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## The Right to Forego Life-Sustaining Treatment: Legal Trends and Emerging Issues

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# THE RIGHT TO FOREGO LIFE-SUSTAINING TREATMENT: LEGAL TRENDS AND EMERGING ISSUES

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"From the day they enter medical school, physicians are taught to cherish and preserve life. However, there comes a time with the terminally ill or irreversible comotose patient that the physician must step back and, at the patient's or the family's request, allow the patient to die with dignity." [1]

In 1988 more than three out of four physicians surveyed favored "withdrawing life support systems, including food and water, from hopelessly ill or irreversibly comotose patients if they or their families request it." [2] Over 90% believed that physicians should initiate discussions with patients and their families on the use of withdrawal of life-sustaining treatment. Yet more than half of these physicians were either uncertain or unsure of the legal risks and responsibilities surrounding decisions to withdraw life-sustaining treatment.

The "right-to-die" movement has come a long way since the *Quinlan* [3] case captured our attention just a decade ago. At that time, both the public and the medical establishment waited anxiously as the court ruled in a case previously reserved to whispering in hospital corridors and discussions among medical ethicists. During the same year, California enacted the first Natural Death Act, granting statutory recognition to the "living will." [4]

In the last twelve years, the courts and the state legislatures, together with health care professionals, hospitals, medical ethicists, legal scholars, and the public have continued to

address the legal and ethical issues raised by foregoing life-sustaining treatment. Progress has been made in opening up debate and reaching consensus on many of the issues. Clear legal trends have emerged, yet questions still remain.

This article will first discuss the legal and ethical foundations that support the right to forego life-sustaining treatment. This right will then be applied to the competent patient. The greater challenge for the law, which will then be analyzed, is how to preserve such a right for the incompetent patient. [5] The article will conclude by highlighting unresolved issues and new questions for further debate.

#### *THE RIGHT TO FOREGO TREATMENT: FOUNDATIONS*

It is now widely accepted by both the medical and legal community—as well as the public at large—that there exists a right to forego treatment. Both the common law right to self-determination and bodily integrity and the constitutional right to privacy provide the legal foundation for this right.

“No right is held more sacred or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraints or interference by others, unless by clear and unquestionable authority of law.” [6] This common law right is recognized in both criminal and tort law. A bodily invasion without consent constitutes a battery or trespass. Beginning in the 1960s, the courts expanded their recognition of self-determination in the medical context to the development of the doctrine of informed consent. This tort doctrine provides that the health care provider has a duty to inform the patient of alternatives and risks to treatment prior to obtaining valid consent. Informed consent has evolved to where the right not to consent—or forego treatment—has been incorporated into the doctrine. Otherwise, the right to self-determination would not be fully realized.

As the law of informed consent evolved, the New Jersey Supreme Court in the *Quinlan* [7] case established another legal source for upholding the right to forego life-sustaining treatment: the constitutional right to privacy. Although the constitution does not explicitly mention a right to privacy, the

*Quinlan* court reasoned that, if the U.S. Supreme Court recognized such a right to protect the individual from state action which would limit such personal choices as contraception and a woman's decision to terminate pregnancy under certain conditions [8], the right to privacy would also be broad enough to encompass a patient's decision to decline medical treatment. [9] The *Quinlan* court determined that a patient in a persistent vegetative state, with no reasonable chance of recovery, had the right to have the respirator sustaining her life withdrawn. Since she was incompetent to express her wishes, her guardian and family would act on her behalf to exercise her right to forego further life-sustaining treatment.

The court did recognize that the right was not absolute and would have to be balanced against the claimed interests of the state in the "preservation of life and defense of the right of the physician to administer medical care according to his best judgment." [10] As more state courts faced such cases, four state interests emerged: (1) the preservation of life; (2) the prevention of suicide; (3) protection of minor children; and (4) protection of the ethical integrity of the medical profession. [11]

The most important state interest, at least in theory, is the preservation of life. In practice, it is now clear that this interest would not outweigh the right of a patient to refuse life-sustaining treatment. Suicide prevention is generally not an issue in right to die cases because the patient does not inflict the illness deliberately on himself. If the patient has no minor children or the family consents, the third interest is usually not at issue. Finally, the ethical standards of the medical profession have evolved since *Quinlan* to a point where the profession supports the right of the patient to refuse treatment.

The United States Supreme Court has yet to hear a case involving the right to forego treatment but, as noted above, the New Jersey court's interpretation of the constitutional right to privacy should extend to recognition of such a right. [12] In the meantime, the right has evolved in most states and federal courts to a point where it is protected by both the common law and the constitutional right to privacy. Both of these legal sources provide the legal foundation for promoting the values of self-determination, bodily integrity, and personal autonomy in

medical decision-making.

To a large extent, the development of law in this area has been influenced by the evolution of medical ethics. In the early 1980s, an influential series of reports were released by the President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, including one entitled "Deciding to Forego Life-Sustaining Treatment." [13] It became clear from the report and the judicial decisions that followed that there was no clear ethical nor legal distinction in this area between withholding and withdrawing life-sustaining treatment. The right to *forego* treatment would include both the withdrawing and withholding of treatment.

