

Critical Care Perspective

Legal Aspects of Withholding and Withdrawing Life Support from Critically Ill Patients in the United States and Providing Palliative Care to Them

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Studies (1–3) have demonstrated that most patients who die in intensive care units (ICUs) in the United States do so during the withholding and withdrawal of life support and the administration of palliative care. Withholding and withdrawal of life support is a process through which various medical interventions are either not given to patients or removed from them with the expectation that the patients will die from their underlying illnesses. Palliative care is the prevention or treatment of pain, dyspnea, and other kinds of suffering in terminally ill patients. These closely related practices are supported by the ethical principles of autonomy, beneficence, and nonmaleficence, as discussed in this (4) and other (5) publications. Physicians and other health professionals may be familiar with these principles, but they may not understand the laws that govern withholding and withdrawing life support and providing palliative care or how to satisfy legal requirements in their practices. This article has been written to increase such understanding.

LEGAL ASPECTS OF WITHHOLDING AND WITHDRAWING LIFE SUPPORT

In the United States, the withholding and withdrawal of life support is legally justified primarily by the principles of informed consent and informed refusal, both of which have strong roots in the common law. The principles hold that treatment may not be initiated without the approval of patients or their surrogates excepting in emergency situations, and that patients or surrogates may refuse any or all therapies. The application of these principles to the care of the critically ill began in the *Quinlan* case (6), in which the New Jersey Supreme Court held that a patient had the right to refuse mechanical ventilation, and that, because she was vegetative and could not exercise that right directly, her parents could act as surrogates for her. The California Court of Appeals took a similar approach in the *Barber* case (7), in which it held that physicians charged with murder had not committed an unlawful act when, with permission from a patient's family, they removed nutrition and hydration from a comatose patient.

Although the principles presented in *Quinlan* and *Barber* are widely accepted, statutory and case law regarding the limitations of life-sustaining treatment vary from state to state. The issue of withholding and withdrawal of life support was first addressed by the U.S. Supreme Court in the *Cruzan* (8) case, which involved a parental request to have a feeding tube removed from their vegetative daughter. The Cruzans lived in Missouri, which required specific evidence that an incompetent patient would want treatment withdrawn. In its decision,

the Court allowed Missouri and other states to require “clear and convincing evidence” of patients' wishes and thereby potentially limited the role of surrogates in making decisions for incompetent patients without advance directives. Nevertheless, the Court accepted the principle that a competent person's right to forgo treatment, including nutrition and hydration, is a liberty interest protected under the Fourteenth Amendment to the Constitution.

Although the Supreme Court approved the withholding and withdrawal of life support under the principle of informed refusal, it did not address the concept of futility in *Cruzan*. Futility is difficult to quantify, notwithstanding the efforts of Scheiderman and colleagues (9), among others, to do so. The concept also may mean different things to physicians than it does to patients and their surrogates. Nevertheless, physicians frequently cite futility in recommending that life-sustaining therapy be foregone (1, 2). Furthermore, in response to a survey conducted by Asch and colleagues (10), some physicians have acknowledged that they have unilaterally withheld or withdrawn life support they considered futile without informing patients or their surrogates or despite their objections.

The history of legal cases involving futility has been that courts have almost uniformly ordered continued treatment when asked to resolve disputes between families who favor treatment and physicians who oppose it (11). Judges also seem unwilling to cause the death of a patient, as was seen in the case of Baby K (12), when the court was asked to approve in advance a physician decision to withhold life-sustaining treatment and refused to do so. However, judges and juries seem equally reluctant to punish physicians who act carefully and within professional standards (4) in refusing to provide treatment they consider inappropriate. In this regard, the only clear legal rule on futile or nonbeneficial treatment is the traditional malpractice test, which measures a physician's treatment decisions against the appropriate standard of medical care and then requires that any standard care cause the patient injury. The issue of malpractice was raised in the *Gilgunn* case (13), in which a Massachusetts jury imposed no liability on a hospital or the physicians practicing there after they removed the ventilator from a patient over the objections of one of her daughters. *Gilgunn* conforms to a trend in futility cases in which physicians are likely to get better legal results when they refuse to provide nonbeneficial treatment and then defend their decisions as consistent with professional standards than when they seek advance permission to withhold care.

Despite the outcome of *Gilgunn* and the trend it represents, we recommend that physicians reject unilateral action. Such actions certainly may be considered ethically appropriate if they support professional integrity, the obligation of each physician to define the moral practice of medicine. Nevertheless, autonomy remains the first ethical principle for removing life-sustaining treatment, even though most critically ill patients must exercise their autonomy through surrogates

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because they cannot make medical decisions themselves. Ethics here reflects law because informed consent and informed refusal are the primary legal principles that justify this practice. Unilateral action also can be risky: disagreements between families and physicians can increase the potential for legal action, and even an unsuccessful lawsuit imposes significant burdens. Finally, negotiation almost always works to resolve even the most contentious disputes (1, 2).

