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# Judges at the Bedside: The Case of Joseph Saikewicz

George J. Annas

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By George J. Annas, J.D., M.P.H.

In what may prove to be the most controversial medicolegal decision of the year, the Massachusetts Supreme Judicial Court has ruled that, in certain cases, courts are the proper forum in which life-sustaining medical decisions should be made.[1] The controversy goes deep. It involves questions of who should make life-prolonging decisions, in what forum, and on what criteria. Until the last few years, these questions arose almost exclusively in the context of Jehovah's Witnesses cases — cases in which life-saving blood transfusions were being refused for religious reasons. But with society's increasing consciousness about the way people die in hospitals, medical decisions are increasingly coming under public scrutiny.

Death, of course, is a natural process and a uniquely personal experience. If pressed to categorize it, most would probably term the major controversies surrounding it ethical, rather than medical or legal. Nevertheless, there is a trend to ask the courts whether or not life-sustaining treatment should or should not be withheld from patients who are unable to make this decision themselves. Judges are asked to decide this question, not because they have any special expertise, but because only they can provide the physicians with civil and criminal immunity for their actions. In seeking this immunity, legal considerations quickly transcend ethical and medical judgments.[2]

Until now, the Quinlan case was the most significant case on these issues.[3] Legally more significant, however, is the case of Joseph Saikewicz. When first heard in probate court, Mr. Saikewicz was a sixty-seven year old gentleman with an I.Q. of ten and a mental age of approximately two years, eight months. He was profoundly mentally retarded, had been institutionalized all of his life, and was unable to communicate verbally. On April 19, 1976, he was diagnosed as suffering from acute myeloblastic monocytic leukemia, an invariably incurable disease.

The only currently known treatment for this condition is chemotherapy which offers a thirty to fifty per cent chance of a remission of two to thirteen months duration. Such treatment, however, has serious side effects, including pain, discomfort, pronounced anemia, bladder irritation, loss of hair, bone marrow depression, and, in rare cases, death. Because of these side effects, and the fact that Mr. Saikewicz would not understand the reason for the pain he was experiencing, he would probably have had to have been physically restrained during the weeks in which the drugs were administered and daily blood transfusions performed. Left untreated, it would be expected that he would live for a number of weeks or perhaps several months, after which time he would probably die a natural and painless death.

One week after the diagnosis was established, the superintendent of the institution at which Saikewicz was a resident petitioned the probate court for the appointment of a guardian empowered to make the necessary decision concerning his medical care. The judge appointed a guardian *ad litem* who, together with two physicians, testified against treatment. The judge entered an order that no such treatment be administered. The order, dated May 13, 1976, was based on the judge's findings that the factors favoring chemotherapy (chance of increased life expectancy and the fact that most people in his situation would accept such therapy) were outweighed by factors against treatment (the patient's age, his inability to cooperate with treatment, the expected side effects, the low probability of remission, immediate suffering, and the quality of life possible if a remission resulted).

An immediate appeal was taken. The Massachusetts Supreme Judicial Court (S.J.C.) affirmed the decision on July 9, 1976, saying that a full opinion would follow. On September 4, 1976, Saikewicz died of bronchial pneumonia, apparently without pain or discomfort. More than fourteen months after his death, the S.J.C. issued its full opinion. The fact that Mr. Saikewicz was dead gave the court time to consider carefully the issues involved without having to rush to a decision because of the necessity of rendering emergency treatment (as is often true in such cases) or of having to watch the patient and family suffer during the proceedings. It is often said that "hard cases make bad law." The fact that Saikewicz was dead made this case "easier," and one would expect, therefore, to find a statement of both what the law is and *should be* in this area. The court has not disappointed those with such high expectations.

The S.J.C.'s opinion deals with three issues: (1) the right of any person, competent or incompetent, to decline potentially life-prolonging treatment; (2) the legal standards that control the decision whether or not potentially life-prolonging, but not life-saving, treatment should be administered to an incompetent; and (3) the procedures that must be followed in arriving at that decision.

