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ARTICLES

FOREGOING LIFE-SUSTAINING TREATMENT: WHAT ARE THE LEGAL LIMITS IN AN AGING SOCIETY?

KAREN H. ROTHENBERG*

INTRODUCTION

Death comes to everyone. However, in our society, due to great advances in medical knowledge and technology over the last few decades, death does not come suddenly or completely unexpectedly to most people. . . . Sophisticated life-sustaining medical technology has made it possible to hold some people on the threshold of death for an indeterminate period of time, "obfuscat[ing] the use of traditional definition of death." . . . Questions of fate have thereby become matters of choice raising profound "moral, social, technological, philosophical, and legal questions involving the interplay of many disciplines."¹

The "right-to-die" movement has come a long way since the *Karen Quinlan*² case captured our attention a decade ago.³ In the last twelve years, courts and state legislatures, together with health care profes-

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1. *In re Farrell*, 529 A.2d 404, 406 (N.J. 1987) (quoting *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976), and *In re Conroy*, 486 A.2d 1209 (N.J. 1985)).

2. *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

3. The same year that the *Quinlan* decision was handed down, California enacted the first Natural Death Act, granting statutory recognition to the "living will." A living will is a legally executed document that 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) [hereinafter HANDBOOK].

sionals, hospitals, medical ethicists, legal scholars, and the public, have continued to address the legal and ethical issues raised by foregoing life-sustaining treatment. Although progress has been made in opening up debate and reaching a consensus on many of the issues, and some legal trends have emerged, many questions still remain.

While courts have had little trouble affording the right to forego treatment to competent persons,⁴ the more difficult challenge has been how to exercise similar rights on behalf of incompetent patients.⁵ The majority of state courts that have addressed the issue of an incompetent patient's right to forego life-sustaining treatment have permitted a surrogate decisionmaker to make the decision for the incompetent patient who is in a permanently unconscious, persistent vegetative state, or in the last stages of a terminal illness.⁶ The more difficult cases, however, arise when an incompetent, severely debilitated person is neither permanently unconscious nor terminally ill.⁷ For these patients, many of whom are elderly and languishing in nursing homes or similar institutions, quality of life judgments cannot be ignored in the surrogate decisionmaking process.⁸

To date, only a few cases have addressed the right to forego life-sustaining treatment for patients who are severely debilitated. These few cases, however, reveal the problems which courts and other decisionmakers face when confronted with these questions. A delicate balance must be drawn between upholding a patient's right to forego life-sustaining treatment and any tendency on the part of the surrogate decisionmaker to confuse the social worth of a person's continued life with the worth of life to the patient.

This Article will first discuss the legal and ethical foundations that support the right to forego life-sustaining treatment. Section II will apply this right specifically to the competent patient. In Section III the greater challenge of how to preserve such a right for the incompetent patient will be analyzed.⁹ The final section will apply evolving legal standards to the elderly, severely debilitated patient, asserting that the best way society can deal with this difficult area is to squarely face

4. See *infra* notes 40-52 and accompanying text.

5. See *infra* notes 53-107 and accompanying text.

6. See N. CANTOR, LEGAL FRONTIERS OF DEATH AND DYING 91-96 (1987); see also *In re Guardianship of Grant*, 747 P.2d 445 (Wash. 1987) (en banc); Merritt, *Equality for the Elderly Incompetent: A Proposal for Dignified Death*, 39 STAN. L. REV. 689, 698 (1987).

7. See N. CANTOR, *supra* note 6, at 96.

8. See Merritt, *supra* note 6, at 712.

9. An incompetent patient may have been formerly competent or never competent, such as the mentally retarded. The special problems of minor patients and severely defective newborns raise many unique legal and ethical issues and are beyond the scope of this Article. See Rothenberg, *Medical Decision Making for Children*, 1 BIO. LAW 149 (1986).

quality of life judgments.

I. THE RIGHT TO FOREGO TREATMENT: LEGAL & ETHICAL FOUNDATIONS

It is well established in the medical and legal community, as well as with the public at large, that a patient has the right to forego life-sustaining 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 to forego medical treatment. "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 restraint or interference by others, unless by clear and unquestionable authority of law."¹⁰ This common law right is recognized in both criminal and tort law.

Beginning in the 1960s, courts expanded their recognition of self-determination in the context of medical treatment to the development of the doctrine of informed consent. This tort doctrine establishes a duty whereby health care providers must inform the patient of treatment alternatives and risks prior to obtaining valid consent. Informed consent has evolved to where the right not to consent to or forego treatment has been incorporated into the doctrine. This incorporation enables all individuals to fully realize their right to self-determination.¹¹

As the law of informed consent evolved, the New Jersey Supreme Court in the *Quinlan* case established another legal source for upholding the right to forego life-sustaining treatment: the constitutional right to privacy.¹² Although the United States Constitution fails to explicitly mention a right to privacy, the *Quinlan* court reasoned that if the United States Supreme Court could recognize such a right to protect the individual from state action which would limit such personal choices as contraception,¹³ and a woman's decision to terminate her pregnancy under certain conditions,¹⁴ the right to privacy would also be broad enough to encompass a patient's decision to decline medical

10. *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891); see *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (en banc); *In re Welfare of Colyer*, 660 P.2d 738 (Wash. 1983).

11. See, e.g., *In re Drabick*, 245 Cal. Rptr. 840 (Ct. App.), cert. denied, 109 S. Ct. 399 (1988); *In re Gardner*, 534 A.2d 947 (Me. 1987). But cf. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc), cert. granted, 109 S.Ct. 3240 (1989) (positing that in the absence of capacity to understand and decide, "neither consent nor refusal can be informed").

12. *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied, 429 U.S. 922 (1976).

13. See *Griswold v. Connecticut*, 381 U.S. 479 (1965).

14. See *Roe v. Wade*, 410 U.S. 113 (1973). For an outstanding article criticizing the "waxing-and-waning" right of privacy borrowed from *Roe v. Wade*, see Capron, *Borrowed Lessons: The Role of Ethical Distinctions in Framing Law on Life-Sustaining Treatment*, 1984 ARIZ. ST. L.J. 647.

treatment.¹⁵ 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 the patient remained in a coma, unable to express her wishes, the court allowed her guardian and family to act on her behalf in exercising her right to forego further life-sustaining treatment.¹⁶

The court did recognize that this right is not absolute and that it must be balanced against the claimed interests of the state in the "preservation and sanctity of human life and defense of the right of the physician to administer medical care according to his best judgment."¹⁷ As more state courts faced similar cases, four state interests emerged: (1) the preservation of life; (2) the prevention of suicide; (3) protection of innocent third parties; and (4) protection of the ethical integrity of the medical profession.¹⁸

The most important state interest, at least in theory, is the preservation of life. In practice, most courts have found that this interest in preserving life would not outweigh the right of a patient to refuse life-sustaining treatment.¹⁹ Suicide prevention is generally not an issue in right to die cases, primarily because the patient does not inflict the illness deliberately on herself. If the patient has no minor children or the family consents, the third interest in protecting innocent parties is usually not at issue. Finally, the ethical standards of the medical profession have evolved since *Quinlan* to a point where a large proportion of the profession supports the right of the patient to refuse treatment.²⁰

The United States Supreme Court has yet to hear a case involving the right to forego treatment.²¹ However, the Court's interpretation of

15. 355 A.2d at 662-63; see *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988) (first federal court to decide that the constitutional right of privacy encompassed the right to decline life-sustaining treatment). *But cf. Cruzan*, 760 S.W.2d at 418. (expressing "grave doubts as to the applicability of privacy rights to decisions to terminate the provision of food and water to an incompetent patient").

16. *Quinlan*, 355 A.2d at 647.

17. *Id.* at 663; accord *Gray v. Romeo*, 697 F. Supp. at 588.

18. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977).

19. The *Cruzan* case, however, contended that other courts had allowed "concerns with the quality of life to discount the state's interest in life." *Cruzan*, 760 S.W.2d at 421. The Missouri Supreme Court held: "[T]he state's interest is not in quality of life. The State's interest is an unqualified interest in life." *Id.* at 422. *Cruzan* ultimately held that the state's interest in the patient's life outweighed any right to refuse treatment. *Id.* at 424. Although Ms. Cruzan remained in a persistent vegetative state, the court deemed her "not dead" nor "terminally ill." *Id.* The court went on to determine that "[h]er life expectancy is thirty years." *Id.*

20. See, e.g., *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988); *In re Welfare of Colyer*, 660 P.2d 738, 743-44 (Wash. 1983).

21. Writ of certiorari has been granted in the *Cruzan* case. 109 S.Ct. 3240 (1989).

the constitutional right to privacy should extend to recognition of such a right.²² Absent a decision by the Supreme Court, state and federal courts have addressed the issue and established a right to the point where it is protected by both the common law and the constitutional right to privacy.²³ Both of these legal sources provide the legal foundation for promoting the values of self-determination, bodily integrity, and personal autonomy in medical decisionmaking.

To a great extent, the evolution of medical ethics has influenced the development of law in this area. In the early 1980s, the President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research released an influential series of reports, including one entitled, "Deciding to Forego Life-Sustaining Treatment."²⁴ The report established that there should be no ethical or legal distinction between withholding and withdrawing life-sustaining treatment.²⁵ Subsequent judicial decisions and commentaries endorsed the position that the right to forego treatment includes both the withdrawing and withholding of treatment.²⁶

Historically, physicians and health care institutions believed—and many still do—that the act of withdrawing a respirator or removing a feeding tube entails an affirmative act which accelerates the dying process.²⁷ Those adhering to this view believe that once this treatment has been initiated, it must continue, regardless of its value to the patient. On the other hand, these same commentators and practitioners find the initial withholding of such treatment ethically and legally permissible.

In fact, it is often more difficult to know how a patient will re-

22. See *Gray*, 697 F. Supp. at 585. The advantage of constitutional protection is that a constitutional right can only be abrogated by a compelling state interest, which would be rare under most circumstances. On the other hand, 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 N. CANTOR, *supra* note 6, at 6.

23. See, e.g., *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1986), *later proceeding*, 241 Cal. Rptr. 239 (Ct. App. 1987); *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713 (Conn. Super. Ct. 1984); *In re Guardianship of Grant*, 747 P.2d 445 (Wash. 1987); *In re Welfare of Colyer*, 660 P.2d 738 (Wash. 1983).

24. 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 PRESIDENT'S COMM'N].

25. *Id.*

26. See, e.g., THE HASTINGS CENTER, *GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING* 130-31 (1988) [hereinafter THE HASTINGS CENTER GUIDELINES].

27. 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 Fletcher, *The Courts and Euthanasia* 15 L. MED. & HEALTH CARE 223, 223-41 (1988), and Glantz, *Withholding and Withdrawing Treatment: The Role of Criminal Law*, 15 L. MED. & HEALTH CARE 231 (1988).

respond to a treatment without a time-limited trial. This remains 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 Supreme Court noted in the *Conroy* decision,²⁸ 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.²⁹ To date, only 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.³⁰

The evolution of ethical standards has also influenced the legal parameters of defining *life-sustaining treatment*. Historically, courts adhered to a distinction between extraordinary and ordinary care.³¹ A patient or her surrogate could refuse those treatments labeled extraordinary, but not those deemed ordinary.³² Within the last five years, the focus has shifted to the withholding or withdrawal of artificial feeding and hydration. Adopting the position of the President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, the courts have either expanded the definition of extraordinary to include artificial feeding and hydration or abandoned the distinction as unhelpful and confusing altogether.³³

To date, courts in over thirteen states have ruled that no difference

28. *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

29. *Id.* at 1234.

30. SOCIETY FOR THE RIGHT TO DIE, THE PHYSICIAN AND THE HOPELESSLY ILL PATIENT 30 (1985).

31. *See Gray v. Romeo*, 697 F. Supp. 580, 588 (D.R.I. 1988) ("courts have distinguished between ordinary and extraordinary treatment").

32. In the *Quinlan* case, the mechanical respirator was labeled as an extraordinary treatment. *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

33. PRESIDENT'S COMM'N, *supra* note 24, encouraged this position and THE HASTINGS CENTER GUIDELINES, *supra* note 26, affirmed it. *See also Gray v. Romeo*, 697 F. Supp. 580, 588 (D.R.I. 1988) ("recent decisions have criticized the distinction as one without meaning").

The courts have also been influenced by an opinion issued by the AMA Council on Ethical and Judicial Affairs. The opinion stated 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. *Withholding or Withdrawing Life Prolonging Medical Treatment*, CURRENT OPINIONS OF THE COUNSEL OF ETHICAL AND JUDICIAL AFFAIRS OF THE AMA § 2.18 (1986); *see also* SOCIETY FOR THE RIGHT TO DIE, *supra* note 30, at 43 (Supp. 1988). State medical societies, including those in Massachusetts and California, have issued similar opinions. *Id.* The Hastings Center *Guidelines* also support the right of both the incompetent and competent patient to have artificial feeding and hydration, as well as the administration of antibiotics, withheld or withdrawn when not necessary for comfort care. THE HASTINGS CENTER GUIDELINES, *supra* note 26, at 66.

exists between the right to refuse artificial feeding and hydration and the right to refuse other forms of medical treatment.³⁴ A number of state courts have adopted the New Jersey Supreme Court's position in *Conroy*: "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."³⁵ Although the common law has moved forward in this area, there is still much confusion on this issue.³⁶

Another life-sustaining treatment worthy of particular attention is cardiopulmonary resuscitation (CPR). Traditionally, many hospitals acted as if there was a "Do Not Resuscitate" (DNR) order for a hopelessly ill patient, but failed to document it in the chart. The decision whether to resuscitate was often not discussed with the patient or the surrogate. Rather, it was handled as a medical decision within the discretion of the attending physician and not as a decision for the patient or her guardian. 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.³⁷

For a hopelessly ill, yet competent patient, the emerging standard allows the patient to decide whether a DNR order should be issued, based upon the patient's understanding of medical diagnosis and prog-

34. SOCIETY FOR THE RIGHT TO DIE, *supra* note 30. *But cf.* *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc) (reversing trial court, which allowed co-guardians' request to withdraw nutrition and hydration from incompetent ward in vegetative state, because public policy mandated the prohibition of such withdrawal under all circumstances).

35. *In re Conroy*, 486 A.2d 1209, 1236 (N.J. 1985).

36. Ironically, part of the confusion centers around the living will statutes. For a general discussion of living wills, *see infra* notes 88-93 and accompanying text. Six states clearly indicate that an advanced directive can provide for the withdrawal of artificial feeding not necessary for comfort care. Seven other states explicitly exclude it as a procedure that may be rejected. A number of other state 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. *See HANDBOOK, supra* note 3, at 6-7. In spite of the confusion, state courts in Florida, Maine, and Colorado have addressed the issue and held that restrictive statutes cannot be read to limit the constitutional and common law rights of patients to have artificial feeding tubes withdrawn. *Id.* at 7. The lower court in *Cruzan* affirmed this view, but the Missouri Supreme Court overturned this decision. *Cruzan v. Harmon*, 760 S.W. 2d. 408, 410 (Mo. 1988) (en banc).

