

Legal Aspects of End-of-Life Care

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Critical care nurses are essential members of the health care team and often assist patients and patients' families who are facing end-of-life concerns. In that role, a nurse needs an understanding of many important factors, including legal implications associated with the end of life. Since the 1970s, courts have decided several cases that have established legal principles in end-of-life care. Courts have found that competent adults have the right to refuse or discontinue medical interventions. For incompetent adults and children, decisions are made by a surrogate. In the absence of an advance directive or documentation of goals of care, the surrogate, in collaboration with the medical team, determines a plan of care, including decisions about end-of-life care. When issues of medical futility occur, attempts to work with patients and their families should be undertaken, but if the dispute cannot be resolved, a transfer in care may be the only option. (*Critical Care Nurse*. 2011;31[5]:64-69)

As patients' advocates, critical care nurses often assist patients and patients' family members and significant others in facing end-of-life situations. According to estimates, approximately 20% of deaths in the United States occur in an intensive care unit,^{1,2} and the majority of those deaths occur after the withdrawal of life support.^{3,4} As key members of the health care team, critical care nurses are uniquely positioned to assist patients and patients' families in facing end-of-life concerns. In that role, a nurse needs an understanding of many important factors, including legal

implications associated with the end of life.

Most end-of-life dilemmas are resolved among the medical team, patients, and patients' families without the need for legal intervention.^{5(p3-9)} However, in the absence of consensus, or perhaps as a consequence of advances in medical technology, some of the difficult end-of-life questions have been brought to the courts for resolution. Some courts have provided a framework for deciding many difficult issues associated with the end of life. In this column, I provide information on the legal principles involved in end-of-life care, including limitations in treatment, assessing capacity and using surrogate decision makers, and medical futility.

Limitations in Treatment

Since the 1970s, both federal and state courts have decided a number of cases that have established a framework of important legal principles in end-of-life care. These cases provide important guidelines for when medical treatments and interventions may be limited or discontinued (see sidebars).

In 1976, the landmark Karen Ann Quinlan case established the right to refuse medical care, on the basis of the right to privacy. This right has been extended to incompetent patients, and can be exercised on their behalf by their legal guardian. The Quinlan court stressed that the decision to withdraw medical treatments can be made by clinicians, patients' families, and hospital ethics committees and does not require court involvement.⁷

A series of state court cases followed and led to considerable public debate.⁴ This case law, certainly influenced by public opinion, broadened the scope of the right to refuse medical care. Courts have established that life-sustaining treatments include not only mechanical ventilation (as in the Quinlan case) but also blood transfusions, dialysis, chemotherapy, artificial nutrition, and hydration.^{4,12}

At least in theory, a patient's right to refuse medical treatments has limitations. The state's interest in (1) preservation of life, (2) prevention of suicide, (3) protection of third parties such as children, and (4) preserving the integrity of the medical profession may supersede a patient's right to refuse a medical intervention.^{12,13(pp5-35-5-57)} However, in practice, these "state" interests almost never override the right of competent patients to refuse treatment and incompetent terminally ill patients to do the same so long as the latter have left explicit advance directives to do so.^{5(pp3-32-3-35)}

Assessing Capacity

A competent patient has the right to refuse or discontinue life-sustaining treatments, even if that desire conflicts with the desires of the patient's family.⁴ For mentally incapacitated patients who have living wills or other advance care documents, those wishes detailed in the document are enforceable and may be carried out on behalf of the now incompetent patient.

A more difficult situation involves patients with some cognitive impairment who have not made previous instructions for their care. In this situation, decision-making capacity is a clinical determination made by those authorized under state law to make the determination, generally physicians and psychologists and often advanced practice nurses.