### Patient's Rights

On the first issue, the S.J.C. determined that "the substantive rights of the competent and the incompetent person are the same in regard to the right to decline potentially life-prolonging treatment." While it is "advisable to consider the framework of medical ethics which influences a doctor's decision as to how to deal with the terminally ill patient," the court notes that such considerations are viewed for "insights" and not as "controlling." In reviewing these, the court stresses

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and approves of the distinction between "curing the ill and comforting the dying." The patient has a right to privacy "against unwanted infringements of bodily integrity in appropriate circumstances," and only in cases where the state has a strong interest can the individual's decision to refuse treatment be overridden.

### State Interests in Treating

From a review of the cases, the court identifies four potential state interests:

1. the preservation of life;
2. the protection of innocent third parties;
3. the prevention of suicide; and
4. maintaining the ethical integrity of the medical profession.

The S.J.C. found the first the most important, but not absolute, especially in a case where life will "soon, and inevitably, be extinguished," and made its strongest statement on self-determination:

> The constitutional right to privacy, as we conceive it, is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice.

The court argued that the second interest was "considerable," but found it unnecessary to discuss it as the patient's only two living relatives did not want to be involved. The question of suicide was summarily dismissed in a footnote which argued that the act of refusal was not suicide, and that the state's only interest is in the prevention of irrational self-destruction, not rational decisions to refuse treatment when death is inevitable. The court further found refusal of necessary treatment in appropriate circumstances "consistent with existing medical mores," noting that such considerations, in any event, are subordinate to the patient's right to decide his own fate.

Accordingly, the S.J.C. concluded that the only state interest in this case was the preservation of life and that the court's duty was to balance this interest against the individual's interest to be free to reject unwanted bodily intrusions. The judgment of the probate court was accordingly affirmed.

### Decision Standards

The next issue dealt with the legal standards to be applied. Here the S.J.C. agreed with the Quinlan court that equity required that a mechanism exist to permit incompetent patients the same right to refuse treatment that competent patients have "because the value of human dignity extends to both." Any such decision must be based solely on the "best interests" of the incompetent patient. Significantly the court found, contrary to the Quinlan court, that "statistical factors indicating that a majority of competent persons similarly situated choose treatment (as all agreed was the case here) [do not] resolve the issue." In the court's words:

> Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the unique perspective of the person called on to make the decision. To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.

The court made the following distinctions between Mr. Saikewicz's condition and the average rational person: "Unlike most people, Saikewicz had no capacity to understand his present situation or prognosis." He would never understand the reason for the pain inflicted upon him by the chemotherapy, and therefore his situation should be compared to the competent individual who is simply told that something very painful will be done to him, over a long period of time, for reasons he will not be told and to attain an end measured by concepts beyond his ability to comprehend. In short, the court rejects the objective "reasonable person" standard (usually applied, for example, in informed consent cases), and opts instead for a subjective test. The goal is to "determine with as much accuracy as possible the wants and needs of the individual involved." This is the doctrine of substituted judgment — trying to discern what the incompetent would do if he could make the choice for himself. It is adopted "because of its straightforward respect for the integrity and autonomy of the individual."

The task of the probate judge is, therefore, to ascertain the incompetent person's actual interests and preferences. While the court approved the specific competing considerations taken into account by the probate court, it rejected any diminution of a patient's rights based on "quality of life." "To the extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it . . . the suposed inability of Saikewicz, by virtue of his mental retardation, to appreciate or experience life had no place in the decision." The court concluded, however, that the probate court did not use the phrase "quality of life" improperly, but used it only in reference to the pain and disorientation likely to be caused Saikewicz by the chemotherapy.

### Procedures to be Used

The final issue is how the question is to be resolved procedurally. The S.J.C. finds the probate court a proper forum and that all such cases should be presented to it for resolution. The probate court should further charge the guardian *ad litem* to present all the arguments in favor of administering life-prolonging treatment, so that all viewpoints are aggressively represented. Only after such an adversary proceeding should the judge render a decision.

