle of Double Effect.<sup>19</sup> The relief of pain is a moral good, according to South Dakota statute:

Any licensed health care professional who administers, prescribes, or dispenses medications or procedures to relieve another person's pain or discomfort, even if the medication or procedure may hasten, or increase the risk of, death, does not violate § 22-16-37, unless the medications or procedures are knowingly administered, prescribed, or dispensed with a purpose to cause death. Any licensed health care professional who withholds or withdraws a life- sustaining procedure, in compliance with chapter 34-12D or in accordance with reasonable medical practice, does not violate § 22-16-37. (SDCL 34-12D-23)<sup>20</sup>

Thus, the hastening of death is not intended, but also not unexpected as a possible consequence. This is not to be mistaken as “killing” or euthanasia, where the intent is the

death of the patient. What about the concern that the patient will escalate his own medicine dose with the intent of death (suicide)? Although often considered unfavorable in traditional and religious thought, suicide itself is not illegal, and in one state, Oregon, physician-assisted suicide has been legalized. In South Dakota, however, SDCL 22-16-37 prohibits aiding or abetting suicide. When a physician prescribes pain-relieving medication that might cause death, prudence dictates thorough documentation of the prescription's purpose.

In summary, numerous ethical and legal challenges may arise in end-of-life situations. Help in determining appropriate surrogate decision-makers and the standards that those decision-makers should apply is available. The withholding and withdrawing of LSMT is supported in health law and in medical ethics, including the ethics codes from medical groups such as the AMA and the ACP.<sup>5,6</sup> Pain and symptom control is a necessity, and state statute and ethical principles should help alleviate physician fears of "causing death," addiction or abetting suicide. Debates about "futility" and how to respond to family or surrogate requests to continue life-prolonging medical treatment at the end of life continue. Until South Dakota has a statute as does Texas, the use of ethics consultation or ethics committees can be employed to resolve these, and indeed, many conflicts at the end of life.

## REFERENCES

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