37. As of January 1, 1989, 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. JOINT COMMISSION ON ACCREDITATION OF HOSPITALS, ACCREDITATION MANUAL FOR HOSPITALS (1988); *see* N.Y. PUB. HEALTH LAW § 2960 (McKinney Supp. 1989) ("appropriate for an attending physician, in certain circumstances, to issue an order not to [resuscitate] where appropriate consent has been obtained.") (emphasis added).

nosis. In other words, the DNR order should be treated like all other medical decisions in which the patient has the right to refuse a life-sustaining treatment.³⁸ If the patient is not competent, the decision should be reached after consultation between the physician and family members or the legal guardian.³⁹

Thus, for the competent patient, exercising the right to have life-sustaining treatment withheld or withdrawn should be relatively easy. The patient decides and communicates his decision to the health care provider. For the patient without such capacity, exercising such a right is more problematic. The application of the right for a competent patient will be addressed first.

II. THE COMPETENT PATIENT: THE "CAPACITY" TO FOREGO TREATMENT

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 accurately, has the capacity to make treatment decisions, when she can understand the relevant information, reflect on it in accordance with her values and goals, and communicate with caregivers.⁴⁰ Most often a person makes this decision with little trouble. Yet problems arise when fear, mental illness, or physical illness cloud a patient's judgment. In practice, if a patient remains in an incapacitated state due to a temporary condition,⁴¹ any determination on competency and treatment decisions should be postponed, if at all possible.

Very few court decisions have clearly defined the terms "capacity to consent to" or "refuse treatment." Most state legislatures, however, have established procedures for a court to determine a person's legal competency. Generally, the courts are wary about second-guessing the choice of a patient. Even if a patient's refusal of treatment seems irrational to the physician, this does not necessarily mean that the patient is incompetent. A patient may be depressed, have periods of confusion and a distorted sense of time, yet still retain the capability to understand the consequences of the decision to refuse treatment. In this type

38. *In re Dinnerstein*, 380 N.E.2d 134 (Mass. App. Ct. 1978) (first decision to uphold the validity of the "no code" or DNR order for the incompetent patient).

39. Once a decision is made, it should be documented in the medical record. Any significant improvement would void the order. *See supra* note 37.

40. THE HASTINGS CENTER GUIDELINES, *supra* note 26, at 23. 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 for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research. *See supra* note 24.

41. Such temporary conditions might result from severe pain, medication, intoxication, or withdrawal.

of case, most courts will not declare the patient incompetent.⁴²

A diagnosed mental illness or even commitment to a mental institution does not mean that a patient is per se incompetent to refuse treatment, as long as she understands the consequences of the decision.⁴³ 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.⁴⁴

In most cases, the determination of competency is not at issue. Recent state court decisions have affirmed the competent patient's right to refuse treatment, regardless of prognosis.⁴⁵ Consistent with the reasoning behind the doctrine of informed consent, the health care provider is to honor the refusal of the patient. A California court held that an incurable, but not terminally ill patient had a right to be withdrawn from a respirator even if that action would hasten his death.⁴⁶ The court held that to do otherwise would frustrate the very essence of the right of informed consent and the constitutional right to privacy.⁴⁷

In the much-publicized *Bouvia* case,⁴⁸ the same California court affirmed its position and held that a quadriplegic, who was not terminally ill, had the right to order the withdrawal of a nasogastric feeding tube, even if the action would hasten or cause her death.⁴⁹ The court found that such a decision was neither medical nor legal, and that the patient alone should make the decision.⁵⁰ More recently, the New Jersey Supreme Court declared that a competent woman with an incurable neurological disease, but for whom death was not imminent, had the right to have a respirator removed at home.⁵¹ The court recognized

42. See, e.g., *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. Ct. 1978) (finding a seventy-seven year old diabetic competent to refuse amputation of her leg because she did want to be an invalid or live in nursing home); *In re Quackenbush*, 383 A.2d 785 (N.J. Super. 1978) (seventy-two year old competent patient refused to have her gangrenous legs amputated).

43. See, e.g., *In re Maida Yetter*, 62 Pa. D. & C.2d 619 (Northampton County Ct. 1973) (patient permitted to refuse surgical biopsy for breast cancer if the patient understood that consequences of the decision might be death). *But cf.* *State Dep't of Human Servs. v. Northern*, 563 S.W.2d 197 (Tenn. Ct. App. 1978) (finding patient not competent to decide to refuse amputation of feet because he could not accept fact that his feet were infected).

44. For an outline of this issue, see M. MACDONALD, K. MEYER & B. ESSIG, *HEALTH CARE LAW, A PRACTICAL GUIDE* § 18.04-.05 (1987).

45. See *infra* notes 46-52.

46. *Bartling v. Superior Court*, 209 Cal. Rptr. 220 (Ct. App. 1984).

47. *Id.*

48. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1987).

49. *Id.* at 306.

50. *Id.* at 305.

51. *In re Farrell*, 529 A.2d 404 (N.J. 1987).

that her life was filled with pain and that it would be unfair and unjust to force her to live any longer.⁵²

III. THE INCOMPETENT PATIENT: HOW TO EXERCISE THE RIGHT?

Most of the "right-to-die" cases in the last decade have not involved competent patients. Not surprisingly, the doctrine of informed consent has protected the right of the competent patient to refuse treatment, and the right has been accepted by both the medical and legal communities. Courts, however, have been presented with the challenge of defining the parameters of the right of the patient incapable of making her 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) who should be the appropriate surrogate decisionmaker? and (2) what decisionmaking standards should be applied?

A. *Who Should Decide?*

Traditionally, the physician relied on the family⁵³ to assist in making medical decisions for the incompetent patient. This medical custom makes sense given the family's unique relationship with the patient. As the *Quinlan* court pointed out, it is the family who is most knowledgeable and concerned with the welfare of the patient. Thus, the next of kin is recognized as a suitable decisionmaker.⁵⁴ Of course, it is possible that family members may have different values and therefore may be unable to separate financial or emotional concerns from appropriate decisionmaking. But absent a showing of bad faith or a physician's belief that the family does not have the best welfare of the patient in mind, the family should be the primary decisionmaker.

Until very recently, the only way to free the physician or institution from potential civil or criminal liability for withdrawing or withholding life-sustaining treatment based on a family member's consent was to go to court,⁵⁵ either to have a family member appointed as a

52. *Id.*

53. The traditional definition of the family may not be appropriate in a number of circumstances. For example, does a homosexual AIDS patient's family include the patient's cohabitant of ten years?

54. *In re Quinlan*, 355 A.2d 647, 670 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

55. To date, no one has successfully brought criminal charges against a physician or health care institution for withdrawing life-sustaining treatment, including the removal of a feeding tube. See *Barber v. Superior Court of California*, 195 Cal. Rptr. 484 (Ct. App. 1983) (dismissed criminal charges against physicians for removal of feeding tube). For an excellent article on criminal liability and its application to this area see Glantz, *supra* note 27. Nor has there been a single reported case of 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 re-

guardian or to obtain judicial approval of the decision itself.⁵⁶ Unfortunately, going to court is burdensome, expensive, and inappropriate in most cases, since the court is ill-equipped to make such personal and complex ethical decisions.⁵⁷ In recent years at least half of the states in response to this problem have explicitly authorized by statute or court opinion the family of adult patients to authorize termination of treatment without going to court.⁵⁸

Within the last two years, the New Jersey Supreme Court has set out comprehensive guidelines for family decisionmaking.⁵⁹ That court declared the family as the primary decisionmaker, in spite of the fact that New Jersey had no statute on point.⁶⁰ The court also stated that with concurrence by the attending physicians and confirmation of the medical condition from two independent physicians, the family, without a court order, had the right to refuse treatment on behalf of the incompetent patient.⁶¹ The family need not present clear and convincing evi-

ported cases recently in which courts have recognized a battery action for damages for failure to abide by the wishes of the patient or her 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. *Leach v. Shapiro*, 469 N.E.2d 1047 (Ohio Ct. App. 1984). California also recognized a cause of action, including the payment of attorneys' fees (under its private attorney general statute), for a hospital's failure to remove the respirator of a competent patient after his informed request that it be removed. *Bartling v. Glendale Adventist Medical Center*, 228 Cal. Rptr. 847 (Ct. App. 1986). In *Bouvia v. Los Angeles County*, 241 Cal. Rptr. 239 (Ct. App. 1987), the California court permitted a cause of action for damages based on feeding the patient against her will.