The S.J.C. invites the probate court to make use of the views of ethics committees, attending physicians, and other medical experts, but does not require this. As to the immunity-granting role of ethics committees envisioned by the Quinlan court, the S.J.C. rejects it outright:

> We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel, or group, *ad hoc* or permanent . . . . The New Jersey Supreme Court concluded that "a practice of applying to a court to confirm such a decision would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome."

The court's final language on the respective roles of ethics committees and courts is as strong as any in the opinion:

> We do not view the judicial resolution of this most difficult and awesome question — whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decision — as constituting a "gratuitous encroachment" on the domain

of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted."

### Judges at the Bedside

This decision is likely to be the subject of heated debate for some time to come. It is both wide-ranging and carefully reasoned. It is also an example of an aggressive judicial opinion in an area that some other courts have been eager to avoid. The S.J.C. has made it clear that it considers judges the only proper people to decide cases of life and death with legal immunity and seems to welcome the challenge that these cases present. It argues strongly in favor of using the adversary process — a process highly favored by lawyers, but generally scorned by members of the health care profession. The decision also quite properly puts ethics committees in their place — as advisors, not decisionmakers and is likely to be followed by other courts on this issue.

> The scope of the case is properly limited to the incompetent patient for whom a life-prolonging treatment, generally used on some patients as standard medical practice, exists and whose physician and family believe that such treatment is not in the best interests of the patient.

Because of these features it should not be surprising that many physicians are publicly hostile to the decision and that the Massachusetts Medical Society is preparing legislation to "correct" it. As one surgeon put it: "I was flabbergasted when I first heard about it. The court seems to be saying that a judicial body is in a better position to make life-and-death decisions than doctors. The doctors I've talked to just think it's awful — patently ridiculous."[5] And, a respiratory care physician has asserted that the decision places "an impossible burden on us," arguing "[W]e're resuscitating everybody — the eighty-five-year-old with brain hemorrhages, the patients dying of metastatic cancer. We often have no machines left for young people."[6]

In a similar vein the editor of the prestigious NEW ENGLAND JOURNAL OF MEDICINE has argued that "this astonishing opinion can only be viewed as a resounding vote of 'no confidence' in the ability of physicians and families to act in the best interests of the incapable patient suffering from a terminal illness."[7] Dr. Arnold S. Relman goes on to recommend that other states follow the New Jersey Court instead of the Massachusetts S.J.C., advising judges who would do otherwise to visit "a large acute care hospital, particularly pediatric and adult intensive-care units, where they can take sober cognizance of the numbers of urgent and complex medical problems that would have to be adjudicated in their courts."[8] The JOURNAL's legal expert also questions whether the court understood what it was doing or the impact its decision would have on the medical community.[9]

Such reactions seem to have two sources: a lack of understanding of what the decision is all about and a desire to keep such decision-making firmly in medical hands and behind closed doors. The case has nothing to do with brain dead corpses or terminally ill people for whom there is no reasonable life-prolonging treatment available. It also, of course, does not apply to any competent patient able to make his or her own decisions. The scope of the case is properly limited to the *incompetent patient* (whether child or adult) *for whom a life-prolonging treatment is available that is used on some patients as standard medical practice and which treatment the physician and family do not want to use because they believe it is not in the best interest of the patient.* While the precise meanings of some of the terms in the previous sentence will have to await judicial clarification for certainty, the decision provides the proper framework within which such terms can be defined in a public forum. It should also be emphasized that the primary reason for going to court is to obtain legal immunity from future civil or criminal charges growing out of withholding treatment. If one is sure of the correctness of his actions, no resort to the courtroom is required.

### Self-Determination Primary

Primarily, however, this is a decision about patients' rights to human dignity and self-determination, and it is here that the decision is likely to have its widest impact. The court finds that all patients have the absolute right to refuse life-sustaining treatment that will not cure or save life. It further argues that such decisions must be based on what is important to the individual patient and not on what a majority of "reasonable persons" might do.