Physicians and health care institutions believed—and many still do—that the act of withdrawing a respirator or removing a feeding tube is an affirmative act that hastens death. [14] Once such treatment is initiated, it must be continued, regardless of its value to the patient. On the other hand, the withholding of such treatment is ethically and legally permissible.

In fact, it is often more difficult to know how a patient will respond to a treatment without a time-limited trial. This is particularly true for the emergency patient. Accordingly, it may be contrary to medical standards to avoid placing a patient on a respirator or inserting a feeding tube merely because of the incorrect belief that such procedures could not be terminated. As the New Jersey court noted in the *Conroy* case [15], such a distinction could in fact discourage families and physicians from even attempting certain types of care and thereby force them into hasty and premature decisions to allow a patient to die. To date, only the State of Ohio has suggested that different procedures are required for withdrawing and withholding treatment and only the Mississippi living will statute authorizes withdrawal of treatment explicitly, but nowhere expressly provides for withholding treatment. [16]

For the competent patient, it should be relatively easy to exercise the right to have treatment withheld or withdrawn. The patient decides and communicates his decision to the health care provider. For the patient without such capacity, the exercise of such a right is more problematic. It is the application of the right for the competent patient that will now be

addressed.

### THE COMPETENT PATIENT

All patients are presumed to be competent. Legally, only a court has the authority to declare a person "incompetent." In practice, a patient is competent or, more correctly, has the capacity to make treatment decisions when he can understand the relevant information, reflect on it according with his values and goals, and communicate with caregivers. [17] Most often this determination is not a problem. If the patient is unconscious or severely retarded, for example, he is clearly incapable of making a decision. The problem becomes more difficult when fear, mental illness or physical illness cloud the patient's judgment. In practice, if a patient is incapacitated by a condition that is temporary (*i.e.*, severe pain, intoxication, withdrawal) any determination on competency and treatment decisions should be postponed, if at all possible.

Very few cases deal with defining capacity to consent to or refuse treatment, although most states have procedures for a court to make a finding of legal competency. Generally, the courts are wary about second-guessing the choice of a patient. Even if a patient's refusal to be treated seems irrational to the physician, this does not mean that the patient is incompetent. A patient may be depressed, have periods of confusion and a distorted sense of time but, if capable of understanding the consequences of the decision to refuse treatment, the court will not declare the patient incompetent. [18] A diagnosed mental illness or even commitment to a mental institution, *per se*, does not mean that a patient is not competent to refuse treatment if he understands the consequences of the decision. [19] Although the reasonableness of the decision to refuse treatment is not the standard for competency, in practice the nature of the treatment and the prognosis may influence whether the health care provider takes the issue to court and whether the court deems the patient incompetent. [20]

In most cases, the determination of competency is not at issue and a number of recent court decisions have affirmed the patient's right to refuse treatment regardless of prognosis. [21]

Consistent with the value underlying informed consent, the health care provider is to honor the refusal of the patient. The California court held that an incurable, but not terminally ill patient, had a right to withdraw from a respirator even if such action would hasten his death. To do otherwise would be to frustrate the very essence of the right of informed consent and the constitutional right to privacy. [22] In the much-publicized *Bouvia* case [23], the same court held that a quadriplegic, who was not terminally ill, had the right to order the withdrawal of a nasogastric feeding tube even if such action would hasten or cause her death. The court determined that such a decision was neither medical nor legal, but hers alone to make. Most recently the New Jersey Supreme Court declared that a competent woman, with an incurable neurological disease but in which death was not imminent, had the right to have a respirator removed at home. [24] The court recognized that her life was filled with pain and that it would be unfair and unjust to force her to live any longer.

#### *THE INCOMPETENT PATIENT*

Most of the "right-to-die" cases in the last decade have not involved a competent patient. Not surprisingly the doctrine of informed consent has protected the right of the competent patient to refuse treatment and this has been accepted by both the medical and legal communities. The challenge has been in defining the parameters of the right of the patient incapable of making his own treatment decisions. Although state courts decide each case on a unique set of facts and state laws vary, certain trends do emerge on the two major issues at stake: (1) what decision-making criteria should be applied when exercising the right of the incompetent patient to forego life-sustaining treatment? and (2) who should be making such decisions?

#### *Decision-making Criteria*

At this point it is appropriate to return to the case of Karen Quinlan, a young adult in a persistent vegetative state. In 1975 her father first petitioned a New Jersey court to be appointed

her guardian for permission to withdraw her from a respirator. No request was made to remove her feeding tube. Her attending physicians and the hospital would not remove the respirator because they deemed it contrary to medical, ethical, and legal standards. They feared the potential of both criminal and civil liability.

Ultimately, the New Jersey Supreme Court decided that Karen, if competent, could have exercised her constitutional right of privacy to refuse what appeared at the time to be life-sustaining treatment. [25] This right which outweighed any state interest would be lost if it could not be exercised by another on her behalf. The court set out the following balancing test: "the state interests *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims." [26] Her treatment was sufficiently invasive and her condition and prognosis sufficiently dim as to allow life-sustaining treatment to be terminated. If Karen's guardian, family, and attending physicians concurred and an "ethics committee" [27] confirmed no reasonable possibility that she might recover to a sapient state, the respirator could be withdrawn and all parties would be immune from civil and criminal liability.