The Right to Privacy: Karen Ann Quinlan

In 1975, 21-year-old Karen Ann Quinlan was brought to a hospital after an apparent drug overdose.⁶ Quinlan stopped breathing for at least two 15-minute periods.⁷ On initial evaluation in the emergency department, her pupils were nonreactive and she was nonresponsive to deep pain. Ms Quinlan was treated with mechanical ventilation. Attempts to wean her from the ventilatory support were unsuccessful. She received nutrition through a feeding tube. The court record⁷ described her as "emaciated, having suffered a weight loss of at least 40 pounds, and undergoing a continuing deteriorative process. Her posture is . . . fetal-like and grotesque; there is extreme flexion-rigidity of the arms, legs, and related muscles, and her joints are severely rigid and deformed." Medical staff thought that she was in a chronic and persistent vegetative state, with no treatment available to improve the condition. Her father then requested that mechanical ventilation be discontinued, but her physician refused, stating that Ms Quinlan did not meet criteria for brain death.

In 1976, after preliminary state court cases, the New Jersey Supreme Court⁷ found that if Ms Quinlan were to become "miraculously lucid for an interval . . . and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death." The court held that a person's right to discontinue medical care was a protected right of privacy and that Ms Quinlan's right of privacy could be asserted on her behalf by her father acting as her guardian. The court further stated that the physicians, hospital, or others would not incur civil or criminal liability for discontinuing mechanical ventilation if the clinicians believed Ms Quinlan to be in a vegetative state and if the hospital's ethics committee or a similar body concurred. Ms Quinlan's treatment with mechanical ventilation was stopped, and she died of pneumonia in 1985.⁶

Although no universally acceptable standard exists for assessing capacity, patients must have the ability to understand the information about the medical problem, evaluate options of treatment, and communicate choice.^{14,15} Capacity does not require a formal legal determination. However,

competence is determined by a judge, on the basis of whether a person has the legal right to make his or her own decisions. Of note, judicial determination of incompetence and appointment of a guardian are generally not required in most end-of-life situations.¹³

Critical care nurses are in an excellent position to assess and report a patient's ability to articulate wants and needs, make simple choices, follow directions, and communicate consistent preferences and goals of care.¹⁶ A nurse can assess a patient's understanding of treatment

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Substituted Judgment

Joseph Saikewicz was profoundly mentally retarded and had been institutionalized nearly his entire life.⁸ His IQ was 10; he had a mental age of 2 years 8 months. In April 1976, when he was 67 years old, acute myeloblastic leukemia was diagnosed. The superintendent of the facility petitioned the court for a guardian ad litem (a temporary guardian for the duration of the trial), who recommended that it would not be in Mr Saikewicz's interests to undergo chemotherapy, partly because the therapy would be painful for him and would offer a 50% chance, at best, of prolonging his life for another 6 months. In May 1976, a probate judge ordered that no chemotherapy be provided. In September 1976, Mr Saikewicz died of pneumonia.

However, his case was heard by the Supreme Court of Massachusetts to establish legal standards for life-prolonging treatments for persons not competent to make decisions.⁸ The Massachusetts Supreme Court ruled that the patient could refuse the necessary medical intervention. The court noted that were Saikewicz a competent and rational person who could view the entire medical situation to which he was subjected, he would reject treatment.

options, facilitate the patient's communication on those understandings and any resultant concerns, and help the patient identify participants in the decision-making process.

Surrogate Decision Makers

If a patient does not have the mental capacity to make medical decisions, a surrogate decision maker should be identified. If the patient had previously identified a surrogate in an advance directive document or proxy form, that surrogate has authority. However, surrogates are often not formally appointed, and relatives are used to make the end-of-life decisions. The order for relatives to be selected as decision maker varies by state, but generally, in order of priority, the decision maker is (1) the spouse, (2) an adult child or children, (3) a parent or parents, (4) an adult sibling or siblings, and (5) an adult relative or relatives.¹⁷ Some state statutes also provide for the

close friends of a patient's to serve as surrogate decision makers when no family member is available.^{5(p3-63)}

Although clear support exists for a patient's family to act as the surrogate decision maker when the patient is incapacitated, evidence indicates that spouses and other family members are not always aware of patients' preferences for life-support interventions. In a review¹⁸ of 16 studies, surrogates incorrectly predicted patients' end-of-life treatment goals in one-third of cases. In another study,¹⁹ even though patients thought both their family members (87%) and their physicians (90%) could accurately represent the patients' wishes, accuracy with the wishes ranged from 59% to 88%. Of note, few patients in the study¹⁹ had ever discussed their resuscitation preferences with either a family member (16%) or a physician (7%). These findings emphasize the need for patients and surrogates

to discuss preferences before the patients lose decision-making capacity. Critical care nurses are often in the position to initiate and facilitate this conversation.