Here, the court rejects the rationale of many previous courts in the informed consent area, which permit juries to find in favor of plaintiffs only if the information not provided by the physician would have caused a "reasonable person" to refuse to undergo the proposed treatment (e.g., would a disclosure of a five per cent complication rate persuade the average reasonable person, *not* the individual plaintiff, to refuse an ulcer operation?). This court finds self-autonomy paramount and non-delegable. Therefore, its logic compels a conclusion that courts and juries should be asked not what the "reasonable person" would do in such circumstances, but what *this particular patient* would have done. It is only such a test which, like the substituted judgment test, protects the patient's right to make important decisions concerning his own body.

While most important, it is also this aspect of the decision that is likely to be most controversial. How can one ever know what another person would or would not do? How can we ever know what Saikewicz would have decided? Such questions may be unanswerable. But, I would argue that they are the proper questions and that a "correct" resolution of them is more likely to come from a judicial decision after an adversary proceeding in which all interested parties have fully participated, bringing in all their own perceptions, beliefs, and biases, than from the individual decisions of the patient's family, the attending physician, an ethics committee, or all of these combined. It is only by using the admittedly difficult machinery of a legal proceeding that we can promote the incompetent's "right of privacy and self-determination" and insure that it is not used as a "license to kill" unwanted patients.

In this regard, the primary impact of the decision may be to promote use of the "living will" in Massachusetts. Since the court is ultimately concerned with the patient's own wishes, a properly executed and drafted declaration of desires prior to coma or incompetence should permit physicians to follow the patient's wishes without going to court for personal immunity. Indeed, one Probate Judge, Henry R. Mayo, Jr., who handled

## SAIKEWICZ *(Continued)*

the first "Saikewicz" type case, has already indicated how important such a document is as evidence of intent (although no judge has yet termed it conclusive). He is quoted as having said: "I have written to the Euthanasia Society [Euthanasia Education Council, 250 West 57th St., New York, New York 10019] and ordered about fifty copies of their Living Will. I plan to distribute them. My wife and I signed them about fifteen years ago."[10] One suggestion for state legislation that should be acted upon as a result of the decision would "legalize" the living will.[11] This could dispel any doubts that might remain about the physician's duty to respect the competently articulated wishes of incompetent patients.

### References


1. Superintendent of Belchertown State School v. Saikewicz, 370 N.E. 2d 417, 433 (Mass. 1977).
2. Kindregan, C.P., "The Court as a Forum for Life and Death Decisions," Symposium, Mental Incompetents and the Right to Die, 11 SUFFOLK U. L. REV. 919-973 (1977). (This issue also includes articles by the attorneys on each side of the *Saikewicz* case.)
3. In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976); *see* Annas, G.J., Karen Ann Quinlan: Legal Comfort for Physicians, HASTINGS CENTER REPORT (June 1976).
4. That court found that a decision to disconnect Karen Ann Quinlan's respirator would be proper because "this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them."
5. George Nardi, M.D., as quoted by Richard Knox, *Bay State Judges and the Right to Die,* BOSTON GLOBE 1, 5 (Jan. 30, 1978).
6. *Id.*, statement of Ralph Epstein, M.D.
7. Relman, A., *The Saikewicz Decision: Judges as Physicians,* NEW ENGLAND JOURNAL OF MEDICINE 298:508 (March 2, 1978).
8. *Id.* at 509.
9. Curran, W.J., *The Saikewicz Decision,* NEW ENGLAND JOURNAL OF MEDICINE 298:499 (March 2, 1978)
10. Quoted by Richard Knox, *Live-die Question Left to Court,* BOSTON GLOBE, 3 (Jan. 31, 1978).
11. See Raible, J., *The Right to Refuse Treatment and Natural Death Legislation,* MEDICOLEGAL NEWS 5(4):6-8 (Fall 1977).


## HOSPITAL FORUM *(Continued)*

It seems likely that the Privacy Commission's findings will generate legislative action in 1978 on both the Federal and State level. The most effective resolution to these issues is, however, strongly linked to the continuing collaborative effort of legislators, hospital officials, physicians, and government agencies to deal with these issues on a multidisciplinary basis with an awareness of the needs and interests of all involved.