Since the *Quinlan* case, most state courts have considered cases involving vegetative state. A few cases have involved the chronically ill who may lack decision-making capacity because of senility but are not facing life-threatening conditions and are not unconscious. [28] A few more cases have dealt with the mentally retarded or the "never competent" patient. [29] From these cases have emerged decision-making criteria for the termination of treatment for the incompetent patient.

Decision-making criteria set standards for determining what the incompetent patient would have decided if capable of communicating his own decision. This is commonly referred to as "substituted judgment," an approach adopted by most of the jurisdictions that have addressed the issue. Such an approach requires the surrogate decision-maker to act in accordance with explicit directives, values, and preferences of the patient. Although this may be a difficult task, most jurisdictions cling to this approach as the best way to preserve the right to self-



determination for the incompetent patient.

Courts attach great significance to evidence of prior wishes of the patient while competent. The best evidence of a patient's wishes is the signing of an advanced directive in which the patient, while competent, expresses his wishes with respect to life-sustaining treatment if he becomes incompetent. Thirty-eight states and the District of Columbia have now enacted natural death, living will or death-with-dignity statutes that grant statutory recognition to such advanced directives. Even in those states without such statutes, the courts have viewed the existence of such a directive as strong evidence of the patient's wishes.

Typically, living will statutes provide for refusing life-sustaining treatment when the patient's condition becomes "terminal" and/or death is "imminent." Statutes take varied approaches to defining what constitutes "life-sustaining" treatment. Some statutes specifically include artificial feeding and hydration and others specifically omit such procedures. All statutes provide for detailed procedures for executing the advanced directive and many include a model form to be filled out by the person when competent. Perhaps, most significantly, all statutes provide immunity for health care providers who act in good faith to comply with a properly executed living will. [30]

The enactment of a living will statute may be more symbolic than either necessary or effective in guaranteeing the right to refuse treatment to the incompetent patient. As noted above, it does not cover the patient in a persistent vegetative state such as Karen Quinlan. Furthermore, many of the statutes are ambiguous in their language about which "life-sustaining" treatments may be withheld or withdrawn—most notably artificial food and hydration and antibiotics.

On a positive note, they do codify the state's recognition—with or without a state court ruling—of the right of the patient to terminate treatment over the state's interest in preserving life. Immunity for health care providers from civil and criminal liability should also encourage more dialogue between patients and providers over long-term treatment plans. [31]

In any case, the living will does not represent the exclusive vehicle for exercising the right to forego treatment. Another

statutory alternative gaining much popularity is the Durable Power of Attorney (DPA). All states and the District of Columbia have statutes which enable a competent person to appoint a proxy decision-maker when the individual is no longer competent to make decisions. Most of these statutes were not passed to deal specifically with medical decision-making but rather with financial matters. Yet, in a recent case, the New Jersey Supreme Court affirmed the right of a proxy, appointed while a persistent vegetative patient was still competent, to act on her behalf to have the nursing home provider remove her nasogastric feeding tube. [32]

A number of states have recently amended their general DPA statutes or passed new statutes which specifically provide for a proxy to make medical decisions. Any competent person may appoint a proxy to act on his behalf once he is declared incapable of making his medical decisions. A proxy may have the power to: provide, withhold or withdraw consent to specific medical procedures, including CPR, antibiotics, artificial feeding and hydration, and blood transfusions; interpret a living will and resort to courts, if necessary, to obtain court authorization regarding treatment decisions or to request civil damages for not honoring the proxy's decision. [33]

Since most patients do not leave explicit instructions nor execute advanced directives [34], the next best evidence available may consist of conversations with family, friends, and physicians. A patient's personal beliefs, values, religious principles, and even consistent attitudes about past medical care may be of some relevance when attempting to evaluate how the patient would weigh the benefits and burdens of life-sustaining treatment.

If there is no reliable evidence, the surrogate may apply the "best interests" test. This is the traditional guardianship standard in which the surrogate objectively weighs the benefits and burdens of treatment to determine how a reasonable person in the patient's circumstances would promote his well-being. [35] Under no circumstance is the social worth of the patient to enter into the formulation. This is particularly critical when the patient is mentally retarded and institutionalized.

Although a presumption for treatment may exist, the court

has recognized that it is not always in a patient's best interests to continue life-sustaining treatment. [36] Recently, ethical guidelines have emerged for applying the "best interests" standard to important categories of patients.

