Withholding Medical Treatment

Should the courts play a role in medical decisions involving dying patients who cannot speak for themselves?

A decision handed down by the Supreme Judicial Court of Massachusetts on 25 November 1977 sent tremors through the medical and legal communities. The high court seemed to say that doctors must get permission from probate courts before they can withhold medical treatment from incompetent patients, including the senile, the newborn, and the comatose. The decision is still being debated and its effects are not yet clear. At the heart of the issue is the question of whether courts will take the responsibility for medical decision-making away from doctors and families of incompetents.

Undeniably, physicians have a problem in deciding whether to treat incompetent patients. Although doctors presumably make treatment decisions after consulting with the incompetent patient's family, the family often leaves the decision to the doctors. Arnold Relman, editor of *The New England Journal of Medicine*, explains, "Sometimes the families are so distraught or so frightened that they will not or cannot say what they want done." Doctors may decide, then, not to operate on infants with major birth defects or they may decide to withhold antibiotics from senile patients who develop respiratory infections. But all too often these decisions are made in private, with little or no open discussion of whether the patients should be treated and no documentation of these decisions in the patient's medical records. Not unexpectedly, some of these decisions later appear controversial. As Relman explains, "Not all doctors are compassionate or sufficiently sensitive to the wishes of the patient's family or next of kin."

These problems with decisions to treat or not to treat incompetents are not new. But only recently has the public become sensitive to them, Relman says. The lawsuit involving Karen Ann Quinlan undoubtedly contributed to the public's awareness of doctors' moral dilemmas. In 1976, the Supreme Court of New Jersey ruled that Quinlan's guardian, family, and physicians could disconnect her respirator if they agreed there was no reasonable possibility that she would ever regain consciousness. Relman and others believe that the desire of the public and doctors to get medical decision-making out of the closet led to increased publicity over these decisions and thence to the current situation in Massachusetts.

The Massachusetts decision involved the case of Joseph Saikewicz, a profoundly mentally retarded man with an IQ of 10. In 1976, Saikewicz was 67 years old and had been a resident of the Belchertown State School for 48 years. Following a routinely administered blood test, he was found to have acute myeloblastic monocytic leukemia, a disease that would kill him in a few months if he were not given medical treatment. But even if he were treated, he probably would live at most only a few more years.

Saikewicz had only two relatives who could be located and they wanted no part in deciding whether he should be treated. So, in April of 1976, the superintendent of the Belchertown State School asked the court to appoint a guardian with the power to decide on Saikewicz's medical treatment.

Thus far, there was nothing special about the case. What is unusual is that the day after he was appointed, Saikewicz's guardian, local attorney Patrick J. Melnik, asked for and received the court's permission for treatment to be withheld. The argument was that treatment would be painful and that Saikewicz would not understand the reason for his discomfort.

The lower court asked the appeals court to hear the case. But the Supreme Judicial Court decided to bypass the appeals court and hear the case itself. On 9 July 1976, the high court upheld the decision. Saikewicz died, apparently peacefully, on 4 September.

Meanwhile, the Massachusetts medical and legal communities waited impatiently for the high court's written opinion. According to William Curran, a lawyer at the Harvard School of Public Health and legal columnist for *The New England Journal of Medicine*, doctors and lawyers could hardly believe the press' interpretation of the oral decision. The newspapers reported that the court really meant to intrude in most life-and-death medical decisions concerning incompetents. When the written opinion was finally released, the storm broke.

Much of the opinion was uncontroversial and even laudable, say many physicians and attorneys. Justice Paul Liakos, who wrote the opinion, began by affirming the rights of competent patients to refuse medical treatment. But at the end of his opinion, he included a section that is frequently interpreted as saying that the courts, rather than doctors and families, must decide whether treatment can be withheld from incompetents.

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Liakos wrote: "We do not view this most difficult and awesome question—whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decisions—as 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 the government was created. Achieving this ideal is our responsibility and is not to be entrusted to any other group. . . ."

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The first reaction of doctors, lawyers, and hospital administrators to this section of the opinion was disbelief, says Curran. Relman explains, "Lots of doctors feel outraged. These problems [of deciding treatments for incompetents] really are agonizing. You feel very inadequate sometimes, very worried all the time. Then to have this kind of impediment placed in your path under the guise of trying to help you! It really is very frustrating."

Lawyers disagreed, however, on just how far they had to go in taking cases to court. Relman says he called Liakos as well as several other judges to ask what the opinion meant. He learned that one cannot just ask. "I was told, politely but firmly, that that's not the way the law works. I was told you must find out [what the court meant] by bringing cases to court."