In practice, plaintiffs have difficulty winning these types of cases against health care providers. The difficulty arises because the provider may seem very sympathetic, it may be hard to prove knowing disregard for the patient's wishes, and damages are very difficult to assess. The possibility of obtaining payment for attorney fees, however, may be enough of an incentive to honor the patient's decision or that of his surrogate decisionmaker to refuse treatment.

56. Generally, the trend has been to remove noncontroversial cases from the court's jurisdiction. Yet a number of cases will continue to come to court. Based on their assessment of liability risk, health care providers will continue to either seek the court's protection prior to terminating treatment or force families to get judicial approval. A court may then order health care providers to honor the family's right to refuse life-sustaining treatment on behalf of the incompetent family member. A misunderstanding of the law and a fear of liability continue to pervade medical practice in this area. For greater insight into this area, see Areen, *The Legal Status of Consent Obtained From Families of Adult Patients to Withhold or Withdraw Treatment*, 258 J. A.M.A. 229, 231 (1987). See Letters to the Editor, 258 J. A.M.A. 2696-97 (1987).

57. Areen, *supra* note 56, at 233.

58. *Id.* at 230.

59. See *In re Jobs* 529 A.2d 434 (N.J. 1987); *In re Farrell*, 529 A.2d 404 (N.J. 1987).

60. *Farrell*, 529 A.2d at 414 ("We believe that this tradition of respect for and confidence in the family should ground our approach to the treatment of the sick.").

61. *Id.*

dence of what the patient would have wanted. Instead, they must simply show the ability to do the best they can under the circumstances, and to make good faith decisions based on their knowledge of the family member.⁶²

Some state statutes also recognize the family as primary decision-maker without court intervention. "Substituted consent" statutes enumerate a priority list of persons the provider must turn to for consent to treatment.⁶³ Statutes vary regarding the conditions in which the surrogate may also authorize the termination of life-sustaining treatment.⁶⁴ Informed consent and living will statutes may also be a source of authority for the family surrogate to request the termination of life-sustaining treatment. Additionally, a durable power of attorney may also specify a family member (or friend) as the proxy for medical decisions. Of course, if the family disagrees or demonstrates bad faith, or no family member is available, the family cannot be relied on as the surrogate decisionmaker.

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 the statutes differ as to whether they specify authority for health care decisions.⁶⁵ 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.⁶⁶ However, some guardianship statutes reserve "life and death" medical decisions for the court.⁶⁷

Even in those states in which the court does not routinely require court approval, there will be disputed cases.⁶⁸ At such times, the court

62. *Id.* Courts in Arizona, California, Connecticut, Florida, Georgia, Massachusetts, Tennessee, Virginia, and Washington also recognize the family as the primary decisionmaker. See AMERICAN ASSOCIATION OF RETIRED PERSONS: LEGAL COUNSEL FOR THE ELDERLY, DECISION-MAKING, INCAPACITY, AND THE ELDERLY 111 (1987) [hereinafter LEGAL COUNSEL FOR THE ELDERLY]. *But cf. In re O'Connor*, 531 N.E.2d 607 (N.Y. 1988) (the court required clear and convincing evidence, but did not recognize application of the family's substituted judgment).

63. LEGAL COUNSEL FOR THE ELDERLY, *supra* note 62, at 111-12.

64. *E.g.*, N.Y. PUB. HEALTH LAW § 2965 (McKinney Supp. 1988). The New York statute provides the authority for family members to consent to DNR orders. Additionally, the New York State Department of Health's pamphlet, *Do Not Resuscitate Orders: A Guide for Patients and Families*, is distributed to all patients upon their admission to a hospital or nursing home.

65. LEGAL COUNSEL FOR THE ELDERLY, *supra* note 62, at 112. Ohio requires that the court make the decision. *Id.* Civil rules of procedure also provide for the appointment of a guardian ad litem to represent the interest of the incompetent patient in health care decisionmaking cases.

66. *Id.*

67. *Id.*

68. When a physician's personal or religious beliefs conflict with a patient's or

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.⁶⁹

Over the last few years, other alternatives have emerged that help assure that the interests of the patient are protected. There has been heightened interest in the use of institutional ethics committees for resolving the complex issues raised by foregoing life-sustaining treatment. These committees, with a diverse membership of professionals, such as physicians, nurses, ethicists, and attorneys, along with the public, could advise on various ethical and social considerations surrounding treatment decisions.⁷⁰ 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 decisionmaker for the incompetent patient. As ethics committees develop in more institutional settings, they should take on a more active role in facilitating decisionmaking outside the courtroom.

Another alternative explored for assuring the protection of pa-

surrogate's decision to terminate life-sustaining treatment, the physician may transfer the patient to another physician, subject to liability for abandonment if appropriate arrangements for transfer are not made in good faith. Both common law and 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 based on the unrealistic fear of liability or convenience? To date, the courts are split on this "accommodation." See *Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626 (Mass. 1986) (requiring hospital, which refused to remove feeding tube for ethical reasons, to cooperate in transferring the patient to another facility); *Delio v. Westchester County Medical Center*, 516 N.Y.S.2d 677 (App. Div. 1987) (transfer to another facility was arranged when hospital, ordered to either remove artificial feeding and hydration tubes from patient or assist in his transfer to his home or another facility, refused to remove the tubes). *But cf. In re Jobes*, 529 A.2d 434 (N.J. 1987) (refusing to force transfer of nursing home patient whose family won right to have her feeding tube removed in contradiction to nursing home's policy written after her arrival); *In re Requena*, 517 A.2d 886 (N.J. Super. Ct. Ch. Div. 1986) (denying hospital's request to have severely neurologically impaired patient either fed artificially, discharged or transferred), *aff'd* 517 A.2d 869 (N.J. Super. Ct. App. Div. 1986) (per curiam); THE HASTINGS CENTER GUIDELINES, *supra* note 26, at 138.

In practice, it may become more difficult for the patient or the institution to find another facility willing to accept the patient. As more facilities address the issue of transferability in advance, they may set policies that prohibit the removal of feeding tubes. Consequently, this may prevent patients from being able to exercise the rights that courts and legislatures have now granted.

69. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

70. See PRESIDENT'S COMM'N, *supra* note 24, at 163. Maryland law requires that each acute care hospital have a "patient care advisory committee" to advise on difficult treatment decisions. MD. HEALTH-GEN. CODE ANN. § 19-370 to -374 (1981 & Supp. 1988).

tients' rights is the "surrogates committee." This committee provides surrogate decisionmakers for those incompetent patients who lack family.⁷¹ 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, 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. Even though surrogate committees are a positive step in assuring the rights of the incompetent patient, mechanisms must continue to develop for protecting these rights in the most effective and efficient manner.

B. *Decisionmaking Standards*

At this point it is appropriate to return to the case of Karen Quinlan, a young adult who was in a persistent vegetative state.⁷² In 1975, her father first petitioned a New Jersey court to be appointed her guardian for permission to withdraw her from a respirator.⁷³ Mr. Quinlan did not, however, request the removal of her feeding tube.⁷⁴ Her attending physicians and the hospital would not remove the respirator because they deemed it contrary to medical, ethical, and legal standards. They feared both criminal and civil liability as well.⁷⁵

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.⁷⁶ This right, which outweighed any state interest, would nevertheless be lost unless it could be exercised by another on her behalf. The court set out the following balancing test: "the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."⁷⁷ Her treatment was sufficiently invasive and her condition and prognosis sufficiently dim so as to allow the termination of life-sustaining treatment. If Karen's guardian, fam-

71. THE HASTINGS CENTER GUIDELINES, *supra* note 26, at 25-26. 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 interest standard to determine whether or not to proceed with treatment. N.Y. MENTAL HYG. LAW §§ 80.01, 80.05 (McKinney Supp. 1988). 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 (1988).