For the patient who is terminally ill, the major considerations are whether foregoing treatment will allow the patient to avoid the burden of prolonged dying with pain or suffering and whether the patient has the potential benefit of achieving some satisfaction if he survives for a longer period. [37]

For the patient with a severe illness or disabling condition that is irreversible, the major consideration is whether termination of treatment would be preferable to a patient's life largely devoid of opportunities to achieve satisfaction or full of pain or suffering with no corresponding benefits. [38]

For a patient with irreversible loss of consciousness, the benefit/burden analysis is different. Such patients do not experience pain. The only possible benefit to them of treatment is that the diagnosis is wrong and they will regain consciousness. Thus, the major considerations are whether a reasonable person in the patient's circumstances would find that this benefit, as well as the benefit to the family and friends, (*i.e.*, satisfaction in caring for the patient and meaningfulness of continued survival) is outweighed by the emotional suffering and financial burden of treatment. [39]

The evolution of ethical standards has also influenced the legal parameters of defining "life-sustaining treatment." Historically, the courts adhered to a distinction between extraordinary and ordinary care. A patient or his surrogate could refuse those treatments and procedures labeled extraordinary, but not those that were deemed ordinary. In the *Quinlan* case, in fact, the mechanical respirator was labeled as an extraordinary treatment.

Within the last few years, the focus has shifted to the withholding or withdrawal of artificial feeding and hydration. Adopting the position of the President's Commission, the courts have either expanded the definition of extraordinary to include such treatment or have abandoned the distinction as unhelpful and confusing altogether. [40] The courts have also been influenced by the AMA Council on Ethical and Judicial Affairs

which issued a major opinion in 1986 that it is ethically permissible to withhold all life-prolonging treatment, *including artificial nutrition and hydration*, from permanently unconscious or dying patients in accordance with their wishes or those of their surrogates. [41]

To date courts in over 13 states have ruled that the right to refusal is no different for artificial feeding and hydration than for other forms of medical treatment. The position of the New Jersey Supreme Court in the *Conroy* case has since been adopted by a number of other state courts. "Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own." [42]

Although the common law has moved forward in this area, there is still much confusion on this issue. Ironically, part of the confusion is based on the living will statutes. Six states clearly do indicate that an advanced directive can provide for the withdrawal of artificial feeding not necessary for comfort care. Seven others explicitly exclude it as a procedure that may be rejected. A number of other statutes provide that food and water may not be rejected, but do not specifically define artificial feeding and hydration. Other statutes make no mention of the issue at all. [43] In spite of this confusion, at least three state courts (Florida, Maine, and California) that have addressed the issue have held that restrictive statutes cannot be read to limit the constitutional and common law rights of patients to have artificial feeding tubes withdrawn. [44]

Another life-sustaining treatment or procedure worthy of particular attention is emergency resuscitation for cardiac arrest and pulmonary failure (CPR). Traditionally, many hospitals would act as if there was a Do Not Resuscitate Order (DNR) for a hopelessly ill patient, but would not document it in the chart. The decision whether to resuscitate was often not discussed with the patient and/or his surrogate, but rather handled as a medical decision that was within the discretion of the attending physician. A number of state medical societies, the New York State legislature, and the Joint Commission for the Accreditation

of Hospitals (JCAH) have recently addressed this issue.

If a hopelessly ill patient is competent, the emerging standard is that the patient should decide on whether a DNR order should be made, based on the patient's understanding of medical diagnosis and prognosis. In other words, the DNR order should be treated like all other medical decisions in which the patient has the right to refuse life-sustaining treatment. [45] If the patient is not competent, the decision should be reached by consultation between physician and family members or the legal guardian. Once a decision is made, it should be documented in the medical record. Any significant improvement would void the order. [46]

#### *Who Should Decide?*

Decision-making criteria enable the surrogate decision-maker to exercise the incompetent patient's right to forego life-sustaining treatment. To accomplish this role best, guidelines have evolved over who this surrogate decision-maker should be.

Traditionally, the physician relied on the family to assist in making medical decisions for the incompetent patient. Such a medical custom makes sense, given the family's unique relationship with the patient. As the *Quinlan* court noted, the family has knowledge of and concern for the welfare of the family member. Of course, it is possible that family members may have different values and may be unable to separate financial or emotional concerns from decision-making. But, absent a showing of bad faith or a physician's belief that the family does not have the welfare of the patient at stake, the family should be the primary decision-maker.

Until very recently, the only way to ensure that the physician or institution would not be subject to civil or criminal liability for relying on a family member to consent to withdrawing or withholding treatment was to go to court either to have a family member appointed as a guardian or to obtain judicial approval of the decision itself. [47] A clear consensus has emerged that going to court is too burdensome, too expensive, and inappropriate in most cases since the court is ill-equipped to make such personal and complex ethical decisions. In recent years, at least

half of the states, either by court opinion or statute, have explicitly authorized the family of adult patients to authorize termination of treatment without going to court. [48]

Two years ago, the New Jersey Supreme Court set out comprehensive guidelines for family decision-making. [49] The court declared the family as the primary decision-maker in spite of the fact that New Jersey had no statute on point. With concurrence by the attending physician and confirmation of the medical condition by two independent physicians, the family without a court order had the right to have treatment refused on behalf of the incompetent patient. There need not be clear and convincing evidence of what the patient would have wanted, but rather the family is to do the best they can under the circumstances to make good faith decisions based on their knowledge of the family member. [50]

State statutes also provide recognition of the family as primary decision-maker without court intervention. The "substituted judgment" statute provides a priority list of persons the provider is to turn to for consent to treatment. Statutes vary as to the conditions in which the surrogate may also authorize the termination of life-sustaining treatment. Informed consent and living will statutes may also be a source of authority for the family surrogate to request termination of life-sustaining treatment. [51] A durable power of attorney may also specify a family member (or friend) as the proxy for decisions.

