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Dealing with Terminally Ill Patients: An Institutional Approach

Larry I. Palmer

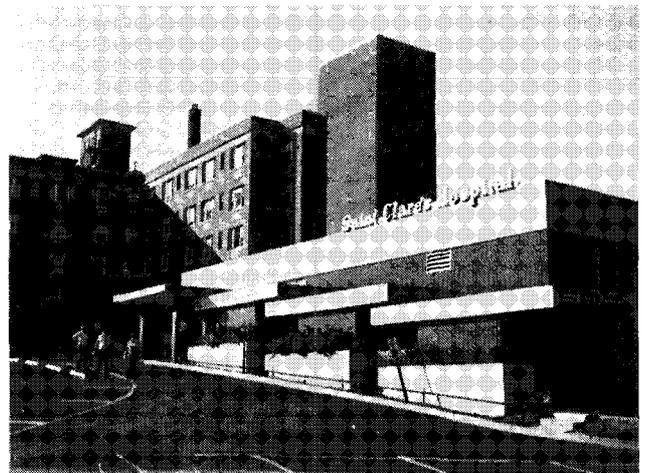
Decisions about the care of hopelessly ill and dying patients are never easy. At one time these decisions were private matters; health care providers and the patient or his family made decisions free from explicit scrutiny by others. Without much public knowledge the people directly affected undertook to resolve the ethical and medical issues presented by hopelessly ill and dying patients.

With the increased success of modern medicine in helping people who have experienced a total cessation of cognitive functions stay alive, public interest about the decisions involved in such activities has increased. One result of heightened public concern is that courts have begun to play a role in monitoring the fate of irremediably ill or dying patients. Judicial involvement has not produced or revealed any societal consensus for dealing with these patients. In fact, recent decisions involving terminally ill patients have diverged in approach and outcome. No new legal doctrine concerning when a patient has a "right to die" emerges from these opinions. Furthermore, since decisions implicating this right have become matters of public concern, the lack of social consensus about the methods and desirability of preserving human life has been apparent.

In trying to answer the various issues put before them, courts have looked to the doctor-patient relationship as a framework for analysis. Under this approach the courts have focused on structuring the decision making of the physician and the patient or his representative. By emphasizing the doctor-patient relationship, the courts have argued that their analysis preserves "medical ethics." The various procedures devised by courts are thus vehicles for preserving the value of life and diffusing responsibility for any decision.

I propose that the legal system should not focus exclusively on the doctor-patient relationship but instead become more sensitive to the institutional arrangement in which those doctor-patient relationships develop. Specifically, courts should rely on the hospital to devise procedures for

I wish to acknowledge the help of Dr. H. Richard Beresford, who, as a coteacher of the course on law and medicine, helped develop the ideas in this essay and commented on earlier versions of it.



Saint Clare's Hospital, scene of one of the first "right-to-withhold-treatment" cases

considering issues involving terminally ill patients. As part of my approach, the courts should be more explicit about the relationship between legal rules and medical science. By focusing on hospitals as institutions, the relationship between law and medicine could develop based on substantive interaction rather than frozen archaic standards.

There are benefits to both law and medicine from the adoption of an approach focused on the institutional settings of most of these cases. First, the legal analyses and solutions of the problems presented by these cases would be more disease-specific; rather than focusing solely on the "rights" of patients or physicians, the law would create a mechanism that recognizes the complexity and uncertainty of medical diagnosis and prognosis. Second, my approach would aid in the resolution of ethical issues present in these cases by frankly recognizing the role of other social institutions in deciding whether treatment should be provided or withheld. Third, I hope the proposed approach would lead legislatures to develop legal standards on some of the other major issues.

Current Judicial Doctrines

The highest state courts in New Jersey, Massachusetts, and New York have developed three different approaches to cases involving hopelessly ill or dying patients.¹ As the first step in demonstrating that these judicial opinions should be viewed as involving the demarcation of roles rather than as cases about rights (as claimed by all three courts), the three doctrines will be briefly described and criticized.

New Jersey. Despite being heralded as the first important right-to-die case, *In re Quinlan*² may be idiosyncratic. In *Quinlan* the New Jersey Supreme Court held that the guardian of a twenty-two-year-old woman, her father, was authorized to decide who should be Karen Ann Quinlan's attending physicians. The court further held that if those physicians and Quinlan's guardian concluded that there was no possibility of Quinlan recovering, they should jointly consult with a hospital body—called an ethics committee³—about any decision to discontinue treatment. If that committee agreed with the judgment of the guardian and treating physicians that recovery was not possible, the life-support treatment could be discontinued without liability on the part of any participant.