72. *In re Quinlan*, 355 A.2d 647, 654 (N.J.).

73. *Id.* at 657-58.

74. *Id.* at 647.

75. *Id.*

76. *Id.* at 664.

77. *Id.* See Capron, *supra* note 14, for a critique of this "waxing-and-waning" right to privacy.

ily, and attending physicians concurred, and an "ethics committee"⁷⁸ confirmed that no reasonable possibility existed of recovery to a sapient state, then the respirator could be withdrawn, and all parties would be immune from civil and criminal liability.⁷⁹

Since the *Quinlan* case, most state courts have considered cases involving formerly competent persons who are terminally ill or in a persistent vegetative state. A few cases have involved the chronically ill who may lack decisionmaking capacity because of senility, but are not unconscious or facing life-threatening conditions.⁸⁰ A few more cases have dealt with the mentally retarded, or the "never competent" patient.⁸¹ From these cases, decisionmaking standards for the termination of treatment for the incompetent patient have emerged.

Most jurisdictions that have addressed decisionmaking criteria have adopted the "substituted judgment" standard.⁸² This standard focuses on what the incompetent patient would have decided, if the patient were capable of communicating her own decision. Generally, the application of substituted judgment necessitates that the patient had been competent at one time and had in some manner expressed her preferences or values concerning life-sustaining treatment.⁸³ Although this may be a difficult task, most jurisdictions cling to this approach as the best way to preserve the right to self-determination of the incompetent patient. The 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 relevant when attempting to evaluate how the patient would judge whether to forego life-sustaining treatment.⁸⁴ It is rare,

78. The committee was, in fact, to function as a prognosis committee. *In re Quinlan*, 355 A.2d at 672.

79. Contrary to all predictions, once the respirator was removed, Karen Quinlan remained alive for almost ten years.

80. See, e.g., *In re Conroy*, 486 A.2d 1209 (N.J. 1985); see also *infra* notes 108-66 and accompanying text.

81. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977) (court acted as the surrogate decisionmaker, determining that a severely retarded patient with leukemia would have refused chemotherapy based on limited prognosis and trauma caused by pain and suffering associated with treatment).

82. *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (en banc); *John F. Kennedy Hosp. v. Blutworth*, 452 So. 2d 921 (Fla. 1984); *Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626 (Mass. 1986); *In re Jobes*, 529 A.2d 434 (N.J. 1987); *In re Conroy*, 486 A.2d 1209 (N.J. 1985). *But cf. In re O'Connor*, 531 N.E.2d 607 (N.Y. 1988).

83. U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY 118 (1987) [hereinafter LIFE-SUSTAINING TECHNOLOGIES]. *But cf. Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977) (applying the substituted judgment test for severely mentally retarded man who had never been competent).

84. LIFE-SUSTAINING TECHNOLOGIES, *supra* note 83, at 118-19.

however, for substituted judgment to function as a purely subjective test.

"In treatment decisions made in the name of incompetent patients, no matter how much evidence we have of subjective intent and actual wishes or how well the guardian knew the patient, and how well-intentioned the patient's guardian, family and physician may be, there will always be some residual doubt that the decision expresses or effectuates the patient's right of self-determination. In less optimal circumstances, the doubt is greater. As doubt grows, factors other than those relating solely to the patient's wishes or views necessarily intrude upon decisionmaking."⁸⁵

New York courts have rejected the substituted judgment standard, holding that there must be "clear and convincing" evidence of an incompetent patient's previously expressed wishes in order to decline life-sustaining treatment.⁸⁶ A signed "advanced directive" in which the patient, while competent, expresses his wishes with respect to life-sustaining treatment will satisfy this evidentiary standard.⁸⁷ Thirty-eight states and the District of Columbia now have enacted natural death, living will, or death-with-dignity statutes that grant statutory recognition to such advanced directives.⁸⁸ Even in those states without these statutes, the courts have viewed the existence of such a directive as strong evidence of the patient's wishes.⁸⁹

Typically, living will statutes provide for refusing life-sustaining treatment when the patient's condition becomes "terminal" 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.⁹⁰ 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 comply in good faith with

85. *In re Jobs*, 529 A.2d 434, 455 (N.J. 1987) (Handler, J., concurring).

86. *In re O'Connor*, 531 N.E.2d 607 (N.Y. 1988) (stating the policy that "if an error occurs it should be made on the side of life."). For a more in-depth discussion of *In re O'Connor*, see *infra* notes 152-66. *But cf. In re Beth Israel Medical Center*, 519 N.Y.S.2d 511 (Sup. Ct. 1987) (applying a "best interests" hybrid test to the decision whether an incompetent elderly woman could forego life-saving amputation of a gangrenous leg).

87. *In re O'Connor*, 531 N.E.2d at 613.

88. For a state-by-state analysis, see HANDBOOK, *supra* note 3; see also Gelfand, *Living Will Statutes: The First Decade*, 1987 WIS. L. REV. 737.

89. Gelfand, *supra* note 88.

90. For example, Missouri's living will statute specifically excludes any procedure that provides nutrition or hydration from its definition of a "death-prolonging" procedure. MO. ANN. STAT. §459.010(3) (Vernon 1986 & Supp. 1989).

a properly executed living will.⁹¹

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, because the statute may only go into effect when death is imminent, the statute fails to cover the patient in a persistent vegetative state, as in the case of 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.⁹²

On a positive note, the statutes 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.⁹³

In any case, the living will does not represent the exclusive vehicle for exercising the right to forego treatment. Another statutory alternative gaining 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 decisionmaker when the individual no longer remains competent to make decisions.⁹⁴ Most state legislatures did not create DPAs in order to specifically deal with medical decision-making, but rather with financial matters. Yet, in a recent case, the New Jersey Supreme Court affirmed the proxy's right to act on behalf of a persistent vegetative patient, to have the nursing home provider remove her nasogastric feeding tube.⁹⁵

A number of states have recently amended their general DPA statutes or passed new statutes that specifically allow for a proxy to make medical decisions.⁹⁶ Any competent person may appoint a proxy to act on her behalf once declared incapable of making her own medical decisions. A proxy may have the power to provide, withhold, or withdraw consent to specific medical procedures. These medical procedures include the administration of CPR, antibiotics, artificial feeding and hydration, and blood transfusions. The proxy may also have the

91. See HANDBOOK, *supra* note 3; Gelfand, *supra* note 88.

92. See HANDBOOK, *supra* note 3.

93. In fact, over two out of three physicians surveyed in 1988 believe that they should have living wills available in their offices. AMERICAN MEDICAL ASSOCIATION, AMA SURVEYS OF PHYSICIAN AND PUBLIC OPINION ON HEALTH CARE ISSUES 25-26 (1988).

94. For an excellent discussion and references on the durable power of attorney, see E. COHEN, APPOINTING A PROXY FOR HEALTH-CARE DECISIONS (1987) (unpublished manuscript) (available from the Society for the Right to Die).

95. *In re Peter*, 529 A.2d 419 (N.J. 1987).