Of course, if there is disagreement among the family, evidence of bad faith or no family member available, the family will not be relied on as the surrogate decision-maker. [52] The next most likely approach will be the appointment of a guardian or conservator. All states and the District of Columbia have statutes that provide for such appointment, but they differ as to whether they specify authority for health care decisions. Either case law or statute will provide that the guardian may have the authority to make decisions about the withholding or withdrawal of life-sustaining treatment without court ratification or review. [53] A few guardianship statutes do reserve "life-and-death" medical decisions to the court.

Even in those states in which the court does not routinely

require court approval, there will be disputed cases in which the court will either approve a surrogate's decision or make the treatment decision directly. When the treatment decision involves the institutionalized patient who was never competent, the court may take an active role.

Over the last few years, there has been heightened interest in the use of institutional ethics committees for resolving the complex issues raised by foregoing life-sustaining treatment. Such committees, with a diverse membership of physicians, nurses, ethicists, other professionals, and the public, could advise on various ethical and social considerations surrounding treatment decisions. Although a few courts have looked to prognosis committees to verify the medical condition of an incompetent patient, case law and statutes do not grant ethics committees authority to serve as the surrogate decision-maker for the incompetent patient. [54] As ethics committees evolve in more institutional settings, they should take on a more active role in facilitating decision-making outside of the courtroom.

Generally, the trend has been to remove uncontroversial cases from the court's jurisdiction. Yet a number of unnecessary cases will continue to come to court. Based on an unrealistic assessment of liability risk, health care providers will continue either to seek the court's protection prior to terminating treatment or force families to go to court to order them to honor the family's right to refuse life-sustaining treatment on behalf of the incompetent family member. Thus, an understanding on the current status of liability risk is in order.

### *CRIMINAL AND CIVIL LIABILITY*

A misunderstanding of the law and a fear of liability continue to pervade medical practice in this area. To date, there has not been one successful prosecution of criminal charges against a physician or health care institution reported for withdrawing life-sustaining treatment, including the removal of a feeding tube. [55] Nor has there been a single case reported for civil liability in which a physician was found negligent pursuant to a family's request to withdraw or withhold life-sustaining treatment.

However, there have been a few cases reported recently in which the court has recognized a battery action for damages for failure to abide by the wishes of the patient and/or family for withholding or withdrawing treatment. The Ohio Court of Appeals held that maintaining a comatose woman on a respirator without her consent was actionable battery, [56] The California court also recognized a cause of action, including the payment of attorney fees (under its private attorney's general statute) for a hospital's failure to remove a competent patient on a respirator against his will and that of his family. [57] In the *Bowvia* case, the California court maintained a cause of action for damages based on her being forced fed against her will and for attorney fees. [58]

In practice, it is not easy for a plaintiff to win such cases against health care providers. The provider may appear very sympathetic, it may be hard to prove knowing disregard for the patient's wishes, and damages will be very difficult to assess. The possibility of payment for attorney fees, however, may be enough of an incentive to honor the right of the patient or his surrogate decision-maker to refuse treatment.

#### *UNRESOLVED ISSUES AND NEW QUESTIONS: HIGHLIGHTS*

Although legal and ethical trends have evolved over the last decade, unresolved issues remain and new questions emerge. A few are highlighted for future debate:

##### *1. Accommodating Conflicting Beliefs*

When a physician's personal or religious beliefs conflict with a patient's or surrogate's decision to terminate life-sustaining treatment, the physician may transfer the patient to another physician and be subject to liability for abandonment if appropriate arrangements for transfer are not made in good faith. Both common law and the living will statutes provide for such an accommodation. Should the health care institution have the same right when its objections are based on ethical and religious principles and not be based on the unrealistic fear of liability or convenience?



To date, the courts are split on this "accommodation." The Massachusetts Supreme Court only required that a hospital that refused to remove a feeding tube based on its ethical principles cooperate in the transfer of the patient to another facility. [59] In a similar case, a New York court ordered a hospital either to remove the artificial feeding and hydration tubes from the patient or assist in his transfer to his home or another facility. The hospital refused to remove the tubes and transfer to another facility was arranged. [60]

On the other hand, a California court held that a hospital could not hide behind its religious principles in not removing a patient from a respirator against his will. [61] In the *Jobes* case, the New Jersey Supreme Court refused to force the transfer of a nursing home patient whose family won the right to have her feeding tube removed in contradiction to the nursing home's policy written after her arrival. [62] In another New Jersey decision, a lower court denied a hospital's request either to have a severely neurologically impaired patient fed artificially, discharged or transferred to another facility. To force the patient to be transferred, if she refused the feeding tube, would, in the court's opinion, be to expose her to hardship and distress in an extremely difficult time in her life. As unpleasant as it might be for the staff to watch her die, their suffering could be less than hers if forced to move. [63] A Colorado trial court, when faced with a similar case, supported the right of a competent patient over the institutional "conscience" of the health care facility to have his feeding tube removed without being transferred to another facility. [64]

In practice, it may often be difficult for the patient or the institution to find another facility willing to accept the patient. As more facilities address this issue in advance, they may set policies that prohibit the removal of feeding tubes. If so, will patients be able to exercise the rights that courts and legislatures have now granted?