Methods for Decision Making

For patients who are mentally incapacitated and did not complete an advance directive or appoint a proxy, courts generally use 1 of 2 criteria to resolve end-of-life dilemmas.

Some courts advocate the substituted judgment standard. With this standard, a proxy tries to determine what a patient would have wanted in the situation if the patient were competent to make the decision.²⁰ The proxy should "ascertain the incompetent person's actual interests and preferences" in making a decision.²¹ The surrogate infers what the patient would choose, often on the basis of previous statements and patterns of decisions making.¹⁶

Under the second criterion, the best interests standard, the surrogate evaluates proposed treatments by assessing their benefits and risks. The surrogate then selects those treatments in which the benefits outweigh the burdens of the treatment.²² This standard is considered an objective standard because it does not rely on imagining what the patient would choose, but rather on weighing benefits and burdens of a proposed intervention or treatment. Although this standard is deemed an objective standard, deciding the benefits and burdens of treatments introduces a surrogate's own values.²³

Critical care nurses can assist surrogates by using the substituted judgment standard to frame issues.

Questions such as What did do you think he would do in this situation? or What has he done in the past? can help decision makers focus on the pivotal issues to be decided. When a patient's wishes are not known or inferable, the best interests standard can be used to frame the questions, asking the surrogate to describe the situation in terms of benefits and burdens and articulate what the patient would be likely to accept on balance.

Further, nurses can help focus the critical care team to come to an agreement about the best plan of care and can assist in communicating that plan to the decision maker. A nurse is often in the best position to understand a surrogate's learning style and level of receptivity to the information. When discussing the situation with a patient's family, a helpful strategy is to acknowledge the difficult nature of the situation and help the surrogate distinguish the patient's interests from the interests of the surrogate and/or family members. No single approach guarantees a desirable outcome, and clinicians will continue to face difficult situations.

Medical Futility

Treatment with no apparent benefit to a patient is generally considered futile.²⁴ Disputes may arise when patients or surrogates demand futile interventions be provided when the medical professionals do not think the interventions would be appropriate. These disagreements often stem from a failure of communication or differences of goals. Although rare,²⁵ unequivocal medical futility is markedly stressful for those involved. One suggested approach²⁶

End of Life and the Supreme Court

One night in 1983, Nancy Cruzan lost control of the vehicle she was driving.⁹ The car overturned, and she was found in a ditch without apparent cardiac or respiratory function. Paramedics were able to restore her respirations and pulse at the scene, but she remained unconscious. It was estimated that Ms. Cruzan was deprived of oxygen for 12 to 14 minutes, and later probable cerebral contusions compounded by marked anoxia were diagnosed.

A gastrostomy tube was placed for nutrition and hydration. However, when it became apparent that Ms Cruzan would not recover her mental faculties, her parents sought to have the gastrostomy tube removed. The medical staff refused without court approval. The parents sought and received authorization from the state court to terminate artificial nutrition and hydration. The court agreed, finding that a person in Ms Cruzan's position "had a fundamental right under State and Federal Constitutions to refuse or direct the withdrawal of death prolonging procedures."⁹ The state court had found that Ms Cruzan had previously expressed that "she would not wish to continue her life unless she could live at least halfway normal," and the court thought that continuing artificial nutrition would be against that wish. The Missouri Supreme Court reversed the decision, finding that the state had a legitimate interest in preserving life regardless of its quality, and that life-sustaining treatment could be removed only if "clear and convincing evidence" confirmed that Ms Cruzan rejected such treatment.^{9(p261)}

Ms Cruzan's family appealed the decision to the United States Supreme Court. The Court held that "we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."⁹ Unlike the Quinlan court, whose judges based the decision on a right to privacy, the Cruzan court based this right on the liberty interest delineated in the Fourteenth Amendment. The Constitution does not prevent a state from applying the "clear and convincing" standard to the wishes of an incompetent person regarding the removal of life-sustaining treatments, as Missouri did. Ms Cruzan's parents presented additional evidence on her prior wishes. The gastrostomy tube was removed, and Ms Cruzan died soon thereafter.

to dealing with cases of medical futility includes the following:

- Make earnest attempts to negotiate an understanding between the patient, surrogate, and clinicians as to what constitutes futile care in advance of actual conflict.
- To the maximum extent possible, use joint decision making

between patient or surrogate and clinicians.