96. See E. COHEN, *supra* note 94.

power to interpret a living will and, if necessary, resort to obtaining court authorization regarding treatment decisions or to request civil damages for not honoring the proxy's decision.⁹⁷

Most patients do not leave explicit instructions nor execute advanced directives.⁹⁸ If there is no advanced directive nor other reliable evidence of the patient's wishes, the surrogate may utilize the "best interest" standard. This traditional guardianship standard allows the surrogate to objectively weigh the benefits and burdens of treatment to determine how a reasonable person in the patient's circumstances would promote her well being.⁹⁹ Under no circumstances should the social worth of the patient enter into the formulation. This remains particularly critical when the patient is mentally retarded or elderly and institutionalized.¹⁰⁰

The decisionmaker determines whether the burdens of the treatment outweigh the benefits of the treatment, weighing such factors as:

- (1) the age of the patient;
- (2) the patient's life expectancy with and without treatment;
- (3) the anticipated degree of pain with and without treatment;
- (4) the extent of the patient's physical and mental disability;
- (5) the quality of life *to the patient* with and without treatment (any pleasure, enjoyment, or satisfaction to be gained from continued existence);
- (6) the risks, side effects, and the degree of invasiveness of treatment; and
- (7) the type of care required if life is prolonged compared to the care required presently.¹⁰¹

97. *Id.*

98. In 1982, a Lou Harris poll revealed that only about 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 about one-fourth had put their instructions in any written form. See 2 PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL RESEARCH, MAKING HEALTH CARE DECISIONS 241-42, Appendix B (1982).

99. See, e.g., *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (en banc) (upholding a trial court determination that a surrogate could direct the removal of a nasogastric tube based on the "best interest" standard).

100. See *infra* notes 108-66 and accompanying text.

101. See *In re Beth Israel Medical Center*, 519 N.Y.S.2d 511, 517 (Sup. Ct. 1987). The New York court considered, in addition to objective factors, 1) the religious or ethical beliefs of the patient, 2) the views of those close to her, and 3) statements, if any, made by the patient that indicate her views on life-sustaining treatment.

In practice, a few courts have blurred the distinction between the substituted judgment and the best interest standards, utilizing both in the same case. *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713 (Conn. Super. Ct. 1984); *In re Torres*, 357 N.W.2d 332 (Minn. 1984); *In re Conroy*, 486 A.2d 1209 (N.J. 1985). 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 interest

Although a presumption for treatment may exist, the court has recognized that it is not always in a patient's best interest to continue life-sustaining treatment.¹⁰²

Recently, ethical guidelines have emerged for applying the "best interest" standard to important categories of patients.¹⁰³ For the terminally ill patient two major considerations exist: (1) whether foregoing treatment will allow the patient to avoid the burden of prolonged dying with pain and suffering;¹⁰⁴ and (2) whether the patient has the potential benefit of achieving some satisfaction if she survives for a longer period of time.¹⁰⁵

For the patient with irreversible loss of consciousness, the benefit/burden analysis is different. These patients do not experience pain. The only possible benefit to these patients is that they may have been misdiagnosed and might 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, is outweighed by the emotional suffering and financial burden of treatment.¹⁰⁶

For the patient with the severe illness or a 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.¹⁰⁷

IV. THE SEVERELY DEBILITATED PATIENT: THE EVOLUTION OF LEGAL STANDARDS FOR THE INSTITUTIONALIZED ELDERLY

How far are we willing to extend the right of a surrogate to refuse

of the patient objectively through the eyes of a decisionmaker may coincide with the decision to terminate life-sustaining treatment.

102. *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (en banc).

103. THE HASTINGS CENTER GUIDELINES, *supra* note 26, at 28.

104. *Id.*

105. *Id.* at 28-29.

106. *Id.* at 29.

107. *Id.* On the other hand, some patients or surrogates may want all treatment provided, even when the provider deems it medically inappropriate under the circumstances. If a patient or her surrogate has the right to refuse life-sustaining treatment, does she also have a corollary right to demand that the provider utilize all means 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? See Brody, *Ethical Questions Raised by the Persistent Vegetative Patient*, HASTINGS CENTER REPORT, Feb.-Mar. 1988, at 33. To date, there is little guidance on this issue.

treatment for a patient who is neither terminally ill nor in a persistent vegetative state, but rather is chronically ill and senile?¹⁰⁸ Typically, this is the elderly patient 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?¹⁰⁹ And how will these decisions be influenced by cost implications? How can we continue to avoid making judgments about the "social worth" of these patients?

To date, only a few courts have expressly examined the special circumstances of these severely debilitated patients. Standards have been borrowed from those cases involving comatose, vegetative, or terminally ill patients. Yet, these are harder cases to consider.

Terminally ill patients, by definition, have a short time to live. The court in *In re Grant*¹¹⁰ held that a patient need not be comatose or in pain before the right to withhold life-sustaining treatment arises:

Certainly, the amount of pain endured by a dying patient is a significant factor, . . . but not the only factor. The individual's right to die with dignity must not be ignored. As one court has noted, a terminally ill patient may wish to avoid not only prolonged suffering, but also "[t]he ultimate horror . . . of being maintained in limbo, in a sterile room, by machines controlled by strangers."¹¹¹

A patient in a persistent vegetative state retains only the most primitive brain functions: heartbeat, breathing, the sleep/wake cycle, and some reflexive movements.¹¹² Since a person in a vegetative state has essentially no interaction with his environment, the patient receives virtually no benefits from life.¹¹³

These judgments become more unclear, however, when applied to patients who are neither comatose nor terminally ill. If the patient remains somewhat cognitive of and responsive to her environment, and if death does not appear imminent, the benefit-burden determination is difficult to quantify. To date, the courts have failed to clarify the significance of these factors.

The greatest danger in not considering all relevant factors is the possibility that the decisionmaker will make quality of life judgments

108. See *infra* notes 109-66.

109. The court considered similar factors in *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987) (en banc).

110. 747 P.2d 445 (Wash. 1987) (en banc) (the patient's mother sought an order authorizing the future withholding of mechanical and artificial life-sustaining procedures, including artificial nutrition).

111. *Id.* at 450-51 (quoting *In re Torres*, 357 N.W.2d 332, 340 (Minn. 1984)).

112. *Gray v. Romeo*, 697 F. Supp. 580, 582 (D.R.I. 1988).

113. See *In Re Quinlan*, 355 A.2d 647 (N.J.) (opining that most people would find such an existence "unendurable"), *cert. denied*, 429 U.S. 922 (1976).

based on social worth. These quality judgments are especially dangerous when age serves as a factor, for there may be an underlying feeling that the patient "has lived long enough." Yet age so often plays a factor in the *medical* decisionmaking process. For example, in the *Saikewicz* decision,¹¹⁴ one of the factors weighing against chemotherapy was Saikewicz' age, because "people of [his] age do not tolerate the chemotherapy as well as younger people and . . . the chance of a remission is decreased."¹¹⁵ The court specifically stated, however, that "[a]ge is irrelevant, of course, to the questions of the value or quality of life."¹¹⁶

In another case, *In re Spring*,¹¹⁷ a Massachusetts court held that dialysis treatment could be terminated on behalf of a seventy-nine year old senile patient who still retained some ability to interact with his environment. The court did not base its decision explicitly on the age of the patient, but on his inability to understand and cooperate with his treatment, and on the burdensome nature of dialysis.

Other courts are even less clear about the role of age as both a medical and objective quality of life factor. For example, in *In re Hier*,¹¹⁸ the court discussed the medical implications of the patient's age, but then characterized her as "a ninety-two year old person who is seriously ill and for whom life has little left to offer."¹¹⁹ Additionally, in *In re Beth Israel Medical Center*,¹²⁰ the court held that the burdens of an emergency amputation for an elderly patient outweighed the benefits of continued life.¹²¹ The court then noted that "[l]ife has no meaning for her."¹²²

Although courts find it difficult to tell whether age is a factor in an objective quality of life judgment, some courts have apparently recognized this danger and have nearly "bent over backwards" to avoid such judgments. In confronting this problem one court noted:

[A] distinction must be drawn between those who are unable to care

114. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

115. *Id.* at 432 n.17.