## 2. *Too Much Treatment?*

On the other hand, there may be patients or surrogates who want all treatment provided, even when the provider deems it

medically inappropriate under the circumstances. If a patient or his surrogate has the right to refuse life-sustaining treatment, is there a corollary right to demand that all means be utilized to keep the patient alive? When can the health care professional and the institution say "NO MORE" without risking liability? How will the standard of care emerge in the future for the hopelessly ill? Will a consensus emerge in which it is deemed unjust in our society to provide unnecessary and inappropriate treatment (over and above supportive care) to those who have no reasonable chance of recovery or return to a sapient life? [65] To date, there is little guidance on this issue.

### 3. *Quality of Life*

How far are we willing to extend the right of a surrogate to refuse treatment for a patient who is neither terminally ill nor in a persistent vegetative state, but rather is chronically ill and senile? Typically, this is the elderly patient often institutionalized in a nursing home. How can we quantify benefit and burden for this patient? How much significance should we attach to recovery, side effects, intrusiveness and severity of treatment, and ability to cooperate in care? [66] And how will such decisions be influenced by cost implications? How can we continue to avoid making judgments about the "social worth" of such patients?

Furthermore, what quality of life will the treatment of the AIDS patient raise at different stages of the disease? Use of antibiotics to cure infection may stabilize the patient for a while until the next infection surfaces. How will the benefit/burden ratio be calculated? What is deemed a life-sustaining treatment and at what time in the course of the illness? AIDS dementia may cause the patient to lose capacity temporarily to make decisions about courses of treatment. Under the circumstances, when should an advanced directive, if executed, become operational?

### 4. *Redefining the Family and Appropriate Decision-Makers*

It is well-established that the family is accepted as the primary decision-maker for the incompetent patient. Yet the

traditional definition of the family may not be appropriate in a number of circumstances. For example, what about the gay AIDS patient who becomes incompetent and has not appointed a proxy decision-maker? Should not his lover of ten years be his family? And what about the senile patient in a nursing home who has no family?

Must one go to court to get a guardian appointed or are there other alternatives to assuring that the interests of the patient are being protected? Clearly, the patient's health care provider should not act as the surrogate unless the patient had previously designated the provider to act in that role. [67] Perhaps an expanded role for the ethics committee or the ombudsman may be appropriate? Another possibility to pursue is the "surrogate committee" to provide surrogate decision-makers for those patients without capacity who lack family. [68] Whether the "stranger" surrogate should have more limited discretion and be subject to closer review than a family surrogate is still open to question. Clearly, we must continue to develop and evaluate mechanisms for protecting the rights of the incompetent patient in the most effective and efficient manner.

## CONCLUSION

The problems just highlighted must be put in perspective. It was just a decade ago that the *Quinlan* case captured national attention. Since then, legal and ethical foundations for the right to forego treatment have become well-established. For the competent patient, the right is relatively easy to apply. For the incompetent patient, the law has moved toward the development of decision-making criteria and a presumption that the family, and not the court, make treatment decisions on behalf of the patient. State legislatures have also made much progress in promoting the development of advanced directives and the appointment of proxies for medical decisions. And the medical community has recognized its duty to initiate discussions with the patient and his family on the use or withdrawal of life-sustaining treatment. Hopefully, open dialogue will reduce the risk of liability and increase prospective planning for medical decision-making.