One common interpretation of the decision was that doctors could not issue "do not resuscitate" orders for dying patients without the court's permission. Some patients "were horribly mistreated" by doctors whose attorneys held to this interpretation, says George Annas, a lawyer at Boston University School of Medicine. For example, a terminally ill woman was subjected to cardiac defibrillation 70 times in a 24-hour period before she finally died. Annas also reports that, on a hospital administrator's advice, a doctor was afraid to issue a "do not resuscitate" order for a stroke patient whose condition was completely hopeless. The patient was kept alive in an intensive care unit for 4 weeks, finally dying the day after a legal aide petitioned the probate court to hear the case. According to Annas, doctors even implanted a cardiac pacemaker in a brain-dead patient, afraid to let the patient succumb without the court's permission.

A number of cases were brought to lower courts, which ruled that certain patients, such as brain-dead patients, could be allowed to die without legal proceedings. And the pressing question of whether the Saikewicz decision bars "do not resuscitate" orders finally was answered when Ronald B. Schram, an attorney with the Boston firm Ropes and Grey, brought a test case to court. The case involved Shirley Dinnerstein, a 67-year-old woman with Alzheimer's disease, an incurable disease of the brain which slowly destroys a patient's abilities to function. At the time her case was brought to court, Dinnerstein was completely paralyzed on her left side, immobile, unable to speak, unable to swallow without choking, and barely able to cough. She also had uncontrolled high blood pressure and atherosclerosis. Her doctors thought she could live no longer than 1 year. In the lawsuit, Dinnerstein's doctors asked for permission to issue "do not resuscitate" orders.

John Walsh of the News and Comment staff will be on leave for 6 months as a fellow of the Center for Advanced Study in the Behavioral Sciences at Stanford, California.

To the great relief of many health professionals, the Massachusetts Appeals Court ruled that the Dinnerstein case did not belong in court. The court said: "The judge's findings make it clear that the case is hopeless. . . . Attempts to apply resuscitation, if successful, will do nothing to cure or relieve the illness. . . . The case does not offer a life-saving or life-prolonging treatment alternative within the meaning of the Saikewicz case."

Still, it was argued that the Saikewicz decision was unclear. When, exactly, must doctors go to court? Many hoped that the issue would be clarified by Liakos himself, who agreed to give a public speech on 27 April at a conference sponsored by a Boston-based organization called Medicine in the Public Interest. It apparently is completely unprecedented for a judge to explain a decision he wrote. Annas says his search of the literature does not reveal another instance of such a speech in all of U.S. history. Although Liakos refused to talk to *Science*, Annas believes he gave his speech because he felt his decision was being butchered by the legal community. Curran believes Liakos was trying to back down from his written opinion because of the furor it created.

Liakos' speech, however, left many confused. He said: "To me [the Dinnerstein case] represents an example not only of an abundance of caution but of hysteria on the part of legal counsel for advising the hospital to take such extreme protective measure." In explaining how he thought the decision should be interpreted, Liakos seemed to say that doctors need only go to court if they want legal immunity for their medical decisions. But his remarks were somewhat elliptical. He said, "if [legal immunity] is what the medical profession feels it must have, then I would suggest that perhaps Saikewicz is a boon; if you [hospitals or physicians] want to interpret it that way, you can get a predetermination of your rights, rather than suffer the risk of having a hindsight determation in which you might be held to have acted improperly."

William W. Feuer, chief counsel for the Affiliated Hospitals Center in Boston, heard Liakos speak and rose afterward to say that, in his opinion, if the Dinnerstein case was unnecessary, so was the Saikewicz case. "All Liakos did was vilify the poor attorney who took the Dinnerstein case to court," Feuer told *Science*. "Liakos did not say anything you could use in court. He spoke ex cathedra, so to speak."

Relman also thinks matters are still not cleared up. "Doctors don't need to be told that they don't have legal immunity. It would be gratuitous for the court to say that doctors should only come to court for immunity," Relman remarks.

These recent court cases are forcing the legal and medical communities in Massachusetts and elsewhere to grapple with the difficult question of what the court's role in medical decision-making should be. So far, most commentators expressed opinions falling between two extremes: that the courts should play a major role in determining treatments for incompetents, or that they should steer clear of making medical decisions, being drawn in only if doctors or hospitals are sued after the decisions are made.

The most outspoken proponent of the view that courts should routinely intervene in medical decision-making is Charles Baron, a lawyer at Boston College. Baron argues, "If you can't put someone in jail or take them off welfare or attach their wages without a court hearing, it seems all the more important that you have a hearing before you take someone's life away."

Baron argues that the courts are more able than medical personnel to be fair and impartial in deciding on treatments for incompetents. Above all else, he says, what goes on in a courtroom goes on in the open, subject to public scrutiny. Judges must defend their decisions and must strive not to let extraneous factors, such as a patient's social status or moral character, affect their opinions. And a courtroom proceeding is adversary in nature. Reasons for treating as well as not treating the patient are argued.