LEGAL ASPECTS OF PROVIDING PALLIATIVE CARE

After *Cruzan*, the Supreme Court confirmed its approval of the foregoing of life-sustaining treatment in *Glucksberg* (14) and *Vacco* (15) and also provided guidelines for administering palliative care. These last two cases dealt with the constitutionality of laws prohibiting physician-assisted suicide in the states of Washington and New York. In *Glucksberg*, the Court affirmed the right of competent patients to refuse therapy as articulated in *Cruzan*. The Court also decided that terminally ill patients did not have a liberty interest in committing suicide or in receiving a physician's assistance in committing suicide, because of both the long tradition of prohibiting suicide in the United States and the state's legitimate reasons for continuing to make assisted suicide illegal. In *Vacco*, the Court drew further distinctions between assisted suicide and withholding and withdrawal of life support. "Everyone, regardless of physical condition, is entitled, if competent, to refuse lifesaving medical treatment; no one is permitted to assist a suicide," the Court wrote. "When a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication."

In *Glucksberg* and *Vacco*, five justices of the Supreme Court reasoned in concurring opinions that Washington and New York could prohibit assisted suicide because these states had no legal barriers to prevent patients from obtaining medications to relieve pain and suffering and therefore had no need for assisted suicide. However, as Justice Breyer wrote in his opinion concurring in the judgment in the two cases, "Were state law to prevent the provision of palliative care, including the administration of drugs as needed to avoid pain at the end of life, an action against such law might be called for by the Supreme Court." Through this and other statements, a majority of Supreme Court justices indicated that the Constitution's guarantee of individual liberty included the liberty to receive adequate pain relief during the dying process (16). Burt (17) has interpreted these separate opinions as indicating a willingness on the part of a majority of the justices to mandate patient access to palliative care.

The Supreme Court distinguished assisted suicide from palliative care in *Glucksberg* and *Vacco* by accepting the principle of double effect. As described by Quill and associates (18), this rule distinguishes between intended and unforeseen effects or consequences. Under it, acts such as the giving of sedatives and analgesics that lead to morally good effects, such as the relief of pain, are permissible even if they produce morally bad effects, such as the hastening of death, provided that only the good effect is intended. The morally bad effect may be foreseen, but it may not be intended. The bad effect also may not be a means to the good effect, and the good effect must outweigh the bad one; that is, risking death is reasonable in palliating a terminally ill patient only if there are no less risky ways of relieving suffering.

The Court's approval of palliative care included sanctioning the practice of terminal sedation, in which patients are rendered comatose and then may have nutrition and hydration

withdrawn. The term "terminal sedation" appears only in a footnote in the *Quill* majority opinion. However, Justice O'Connor wrote favorably of "relieving pain even to the point of unconsciousness," and Justice Breyer noted the "need for sedation which can end in coma." Orentlicher (19) has equated terminal sedation with euthanasia because the withdrawal of food and water "does nothing to relieve the patient's suffering but only serves to bring about the patient's death." Nevertheless, under *Quill*, a state may allow terminal sedation if it is "based on informed consent and the double effect. Just as a state may prohibit assisting suicide while permitting patients to refuse unwanted lifesaving treatment, it may permit palliative care related to that refusal, which may have the foreseen but unintended double 'effect' of hastening the patient's death."

Quill and associates (18) have argued that terminal sedation does not conform with the rule of double effect because "life-prolonging therapies are withdrawn with the intent of hastening death." However, terminal sedation may be compatible with the rule of double effect if the physicians intend only to relieve pain and suffering and to honor patients' informed refusal, assuming that the patients or their surrogates regard nutrition and hydration as unwanted therapies. Nevertheless, physicians, patients, and surrogates alike may also wish to hasten death in such circumstances, and Quill and colleagues are correct in noting that human intention is complex. Such complexity was demonstrated in a study performed by Wilson and associates (20) of the administration of sedatives and analgesics during the withholding and withdrawal of life support, in which physicians indicated that they ordered drugs to hasten death, albeit primarily to decrease pain, anxiety, and dyspnea, in 39% of critically ill patients. Similarly, in a survey conducted by Asch (21), 16% of a sample of critical care nurses reported that they had engaged in assisted suicide or euthanasia while trying to relieve suffering, often without physician's knowledge.

Just as some physicians and nurses have mixed motives in caring for dying patients, so do some family members want to ease pain and hasten death simultaneously when their loved ones are suffering. That such motivation is widespread presumably accounts for the fact that few physicians who are suspected of participating in assisted suicide or euthanasia have been punished through the criminal justice system. Alpers (22) recently reviewed legal databases to identify health professionals who had allegedly given patients lethal doses of medications and whose cases were discussed through public media, criminal indictment proceedings, or trials since the *Cruzan* decision in 1990. Alpers found that at least 13 physicians (not including Dr. Jack Kervorkian) have been criminally investigated but not formally indicted or prosecuted. Four physicians have been tried for murder in connection with the treatment of dying patients, and two more have been charged with or indicted for murder; of the four tried so far, one was acquitted, one's conviction was overturned on appeal, one was convicted and his appeal is pending, and one's trial resulted in a hung jury. During the same period, two nurses have been investigated; the trial of one is underway. Overall, cases of suspected assisted suicide or euthanasia are difficult to prosecute successfully if credible expert testimony supports the practitioner's actions or the patient and family consented to palliative care.