The *Quinlan* court had to assess issues of medical diagnosis and prognosis and devise a procedure for action to be taken. Karen Ann Quinlan was in a "persistent vegetative coma" with irreversible brain damage. Her breathing was assisted by a respirator. There was no clear explanation of why she had lapsed into a coma. The limited number of similar cases of young people in a persistent vegetative state made prognosis difficult in her case. Karen Ann Quinlan remains "alive" at the time of this writing, despite earlier predictions of her likely death. Even though Karen Ann Quinlan's condition was medically *sui generis*, the court, as it derived its set of legal procedures, was fully informed of the state of her medical condition.⁴

The New Jersey doctrine was founded on the notion that an adult patient has a constitutional right to privacy that allows the patient or a representative to cease or curtail treatment. The New Jersey court also implied that in some circumstances it would not be necessary to come before a court seeking declaratory relief but suggested that the use of ethics committees by the hospitals would be an acceptable means of approving the termination of treatment. Reliance on ethics committees would provide immunity from both civil and criminal liability.⁵

Massachusetts. After *Quinlan*, the Supreme Judicial Court of Massachusetts was presented with the case of *Belchertown State School v. Saikewicz*.⁶ Saikewicz was a sixty-seven-year-old man with myeloblastic monocytic

leukemia. He was also severely mentally retarded, having an IQ of ten and a mental age of about three years. Saikewicz had been institutionalized for fifty-three years. The prognosis for his leukemia was discussed extensively. Chemotherapy was recommended because 30 to 50 percent of the patients with that form of leukemia are treated by chemotherapy. While prognoses are difficult in cases of leukemia, doctors estimated that if left untreated, a patient in Saikewicz's condition and of his age would live for a matter of weeks or perhaps months.

When presented with a request by the parties to discontinue treatment, the court directed that a guardian be appointed and that a lower court review any decision, even if consented to by the guardian, to discontinue treatment of Saikewicz. The Massachusetts court agreed with the *Quinlan* court that the origin of the patient's right was Saikewicz's constitutional right of privacy. The appointment of the guardian was necessary because Saikewicz was legally incompetent and therefore had to have a representative. In this respect his severe mental retardation was an important aspect of the court's holding. The guardian was in effect being asked to seek judicial authorization to exercise Saikewicz's right of privacy and decline treatment.⁷

Saikewicz does not accurately reflect current Massachusetts doctrine. The court first announced that under some circumstances prior judicial approval was not required before termination of treatment for an incompetent patient.⁸ Then the Massachusetts court made it clear that the constitutional right to decline treatment was not absolute, since the court has ordered treatment for a competent adult prisoner.⁹ In its latest pronouncement, however, the Massachusetts court has reaffirmed the primary decisional role of courts in these life-and-death cases by requiring prior judicial approval before discontinuing treatment of an incompetent patient.¹⁰

The Massachusetts doctrine, in contrast to the New Jersey doctrine, emphasizes judicial review. The New Jersey doctrine saw the necessity of collective decision making by hospital committees, attending physicians, and the patient's representatives. Even though both doctrines are based on notions of the patient's constitutional right to refuse treatment, one court sees the judiciary and another sees collective institutions as the interpreter of those rights.

New York. In a recent opinion, *Matter of Storar*,¹¹ involving two cases, the New York Court of Appeals announced its position on how courts should respond to hopelessly ill or dying patients. In the first of these cases, involving Brother Fox, the court indicated that when there is "clear and convincing proof" that a patient in a persistent vegetative state previously indicated that he or she did not

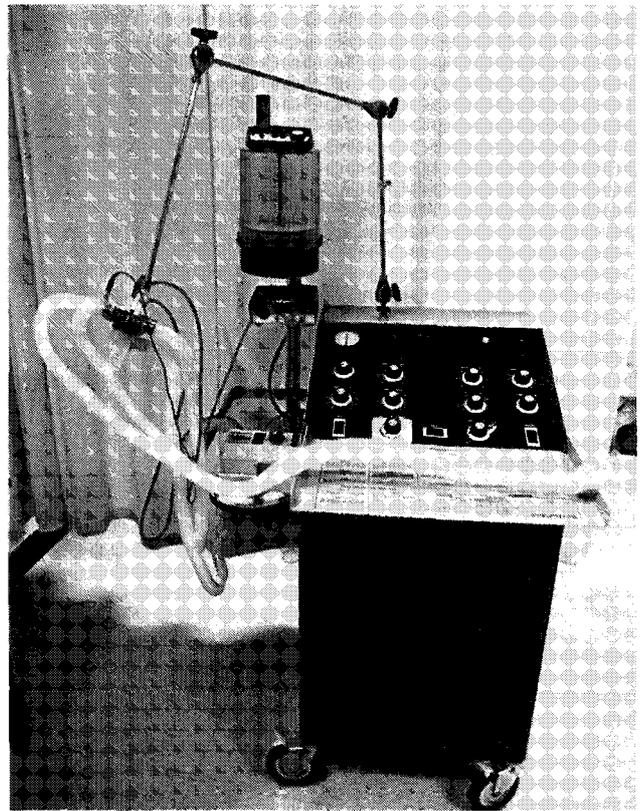
want life-supporting treatment, a guardian is authorized to discontinue treatment. Under the court of appeals' view, the guardian is not obligated to seek prior judicial approval of the decision to withhold treatment. The court further held that the authority to refuse treatment is grounded in common-law notions, rather than in a constitutional right, as the lower courts had assumed.¹²