- Negotiate disagreements as they arise to reach a resolution satisfactory to all parties; use consultations when needed.
- Involve an institutional committee such as the ethics committee when disagreements cannot be resolved.

The Great Debate: Terri Schiavo

The most recent case to stir national debate on termination of interventions was that of Terri Schiavo. In 1999, Ms Schiavo was 27 years old when she had a cardiac arrest, thought to be associated with a potassium imbalance.¹⁰ She subsequently was found to be in a persistent vegetative state and required hydration and nutrition administered through a gastrostomy tube. Eight years later, her husband sought to discontinue the feeding tube, but Ms Schiavo's parents objected. When the case was brought to court, a judge found clear and convincing evidence that Ms Schiavo was in a persistent vegetative state and that if she could make her own decision, she would choose to discontinue life-prolonging procedures. An appeals court affirmed the judge's decision, and the Florida Supreme Court chose not to review the case.

However, Ms Schiavo's parents tried several times to bring the case to the courts, claiming they had found new evidence, including testimony from physicians that their daughter was not in a persistent vegetative state or that new treatments might restore her cognitive functioning. The courts were unpersuaded and ruled against Ms Schiavo's parents on each occasion, and the Florida Supreme Court repeatedly refused to hear the case. Both Florida and national politicians attempted to promulgate laws directed at Ms Schiavo's situation alone. These efforts also were unsuccessful. Ms Schiavo's gastrostomy tube was discontinued, and she died in March 2005, a total of 7 years after the legal battles began and 15 years after her cardiac arrest.¹¹

Although no new law was developed from the Schiavo case, existing understandings were affirmed. The right of incompetent individuals, like competent individuals, to receive or discontinue medical treatments was confirmed. In addition, like dialysis, mechanical ventilation, and chemotherapy, artificial nutrition and hydration are deemed medical interventions and can be withdrawn or withheld to allow the person to die.⁴

- If an institutional review supports the patient's position and the attending physician remains unpersuaded, transfer of care to another physician within the institution may be arranged.

- If an institutional review supports the physician's position and

the patient or surrogate remains unpersuaded, transfer to another institution may be sought.

- If a patient cannot be transferred, the intervention need not be offered.

The American Nurses Association Code of Ethics for Nurses²⁷ does not specifically address medical futility, but it does acknowledge that conflicts can arise in health care decisions, including instances of conflicting expectations of patients, patients' families, physicians, and colleagues:

Nurses strive to resolve such conflicts in ways that ensure patient safety, guard the patient's best interests, and preserve the professional integrity of the nurse.²⁷

Conclusion

As medical technology continues to advance, critical care nurses will remain at the forefront of the health care team, working with patients and patients' families to deliver high-quality care. As part of the continuum of care, end-of-life care is an essential component of a critical care nurse's skill set and should include a basic knowledge of legal aspects.

Courts have clearly stated that competent adults have the right to refuse or discontinue medical interventions. Patients who are incompetent, either because of cognitive impairment or immaturity, may have decisions made by a surrogate. In the absence of an advance directive or documentation of goals of care, the surrogate, in collaboration with the medical team, may determine a plan of care, by using either the substituted judgment standard or the best interests standard. When issues of medical futility arise, earnest attempts to work with patients and their families should be undertaken, with special emphasis on clear communications. However, when disputes continue, transfer of a patient out of a physician's service or to another facility may be the only reasonable solution. **CCN**

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To learn more about end-of-life care, read "Nurses' Perceptions of End-of-Life Care After Multiple Interventions for Improvement" by Hansen et al in the *American Journal of Critical Care*, 2009;18:263-271. Available at www.ajconline.org.

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Financial Disclosures
None reported.

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