Although the court found no constitutional right to physician-assisted suicide in *Glucksberg* and *Vacco*, it, nevertheless, allowed the states to legalize this practice. Currently, the state of Oregon permits physicians to prescribe doses of controlled substances to terminally ill patients. Experience in that state

so far suggests that physician-assisted suicide is not widespread, that the practice does not occur in ICUs, and that patients most commonly request prescriptions for potentially lethal medications because of concern about loss of autonomy and not because of uncontrollable pain (23). Nevertheless, Congress has drafted legislation, entitled the Pain Relief Promotion Act of 1999, "to amend the Controlled Substances Act to promote pain management and palliative care without permitting assisted suicide and euthanasia, and for other purposes" (24). As noted by Angell (25), the bill allows physicians to give sedatives and analgesics to dying patients even if the risk of death may be increased, but it forbids "intentional dispensing, distributing, or administering a controlled substances for the purpose of causing death or assisting another person in causing death." Thus, in keeping with the *Glucksberg* and *Vacco* decisions, the bill bases the propriety of physicians' acts not on the consequences of these acts but on the nature of the physician's intentions.

SATISFYING LEGAL REQUIREMENTS

The future of the Pain Relief Promotion Act remains unclear at this writing, and even if Congress passes the bill and the president signs it, the bill is likely to be challenged by Oregon on the grounds that it interferes with state's rights. Regardless of the future of the act, however, physicians who care for critically ill patients should appreciate that its sentiments are shared by many lawmakers, and that the bill has been supported by the American Medical Association. Given such support and the position of the Supreme Court, how should physicians and other practitioners properly withhold and withdraw life support and provide palliative care to the critically ill? In other words, what actions by physicians manifest an intent to relieve suffering but not to hasten death?

First, because the foregoing of life-sustaining therapy is only legally justified if such support represents unwanted treatment, it should be withheld or withdrawn only with the consent of patients or their surrogates, assuming surrogates are available. Physicians may base their recommendations to limit treatment on futility, but this concept should not be invoked to remove support without patients' or surrogates' knowledge or over their objections. Furthermore, even if they practice in hospitals that have developed futility policies, physicians should recognize that such policies serve primarily as vehicles for reinforcing joint decision-making between health professionals and patients and their surrogates, not as devices for enforcing decisions made by physicians unilaterally (26). Finally, physicians may forego life-sustaining treatment for patients who cannot make decisions and lack surrogates, but they should base their actions, as formal surrogates should, on their best understanding of what the patients themselves would want done. In the absence of such understanding, physicians may act on what they believe to be the patients' best interests.

Second, because the withholding and withdrawal of life support and the administration of palliative care usually involve other practitioners in addition to the attending physician, all involved parties should participate in planning how such care is realized. Alpers's legal research on criminal prosecutions cited earlier shows that disagreement among professional caregivers about the goal of care can increase the risk of liability. Ideally, all involved practitioners can agree to deliver the maximum of comfort with a minimum of invasive interventions. Then the patient or family can be approached for their input and approval.

Third, because the goal of palliative care is to provide comfort, measures that do not relieve suffering but merely hasten

death should be avoided. Although most patients die within 24 h after life support is withheld or withdrawn, the dying process may last for several days (20, 27). Whatever time is required for death to occur, the palliative measures undertaken and their tempo should be dictated by objective manifestations of patient distress whenever possible. For example, physicians should order sedatives and analgesics for patients who can benefit from these agents, but not in doses that suggest they are given primarily to cause death. Instead, the drug dosages should be titrated upward or downward in response to physiological manifestations of pain and discomfort, such as grimacing or hypertension, and ideally according to written protocols. Truog and colleagues (28) have recommended that neuromuscular blocking agents, which could prevent spontaneous breathing, should not be introduced when the ventilator is withdrawn and that, in patients already receiving these agents, neuromuscular function should be restored unless death is expected to be rapid after ventilator removal and waiting for the neuromuscular blockade to wear off would burden the patient. Similarly, injections of potassium chloride have no place during the withholding and withdrawal of life support because they do not contribute to patient comfort and suggest an intention of hastening death.

Finally, because intent can be conveyed in words as well as through actions, the goal of palliative care and the means of achieving that goal should be spelled out in the record. In their notes, physicians should document how decisions were made to forego life-sustaining treatment and how the process of achieving patient comfort was conducted. Orders for sedatives and analgesics should be written in such a way that they provide proper dosage boundaries while also allowing nurses to use some discretion in giving the drugs so that patient comfort can be facilitated. In their notes, nurses should also describe how the goal of palliative care was decided on and what steps they took to achieve it, including an indication of all sedatives and analgesics they have administered. Chart notes reflecting the goal of palliative care make physicians' and nurses' ethical and perhaps legal obligation to relieve suffering a part of any attempt to evaluate care retrospectively, as might occur in a criminal or civil trial.

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