In a second case involving a different medical situation, the legal analysis developed in *Brother Fox's* case was applied. The patient, John M. Storar, was a fifty-two-year-old male who suffered from terminal bladder cancer. Lesions in his bladder had led to internal bleeding. His physicians ordered blood transfusions to sustain his life. The patient was severely mentally retarded and had been institutionalized. The patient's mother and guardian refused permission for the transfusions, and the director of Storar's state residence sought an order permitting the blood transfusions. The court of appeals held that the judicial order for a blood transfusion was appropriate, since the incompetent adult was like an infant in the sense that he could not have expressed his desires about life-sustaining treatment.¹³

Comparison. There are significant differences in analysis among the foregoing decisions. First, the source of the "right to withhold treatment" exists as a matter of constitutional law in *Quinlan* and *Saikewicz* and of common law in *Storar*. The obvious implication of the difference is that the New York court's analysis in *Storar* leaves theoretically greater latitude for legislative action. The New York court explicitly invited legislative solutions.¹⁴

Second, there is a difference in the judicial assessment of which institution, if any, should ratify the decision to withhold or curtail treatment. The New Jersey court placed its faith in collective decision making—the guardian, the hospital committee, the attending physician—outside the court. The Massachusetts court insisted on judicial approval of the decision to withhold treatment, except in some very limited circumstances. The New York court indicated that prior judicial approval was not required if there was clear evidence of the patient's intentions in this type of situation.¹⁵

Third, since the various courts rely on different procedural devices in making decisions that come before them, patients, relatives of patients, physicians, and hospitals are encouraged to act in certain ways. *Quinlan* encourages hospitals to establish prognosis committees to monitor cessations of treatment. *Saikewicz* encourages parties to bring most cases to courts for involvement in the decision to withhold or discontinue treatment. *Storar*, by making the "clear and convincing proof" determinative of the patient's intentions, encourages the practice of writing "living wills,"



where a prospective patient's attitudes toward life-sustaining treatment can be expressed.¹⁶

If the New York court's analysis were viewed as the high point of development of an analysis for a new area of the law, one might be reasonably satisfied with the two main features of the doctrine:

1. A common-law right exists for persons, including incompetents, to choose to have life-sustaining treatment withheld.
2. The right can be exercised without prior judicial supervision provided there is "clear and convincing evidence" of the patient's intentions.

The New York doctrine might be viewed as sufficiently attractive to justify its being adopted by other courts. But the court of appeals is naive in its treatment of the degree of medical uncertainty in most cases. As a result, while the doctrine appears to be legally tidy, the court has not established for the many cases standards of conduct that can be applied easily.

An Institutional Solution: Legal Standards for Care of Terminally Ill Patients

The courts' failure to evaluate the role of medical science in their opinions has several important consequences. First, the courts seem to recast the medical facts to fit their proposed doctrines, ignoring medical and scientific uncertainty in developing their legal analyses. Second, the role of competing institutions, such as families, state facilities for the developmentally disabled, hospitals, and so on, is not openly acknowledged in the judicial opinions.

In my view, since the decisions about terminally ill patients are made within the institutional context of the hospital, the hospital should establish a decision-making process for the participants in the decision to discontinue or withhold treatment. I suggest that hospitals should establish medical prognosis committees to deal with patients. After consulting with family, nurses, and others, the attending physician should be required to bring before the committee his or her request to terminate or curtail treatment to patients in acute vegetative states, to patients suffering certain degenerative brain diseases, or to patients who have experienced "brain death." The committee would have the responsibility to accept or reject the doctor's prognosis.

The primary purpose of this committee is to objectify that which can be objectified, the medical prognosis. The other purpose is to provide assurance to the hospital as an institution that the various individuals within it are exercising their professional responsibilities vis-à-vis patients. This committee is not an ethics committee that could legitimate a decision to terminate treatment.