## NOTES

1. "Most MDs favor withdrawal of life support - survey." *American Medical News*, June 3, 1988 at 9, quoting James H. Sammons, M.D., Executive Vice President, American Medical Association.
2. *Id.*; See American Medical Association, "AMA Surveys of Physician and Public Opinion on Health Care Issues: 1988" at 23-26. Almost identical findings were made when the public was surveyed in 1986. See American Medical Association, "AMA Surveys of Physician and Public Opinion: 1986" at 22.
3. *In re Quinlan*, 70 N.J. 10, 355 A.2d 547, cert. denied, 420 U.S. 922 (1976).
4. A living will is a legally executed document which sets forth an individual's wishes not to receive "life-sustaining" treatment in the event the individual suffers a "terminal condition" and becomes incapable of making such decisions. For an excellent state by state analysis of living will legislation, see Society for the Right to Die, *Handbook of Living Will Laws* (1987).
5. Such patients may be either those that were formerly competent or those that were never competent, such as the mentally retarded. The special problems of the minor patient and the severely defective newborn raise many unique legal and ethical issues and are beyond the scope of this article. See, e.g., Rothenberg, "Medical Decision Making for Children," 1 *Biolaw* 149 (1986).
6. *Union Pacific Railway Co. v. Botsforth*, 141 U.S. 250, 251 (1891).
7. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).
8. The court was referring to *Roe v. Wade*, 410 U.S. 113 (1973).
9. *In re Quinlan*, 70 N.J. at 38-40, 355 A.2d at 662-63.
10. *Id.* at 40, 355 A.2d at 663.
11. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).
12. The advantage of constitutional protection is that a constitutional right can only be abrogated by a compelling state interest which would be rare under the circumstances, whereas a common law right can be abrogated by statute. Some commentators, however, consider the common law right more helpful for patients since they do not need to assert state action and have an opportunity for collecting damages under tort law. See, e.g., Cantor, *Legal Frontiers of Death and Dying* (Indiana University Press: 1987) at 8.
13. See, President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Deciding to Forego Life-Sustaining Treatment" (1983) (hereinafter "Deciding to Forego Treatment").
14. Such a characterization, however, should be distinguished from "mercy killing" or "active" euthanasia, a subject beyond the scope of this article. For an excellent set of articles on euthanasia, see, 15 *Law, Medicine, and Health Care* 223-41.
15. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).
16. Society for the Right to Die, "The Physician and the Hopelessly Ill Patient," (1985) at 30.
17. The Hastings Center, "Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying" (1988) at 23 (hereinafter "Guidelines"). These recent ethical guidelines represent consensus by an interdisciplinary group of experts. The guidelines build on the important and influential work of the President's Commission, "Deciding to Forego Life-Sustaining Treatment."
18. See, e.g., *Lane v. Candura*, 6 Mass. App. 377, 576 N.E. 2d 1232 (1978) (77-year old diabetic competent to refuse amputation of her leg because she did not want to be invalid or live in a nursing home); *Matter of Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978).
19. See, e.g., *In re Maida Yetter*, 62 Pa.D. & C.2d 619 (1973) (permitted to refuse surgical biopsy for breast cancer if understood that consequences of decision might be death); but cf., *State Dept. of Human Services v. Northern*, 563 S.W. 2d 197 (Tenn. Ct. App. 1978) (patient not competent to decide to refuse the

- amputation of feet because could not accept fact that feet were infected).
20. For an outline of the issues, see generally Macdonald, Meyer, & Essig, *Health Care Law* (Matthew Bender, 1987) at §18.04-1805.
  21. Although beyond the scope of this article, the general rule is that a competent Jehovah's Witness has the right to refuse blood because of religious beliefs, but does not have the right to refuse blood on behalf of a minor child.
  22. *Bartling v. Superior Court*, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220 (Ct. App. 1984).
  23. *Bouvia v. Superior Court*, 179 Cal. App. 1127, 225 Cal. Rptr. 297 (Ct. App. 1986), review denied, (Cal. June 5, 1986).
  24. *In re Farrell*, 109 N.J. 335, 529 A.2d 404 (1987).
  25. Contrary to all predictions, once the respirator was removed, she remained alive for almost ten years.
  26. *In re Quinlan*, 70 N.J. at 41, 355 A.2d at 664.
  27. The committee was, in fact, to function as a prognosis committee.
  28. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).
  29. *Superintendent of Belchertown State School v. Saikewics*, 372 Mass. 728, 370 N.E.2d 417 (1977) (court was the surrogate decision-maker to determine that severely retarded patient with leukemia would have refused chemotherapy based on limited prognosis and trauma caused by pain and suffering associated with treatment).
  30. For a state-by-state analysis, see Society for the Right to Die, "Handbook of Living Will Laws — 1987 Edition"; Gelfand, "Living Will Statutes: The First Decade" 1987 *Wisconsin Law Review* 737 (1987).
  31. In fact, over two out of three physicians surveyed in 1988 believe that they should have living wills available in their offices for patients' use or not. American Medical Association, "AMA Surveys of Physicians and Public Opinion on Health Care Issues: 1988," at 25-26.
  32. *In re Peter*, 108 N.J. 365, 529 A. 2d 419 (1987).
  33. For an excellent discussion and references on the durable power of attorney, see Cohen, "Appointing a Proxy for Health-Care Decisions: Analysis and Chart of State Laws" (1987) (available from the Society for the Right to Die).
  34. In 1982, a Lou Harris poll revealed that only one-third of the population had given any instructions on how they wanted to be treated in the event they were incapable of making their own decisions. Of those, only one-fourth had put such instructions in any written form. See President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research, "Making Health Care Decisions," Vol. 2, Appendix B (1982).
  35. See, e.g., *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987).
  36. *Id.* In practice, a few courts have blurred the distinction between substituted judgment and best interest standards, utilizing both in the same case. See, e.g., *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *Foody v. Manchester Memorial Hospital*, 40 Conn. Supp. 127, 482 A.2d 713 (1984); *In re Torres*, 357 N.W.2d 332 (Minn. 1984). This has been particularly evident in cases involving the chronically ill and institutionalized patient. Perhaps this is because both the wishes of the patient subjectively and the best interests of the patient objectively may coincide with the decision to terminate life-sustaining treatment.
  37. See "Guidelines" at 28.
  38. *Id.* at 29.
  39. *Id.*
  40. This position was encouraged by the President's Commission and reaffirmed by the Hastings Center Guidelines.
  41. Reprinted in Society for the Right to Die, "The Physician and the Hopelessly Ill Patient" (1988 Supp.) at 45 (emphasis added). State medical societies, including those in Massachusetts and California have issued similar opinions. The Hastings Center Guidelines also support the right of the incompetent, as well as the competent, patient to have artificial feeding and hydration, as well as the