116. *Id.*

117. 405 N.E.2d 115 (Mass. 1980).

118. 464 N.E.2d 959, 964 (Mass. 1984) (patient's age of ninety-two made "the proposed gastrostomy substantially more onerous or burdensome . . . than it would be for a younger, healthier person"). *But cf. In re Clark*, 510 A.2d 136 (N.J. Super. Ct. Ch. Div. 1986) (holding benefits of continued life outweighed burdens of enterostomy surgery to maintain artificial feeding for forty-five year old patient with organic brain damage), *later proceeding*, 515 A.2d 276 (N.J. Super. Ct. Ch. Div. 1986), *aff'd*, 524 A.2d 448 (N.J. Super. Ct. App. Div. 1987).

119. 464 N.E.2d at 965.

120. 519 N.Y.S.2d 511 (Sup. Ct. 1987).

121. *Id.* at 517 ("[S]uch prolongation of her life would be simply cruel.").

122. *Id.*

for themselves due to infirmities of illness, age or other physical disabilities and those who are brain-dead or terminally ill, without hope of recovery, and are being kept alive solely by use of artificial means

...
 In the former, it is a function of humanity to care for those who are unable to care for themselves by reason of illness, age or infirmities. This function of humanity springs not from a consideration of the quality of life of the ill, but rather from the human spirit. It is the quintessential difference between man . . . and the lower forms of animal life.¹²³

The Supreme Court of New Jersey has applied special standards to an elderly, severely debilitated person. *In re Conroy*¹²⁴ involved a request by the guardian of an eighty-four year old, severely debilitated nursing home patient to remove a nasogastric feeding tube. The lower court had denied permission, holding that the right to terminate life-sustaining treatment on behalf of an incompetent patient was limited to comatose, brain-dead, or vegetative patients.¹²⁵ The New Jersey court, in considering this issue, discussed the special problems involved with elderly nursing home residents.¹²⁶ First, the court recognized New Jersey's strong public policy in favor of protecting the rights of nursing home patients,¹²⁷ and restricted its holding to them because of a number of state statutes that applied specifically to this population.¹²⁸ The court noted that an elderly institutionalized patient, "whatever his physical and mental limitations and life expectancy, has the same right to receive [or decline] medical treatment as a competent young person whose physical functioning is basically intact."¹²⁹ The court then went on to discuss the significant differences between *Quinlan*-type patients and *Conroy*-type patients. The court noted that:

We now are faced with [a case involving] elderly, formerly competent nursing-home residents who, unlike Karen Quinlan, are awake and conscious and can interact with their environment to a limited extent, but whose mental and physical functioning is severely and permanently impaired and whose life expectancy, even with the treatment, is relatively short. The capacities of such people, while

123. *In re Vogel*, 512 N.Y.S.2d 622, 624 (Super. Ct. 1986). The New York Court of Appeals in *In re O'Connor*, 531 N.E.2d 607, 614-15 (N.Y. 1988), expressed a similar sentiment. See *infra* notes 152-66 and accompanying text.

124. 486 A.2d 1209 (N.J. 1985).

125. *Id.* at 1219.

126. *Id.*

127. *Id.* at 1224.

128. *Id.* at 1219 n.1.

129. *Id.* at 1226 (citing N.J. STAT. ANN. § 52:27G-1 (West 1986)). The New Jersey statute states: "[I]t is the public policy of this State to secure for elderly patients, residents and clients of health care facilities serving their specialized needs and problems, the same civil and human rights guaranteed to all citizens." *Id.*

significantly diminished, are not as limited as those of irreversibly comatose persons, and their deaths, while no longer distant, may not be imminent. Large numbers of aged, chronically ill, institutionalized persons fall within this general category.¹³⁰

The New Jersey Supreme Court also highlighted the special problems of elderly patients who are institutionalized by noting:

First, residents of nursing homes are a particularly vulnerable population. [They] are often quite elderly, . . . suffer from chronic or crippling disabilities and mental impairments and need assistance in activities of daily living.

Second, [they] are often without any surviving family. . . . Thus, the involvement of caring family members that was an integral part of the decision-making process in *Quinlan* may not be a realistic possibility for many nursing-home residents.¹³¹

The court also noted that physicians are less available at nursing homes, and that nursing homes suffer from unique problems, including the problem of patient abuse.¹³² The court went on to hold that "[b]ecause of the special vulnerability of the mentally and physically impaired, elderly persons in nursing homes . . . , life-sustaining treatment should not be withdrawn or withheld . . . in the absence of a guardian's decision, made in accordance with the procedure outlined below"¹³³

The elaborate procedure that the New Jersey Supreme Court followed involved, in part, a set of three standards for decisionmaking.¹³⁴ The first standard is the "subjective test" which determines what the patient would have done if able to choose for herself.¹³⁵ Under this test, the decisionmaker weighs evidence of the patient's expressed intentions, the patient's religious convictions, the patient's consistent pattern of conduct, and the condition, treatment, and prognosis of the patient.¹³⁶

If not enough reliable evidence exists to satisfy the subjective test,¹³⁷ then the decisionmaker must apply one of two objective tests.¹³⁸ The "limited objective" test applies "when there is some trustworthy

130. *In re Conroy*, 486 A.2d 1209, 1228-29 (N.J. 1985).

131. *Id.* at 1237.

132. *Id.* at 1237-38.

133. *Id.* at 1240.

134. *Id.* The court also required an initial judicial determination of incompetency.

135. *Id.* at 1229.

136. *Id.* at 1229-31; see *supra* notes 82-85 and accompanying text.

137. The court noted that "in the absence of adequate proof of the patient's wishes, it is naive to pretend that the right to self-determination serves as a basis for substituted decision-making." 486 A.2d at 1231.

138. *Id.* at 1232. The two objective tests are, namely, the "limited objective" and "pure objective" tests.

evidence that the patient would have refused treatment, and [where] it is clear that the burdens of the patient's continued life with treatment outweigh the benefits of that life for him."¹³⁹ The court explained that the patient must be suffering continued and unavoidable pain, and that this burden must "markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life."¹⁴⁰

If there is no evidence of the patient's wishes, the "pure objective" test applies. Under this standard, the benefits of life with treatment must be outweighed by the burdens.¹⁴¹ A further requirement, however, is that "the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane."¹⁴²

The *Conroy* court cautioned that the adoption of these tests in no way served to:

[a]uthorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others. We do not believe that it would be appropriate . . . to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's "quality of life" or value to society seems negligible.¹⁴³

In applying these standards, the court denied the request to remove the feeding tube, finding none of the tests satisfied.¹⁴⁴ The record failed to establish a "clear" intent to decline life-sustaining treatment, and no conclusive evidence that Ms. Conroy experienced pain, distress, or thirst.¹⁴⁵ In practice, it is often difficult to obtain such evidence¹⁴⁶ from incompetent, bedridden patients.

There are limits to the *Conroy* analysis. For the tests to apply, the patient must: (1) be elderly and incompetent; (2) be a nursing home resident; (3) suffer from severe, permanent mental and physical disabilities; and (4) have a life expectancy of one year or less.¹⁴⁷ Some of these requirements have been modified in more recent New Jersey

139. *Id.*

140. *Id.*

141. *Id.*

142. *Id.* The court noted that life-sustaining treatment should not be withheld or withdrawn even under the pure objective test where the patient had previously expressed the desire that she be kept alive, regardless of any amount of pain. *Id.*

143. *Id.* at 1232-33.

144. *Id.*

145. *Id.* at 1242-43.