The consultation process is to ensure that the doctor-patient relationship is maintained as the fundamental basis for ethical decisions. If the doctor is not willing to take personal responsibility for the decision, he or she should not propose to the patient or the patient's representative that a certain action be taken. Ethics are a matter for all people in the society, not simply the doctors involved.

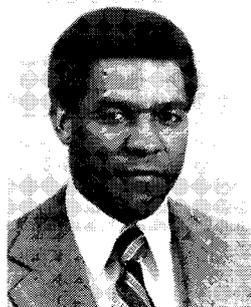
If such committees were effective, perhaps legislatures would be encouraged to enact legislation that would require hospitals to have an additional committee to legitimate the discontinuation of treatment. A bill might read something like the following: "When death is a likely consequence for an adult patient, no order to withhold or terminate treatment should be undertaken by a physician unless an appropriate hospital committee has reviewed and approved the decision to withhold or terminate treatment." This broader committee legislation would legitimate the proposed committees and create other committees to deal with aspects of such cases other than medical prognosis. For instance, the

real problem in the case of John Storar is that there is no one to exercise the decision that the New York Court of Appeals says is his to make. An appropriate committee for the Storar case is a committee composed of employees of the state residence where he lives, social workers, clergy, and laypeople. Furthermore, a committee in Storar's case must be able to support the physician's ethical decision as it contends with the conflicting views of the guardian and the state official. This second kind of committee would not replace the refusal of a guardian or a competent individual or an attending physician to curtail treatment.

These court cases present us with an opportunity to think about structuring the legal system in such a way that hospitals and other institutions could become more visible and be given more credence. We could thus rely on the health care institutions to help exercise control over the professionals who are operating within these institutions. In addition, we could allow medicine to play its appropriate role in the society and allow law to play its role of providing order in situations of deep conflict.

I am not offering a legal definition of death or the end of all litigation concerning termination of treatment. Rather, my approach to this issue allows law to leave some questions unresolved, perhaps to be resolved by others outside the institution of law.

The suggested approach reflects a belief that the lack of social consensus about the care of hopelessly ill and dying patients is a function of modern medicine itself. The approach therefore encourages courts to define the role of law in relation to the realities of modern medicine and to avoid existing analyses of "consent" that provide little practical guidance for health care providers or for their legal consultants. The risk of the current approach of focusing on the doctor-patient relationship is that law will be ignored, either because it fails to take account of the value system of modern medicine or because it inhibits the proper functioning of medicine—a major institution of the society.



Professor Palmer teaches criminal law, criminal procedure, children and the law, and law and medicine.

1. Although I will focus only on New Jersey, Massachusetts, and New York, the judiciaries of other states have also dealt with issues surrounding the terminally ill [e.g., *Satz v. Perlmutter*, 379 So. 2d 359 (Fla. 1980)].

2. 70 N.J. 10, 355 A. 2d 647 (N.J. 1976), *cert. denied sub nom. Garger v. N.J.*, 429 U.S. 922 (1976).

3. Despite the court's label of "ethics committee," the committee was to function as a medical prognosis committee rather than as a body to decide ethics.

4. *Supra* note 2, at 51, 355 A. 2d at 669.

5. *Id.* at 55, 355 A. 2d at 672.

6. 373 Mass. 728, 370 N.E. 2d 417 (Mass. 1977).

7. *Id.* at 759, 370 N.E. 2d at 424.

8. *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E. 2d 134 (Mass. App. 1978).

9. *Commissioner of Correction v. Myers*, Mass. Adv. Sh. (1979) 2523, 399 N.E. 2d 452 (Mass. 1979).

10. *In re Spring*, Mass. Adv. Sh. (1980) 1209, 405 N.D. 2d 115 (Mass. 1980).

11. 52 N.Y. 2d 363, 420 N.E. 2d 64 (N.Y. 1981).

12. *Id.* at 379, 420 N.E. 2d at 72.

13. *Id.* at 382, 420 N.E. 2d at 73.

14. *Id.* at 382-83, 420 N.E. 2d at 74.

15. *Id.*

16. The *Storar* court implies that "living wills" might be used. 52 N.Y. 2d 376-77, 420 N.E. 2d 70-71 (N.Y. 1981). *In re Living Will*, 5 *Nova L. J.* 445 (1981) encourages the use of "living wills," or documents executed by people during their lifetime that express their wishes concerning medical treatment in contemplation of illness or death. A more complete analysis of this problem would require us to examine the institutional context in which living wills become operative. Imagine that one spouse has signed a living will and is now comatose; contrary to the desires expressed in a living will, the other spouse does not want treatment discontinued. In this situation, is it appropriate under an institutional approach for a doctor to discontinue treatment?