- administration of antibiotics withheld or withdrawn when not necessary for comfort care.
42. *In re Conroy*, 98 N.J. at 373, 486 A.2d at 1236.
  43. Society for the Right to Die, "The Physician and the Hopelessly Ill Patient" (1988 Supp.) at 11.
  44. *Id.*
  45. *In re Dinnerstein*, 6 Mass. App. 466, 380 N.E.2d 134 (Ct. App. 1978) was the first decision to uphold the validity of the "no code" or DNR order for the incompetent patient.
  46. As of January 1, 1988 JCAH standards require hospitals to have in place policies and procedures for reaching decisions on resuscitative services, including adequate provisions for protection of the patient's rights.
  47. Areen, "The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment," 258 *JAMA* 229, 231 (July 10, 1987). See also 258 *JAMA* 2696-97 (Nov. 20, 1987) (letters to the editor on Areen article).
  48. *Id.*
  49. *In re Jobs*, 108 N.J. 394, 529 A.2d 434; *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987).
  50. Case law in Arizona, California, Connecticut, Florida, Georgia, Massachusetts, Tennessee, Virginia (lower court), and Washington also recognizes the family as primary decision-maker. See Legal Counsel for the Elderly, "Decision-Making, Incapacity, and the Elderly," (AARP, 1987) at 111 (case cites).
  51. *Id.* A recent New York statute provides authority for family members to consent to DNR orders. The New York State Department of Health's pamphlet, "Do Not Resuscitate Orders: A Guide for Patients and Families," is to be distributed to all patients on admission to a hospital or nursing home.
  52. The court may often have a more active role when the refusal to treat involves infants, minors, the institutionalized, and the mentally retarded.
  53. *Id.* at 112. Ohio does require that the court make the decision. Civil rules of procedure also provide the appointment of guardian *ad litem* to represent the interests of the incompetent patient in health care decision-making cases.
  54. "Deciding to Forgo Treatment" at 163. Maryland law provides that each acute care hospital have a "patient care advisory committee" established to advise on difficult treatment decisions. Md. Health-Gen. Ann. §19-370-374.
  55. *Barber v. Superior Court of California*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (Ct. App. 1983) (dismissed criminal charges for removal of feeding tube). For an excellent article on criminal law and its application to this area, see Glantz, "Withholding and Withdrawing Treatment: The Role of the Criminal Law," 15 *Law, Medicine, & Health Care* 231 (1988).
  56. *Leach v. Shapiro*, 13 Ohio App. 3d 393, 469 N.E.2d 1047 (Ct. App. 1984).
  57. *Bartling v. Glendale Adventist Medical Center*, 184 Cal. App. 3d 97, 228 Cal. Rptr. 847 (Ct. App. 1986), *on remand*, No. 500735 (Cal. Super. Ct. Los Angeles County, Oct. 14, 1987) (attorney fees).
  58. *Bouvia v. Glenchur*, 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (Ct. App. 1987) (attorney fees).
  59. *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 427, 497 N.E.2d 626 (1986).
  60. *Delio v. Westchester Cty. Medical Center*, 129 A.D.2d 1, 516 N.Y.S. 2d 677 (App. Div. 2d Dep't. 1987).
  61. *Bartling v. Superior Court*, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220 (Ct. App. 1984).
  52. *In re Jobs*, 108 N.J. 394, 529 A.2d 434 (1987).
  63. *In re Requena*, 213 N.J. Super. 475, 517 A.2d 886 (Super. Ct. Ch. Div.), *aff'd*, 213 N.J. Super. 443, 517 A.2d 869 (Super. Ct. App. Div. 1986 (per curiam)). See also "Guidelines" at 138.
  64. *In re Rodas*, No. 86PR139 (Colo. Distr. Ct. Mesa City. 1/22/87) (Buss, J.).
  65. Brody, "Ethical Questions Raised by the Persistent Vegetative Patient," 18

*Hastings Center Report* 33 (1988).

66. Such factors were considered in *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987).
67. "Guidelines" at 26.
68. *Id.* at 25. A recent New York statute authorizes such a committee on a demonstration basis in two geographic areas. The committee, which would be interdisciplinary and work through four member panels, would first assess whether the patient was incapable of making treatment decisions. If so, the panel would apply the best interests standard to determine whether or not to proceed with treatment. N.Y. Mental Hyg. Law §80.01, 80.05 (McKinney Supp. 1987). For a one-year evaluation of the program, see Sundram, "Informed Consent for Major Medical Treatment of Mentally Disabled People," 318 *New Eng. J. Med.* 1368 (May 26, 1988).