146. See Merritt, *supra* note 6, at 729 (difficulty of demonstrating sufficient evidence to meet tests).

147. *In re Conroy*, 486 A.2d at 1232.

cases. For example, the court in *In re Peter*¹⁴⁸ held that the *Conroy* subjective test "is applicable in every surrogate-refusal-of-treatment case, regardless of the patient's medical condition or life-expectancy."¹⁴⁹ The one-year life-expectancy requirement did not apply in determining whether life-sustaining treatment may be withheld from a patient in a persistent vegetative state, because the requirement has meaning only when a possibility of some benefit from continued existence exists.¹⁵⁰ *Conroy's* objective tests have also been criticized for their focus on the patient's pain, in part because the availability of pain-relieving medication may nullify the importance of this factor.¹⁵¹ Perhaps the focus on pain was an indirect attempt to limit the effect of societal judgments about the worth of an elderly, debilitated person's life.

Most recently, in *In re O'Connor*,¹⁵² New York's highest court refused to prevent the insertion of a nasogastric tube in an elderly, institutionalized patient. Mary O'Connor was a seventy-seven year old stroke victim, conscious but severely demented, unresponsive, unable to feed herself, and incapable of making medical decisions.¹⁵³ When the hospital requested permission from her daughters to insert a nasogastric tube, they both refused.¹⁵⁴ The daughters claimed that their mother had expressed that she did not want to be maintained by artificial means or to become a burden to her family.¹⁵⁵ The hospital consulted its ethics committee, and based on Mrs. O'Connor's medical condition, the committee advised that the nasogastric tube feeding should not be withheld.¹⁵⁶

148. 529 A.2d 419 (N.J. 1987).

149. *Id.* at 425.

150. *Id.* at 424.

151. See Merritt, *supra* note 6, at 729 ("The *Conroy* limited objective and pure-objective tests are inadequate because they ultimately focus on physical pain"); see also *Conroy*, 486 A.2d at 1247 (Handler, J., concurring in part and dissenting in part) ("Pain" thus eclipses a whole cluster of other human values that have a proper place in the subtle weighing that will ultimately determine how life should end.').

152. 531 N.E.2d 607 (N.Y. 1988).

153. *Id.* at 609.

154. *Id.* The daughters were both nurses and had arranged for a signed document to be placed in their mother's medical file in which they stated that it was their mother's "expressed wishes" not to have life support started or maintained. *Id.* Perhaps it was the existence of this document that prompted the hospital, Westchester County Medical Center, to seek consent prior to insertion of the feeding tube. Furthermore, the hospital had previously been a party to another case in which it was required to either withdraw a nasogastric tube from a patient in a persistent vegetative state or arrange for appropriate transfer. See *Delio v. Westchester County Medical Center*, 516 N.Y.S.2d 677 (App. Div. 1987). In practice, it may be rare for a hospital or nursing home to seek permission prior to the insertion of a feeding tube.

155. *In re O'Connor*, 531 N.E.2d at 609.

156. *Id.*

The hospital sought court authorization to insert the nasogastric tube.¹⁵⁷ Although the patient had not specifically articulated her position with respect to artificial feeding and hydration, the lower court found that New York's standard for clear and convincing evidence had been met by her "expressed wishes" to decline life support.¹⁵⁸

Following expedited review by the Appellate Division, which affirmed the lower court opinion, the hospital appealed to the New York Court of Appeals. In a 5-2 opinion, New York's highest court reversed, holding that her prior expressions failed to meet its clear and convincing evidence test. Based on Mrs. O'Connor's condition, the court held that the nasogastric tubes could not be withheld because: "Every person has a right to life, and no one should be denied essential medical care unless the evidence clearly and convincingly shows that the patient intended to decline the treatment under some particular circumstances."¹⁵⁹ Such evidence would include a specific writing, such as a living will or durable power of attorney, which would demonstrate a "firm and settled commitment"¹⁶⁰ to decline medical treatment, not established by casual remarks made to family members and friends.¹⁶¹

In rejecting the substituted judgment standard adopted by most other jurisdictions,¹⁶² the court appeared to distrust the family because it might impose quality of life judgments contrary to interests of the patient. The court held that "no person or court should substitute its judgment as to what would be an acceptable quality of life for another."¹⁶³ Yet the New York court did exactly this. It imposed its quality of life judgment upon Mrs. O'Connor. It was the court's position that her medical condition did not justify the withholding of a nasogastric tube. The court determined that Mrs. O'Connor's family could not

157. *Id.*

158. *Id.* at 611. For example, her daughters testified that she had repeatedly stated that she did not want to be kept alive by artificial means. Furthermore, during 20 years of hospital employment, a co-worker and long-time friend, as well as her daughters, testified that Mrs. O'Connor had stated that it was "monstrous" to be kept alive on "machinery, things like that" when one was "not going to get better." After nursing her husband and brothers through long illnesses, and upon returning home from a hospitalization for a heart attack, she also expressed the position that she never wanted life support to maintain her artificially. *Id.* at 608-11. The lower court concluded that her past expressions plainly covered withholding any form of life-prolonging treatment, even though Mrs. O'Connor had never discussed providing food and water with medical assistance, nor had she ever stated that she would adhere to her view and decline medical treatment by artificial means if that would produce a painful death.

159. *Id.* at 613 (citation omitted).

160. *Id.* at 613-14.

161. *Id.* at 614. Oral evidence would be considered, but would need to meet the clear and convincing standard.

162. See *supra* notes 82-85 and accompanying text.

163. *In re O'Connor*, 531 N.E.2d at 615-16.

be trusted to take into account her values, personal beliefs, background, and her prior statements concerning medical treatment. Nor could they serve as the surrogate to exercise her right to refuse the artificial feeding.

Perhaps if Mrs. O'Connor had been terminally ill or in a persistent vegetative state, the outcome would have been different. The court observed that:

Mrs. O'Connor does not have a terminal illness, except in the sense that she is aged and infirm. Neither is she in a coma nor vegetative state. She is awake and conscious; she can feel pain, responds to simple commands, can carry on limited conversations, and is not experiencing any pain. She is simply an elderly person who as a result of several strokes suffers certain disabilities, including an inability to feed herself or eat in a normal manner. . . . But that is true of many nursing home patients. The key thing that sets her apart—though there are likely thousands like her—is her inability to eat or obtain nourishment without medical assistance.¹⁶⁴

Although the court then conceded that Mrs. O'Connor expressed her desire not to be kept alive artificially if she could not care for herself, it rationalized that the record was not clear whether she might be able in the future to obtain food and water without medical assistance.¹⁶⁵ Thus, based on her uncertain prognosis, the court did not view Mrs. O'Connor's wishes as "clear and convincing" under the circumstances.¹⁶⁶

Obviously, the court was reacting to a perceived need to protect the institutionalized elderly from potential neglect. Yet, such a reaction in this case may be ill-advised. Particularly for those patients with caring and loving family members, the trend should not be to move back into the courtroom every time a treatment decision needs to be made. Of course, as our aging society grows, it is inevitable that more cases will involve minimally conscious and severely debilitated, elderly patients. Hopefully, the courts will discourage, and not encourage, such cases when family surrogate decisionmakers are available. For those patients without family, the courts, health care providers, and the public will struggle to reach consensus on how to establish standards that protect such patients from the indifference and abuse that both denies some patients necessary treatment while continuing treatment for others simply because no one cares enough to let it end.

CONCLUSION

In the last decade, the legal and ethical foundations for the right

164. *Id.* at 615.

165. *Id.*

166. *Id.*

to forego treatment have been well established. For the competent patient, the right is relatively easy to apply. For the incompetent patient, who is terminally ill or permanently unconscious, the majority of state courts that have addressed the issue have moved toward the development of decisionmaking standards and a preference that the family, and not the court, make treatment decisions on behalf of the patient. State legislatures have also made progress in promoting the development of advanced directives and the appointment of proxies for medical decisions. The next step will be to establish legal standards that protect the rights of severely debilitated patients in our aging society. Towards that goal, we must all initiate discussions with family, friends, and health care providers in order to clarify our position on foregoing life-sustaining treatment.