### References


1. Hutchins v. Rehabilitation Commission, 544 S.W. 2d 802 (1976).
2. *See* Anthony, *Issues Relating to Patients' Access to Their Medical Records,* MEDICAL RECORD NEWS at 48 (December 1977).
3. MASS. GEN. LAWS ANN., ch. 111, § 70.
4. MASS. GEN. LAWS ANN., ch. 123, § 55.
5. Gotkin v. Miller, 514 F.2d 125 (1975).
6. Golodetz and others, *The Right to Know: Giving the Patient His Medical Record,* 57 ARCH. PHYS. MED. AND REHAB. 78 (1976).


## RATTIGAN ESSAY COMPETITION RESULTS ANNOUNCED

The American Society of Law & Medicine is proud to announce the winners of the 1977 John P. Rattigan Memorial Student Essay Competition. The first, second, and third prize winners, as well as the five Honorable Mention awardees, are to be congratulated for the excellently written and researched papers they submitted to the competition.

The first prize, which carried a cash award of $300, was awarded to Gerald B. Robertson, a candidate for the LL.M. degree at McGill University, Montreal, Canada. Mr. Robertson's article was entitled: *An Examination of the Question of Civil Liability Arising from the Birth of a Child Following an Unsuccessful Sterilization Operation.* This paper will be published in a forthcoming issue of the AMERICAN JOURNAL OF LAW & MEDICINE.

The $150 second prize went to Meryl Amster, a candidate for the J.D. degree from the State University of New York at Buffalo. Ms. Amster's article was entitled, *Legal Aspects of Artificial Insemination.*

A third prize of $100 was awarded to Judy Freiberg, M.S.W., a third year law student at St. Louis University, for her manuscript entitled, *The Song Is Ended But the Malady Lingers On: Legal Regulation of Psychotherapy.*

Judges for the 1977 Rattigan Competition included: George J. Annas, J.D., M.P.H., Director of the Center for Law & Health Sciences at Boston University and Editor-in-Chief of MEDICOLEGAL NEWS; Paul D. Goldenheim, M.D., Assistant Resident in Medicine, Beth Israel Hospital, Boston; Richard G. Huber, LL.M., Dean of Boston College Law School; Jim McMahon, J.D., Managing Editor, AMERICAN JOURNAL OF LAW & MEDICINE; William O. Morris, J.D., Professor of Law at West Virginia University Law Center; John A. Norris, J.D., M.B.A., Editor-in-Chief of the AMERICAN JOURNAL OF LAW & MEDICINE and an attorney-consultant in health law; Elliot L. Sagall, M.D., President of the American Society of Law & Medicine and Assistant Clinical Professor of Medicine at Harvard Medical School; Lawrence J. Smith, J.D., trial attorney, New Orleans and Lecturer at Louisiana State University of Dentistry; and James G. Zimmerly, M.D., J.D., M.P.H., Chief, Division of Legal Medicine, Armed Forces Institute of Pathology, Washington, D.C., and Editor of the JOURNAL OF LEGAL MEDICINE.

Five contestants were also awarded Honorable Mention: Jeffrey M. Kichen for *The Massachusetts Anatomy Law of 1831;* Barry A. Oster for *Medical Malpractice Statute of Limitations: The New York Experience;* George F. Murphy for *Medical Countersuits – the Prognosis Is Guarded;* Terrance J. O'Hara for *Active Euthanasia and the Defective Newborn: A Viable Alternative;* and John F. Gardner for *Neonatal Technology and the Abortion Decisions: Medical Science and Constitutional Rights.*

In order to continue this unique essay competition, as well as other educational programs, for graduate students interested in medicolegal issues and problems, the John P. Rattigan Fund solicits contributions of any amount. All donations are tax-deductible. Further information about the 1978 Rattigan Competition of the American Society of Law & Medicine may be obtained by writing the Society at 454 Brookline Avenue, Boston, Massachusetts 02215.