In contrast, Baron says, doctors tend to make decisions in a biased way and to let extraneous factors affect their judgment. For example, he says they are less likely to try to resuscitate an emergency room patient who is poorly dressed and reeks of alcohol than a well-dressed, so-

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Antinuclear Rally Surveyed

The antinuclear movement in the United States has for the most part developed locally and regionally, as first one then another nuclear power plant project has sparked controversy. But from their survey of the big May 6 antinuclear demonstration in Washington three University of Tennessee sociologists have concluded that opposition to nuclear power is "becoming less fragmented and locally oriented" and that "people and groups in many parts of the country are forming an effective communications network useful in pooling resources and increasing political clout."

The May 6 event, attended by some 65,000 demonstrators (the police estimate), was the biggest political rally to take place in Washington since the civil rights and anti-Vietnam war demonstrations of the 1960's and early 1970's. The three sociologists—Kent D. Van Liere, Anthony E. Ladd, and Thomas C. Hood—divided the huge crowd into zones and distributed questionnaires to 1000 randomly chosen individuals. More than 400 were later returned by mail.

The investigators found that the demonstrators were predominantly "young, well educated, liberal and from urban areas." Nearly two-thirds of the respondents had traveled more than 100 miles to attend the rally, and 10 percent had come more than 600 miles. Almost a quarter of them came with an organized group, and most had first learned the demonstration was to be held not from the news media but from friends, announcements at meetings, posters, and special mailings and telephone calls.

Forty-two percent of the respondents belong to organizations which had taken a position against nuclear power, but many of these some 150 organizations were not antinuclear groups as such. Most respondents had been involved in other "movements," such as those over the Vietnam war and civil rights, but almost half had never taken part in an antinuclear event before. The investigators suggested that this points up the importance of the Three Mile Island accident in fueling "activism against nuclear power." Ninety percent of the respondents want all nuclear power plants shut down. ***Luther J. Carter***

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ber businessman. Even more disturbing to Baron is that doctors are making these decisions with no open discussion of their merits.

However, some doctors and lawyers contend that the courts could never handle all the cases Baron wants brought. To these critics Baron replies that the caseload would not be overwhelming because after awhile some general principles would be hammered out. Then most cases would not have to be brought to court. The appropriate decisions would be clear.

Relman is perhaps the most outspoken critic of Baron's view. "It is a grave misunderstanding of what medicine is about to ask for court-decreed guidelines," he says. He agrees with Baron that too many medical decisions are made on an ad hoc, personal basis and many are made, he says, "almost in a clandestine way." But, Relman explains, "the weakness of Baron's argument is that every patient is different and minor variations are absolutely vital in deciding what to do. The factual basis of these decisions are often very fuzzy and most of the time no one can be sure what the alternatives are." It is not clear that judges would be any better than doctors and families in making these decisions.

Also sharply opposed to Baron, but on legal grounds, is Robert Burt of Yale Law School. Burt believes that courts should not make medical decisions, but should be available to review the decisions after they are made. Thus doctors should be made aware that they are subject to civil or criminal suits if they make a "wrong" decision. "I am asking for doctors to live in some sort of regime of uncertainty," he says. Of course, doctors already live this way in principle, but in practice there have been few, if any, cases in which doctors were prosecuted for withholding treatment. Relman, who basically agrees with Burt, attributes this lack of prosecutions to the fact that the public is only now becoming conscious of the doctors' roles and ethical problems in such treatment decisions.

According to Burt, the problem with cases like that of Saikewicz is that they are not truly adversary in nature but are more often sham proceedings. "Everyone is winking and nodding," he says. Yet, in the Saikewicz case no one wanted to take personal responsibility for the awesome decision to let the man die, especially when it was admitted at the onset that competent patients in Saikewicz's condition nearly always opt for treatment. (Although Saikewicz's court-appointed guardian was given the power to decide on Saikewicz's treatment, he asked the court to approve the decision to withhold treatment.)

As evidence for his belief that no one wanted to decide Saikewicz's fate, Burt refers to the transcript of the lower court hearing. At the end of the transcript, the doctor says he doesn't know what to do; he leaves the decision to the judge. "I don't have that deep knowledge," the doctor says. The judge then said, "I am inclined to give treatment." At this point, the doctor explained that the judge would have to see Saikewicz, that he is wild. "He flails at you and there is no way of communicating with him and he is quite strong." Hearing this, the judge reversed himself and decided against having Saikewicz treated.

Burt points out that in this case, the judge apparently thought he was acting on the doctor's advice. The doctor thought the judge made the decision. Neither was fully responsible. But no one ever tried treating Saikewicz. Burt speculates that if the doctors were concerned about accounting for their decision, they would have at least tried treating him.

To rectify some of these problems, Boston lawyer Neil Chayet proposes what he sees as a way to, as he says, "keep the court in but not in a meddling way." Chayet suggests that a patient representative be appointed by the court to facilitate communication between families of incompetents and doctors. This representative would be a full-time hospital employee and would certify in each case that there is no reason to expect foul play. If the patient has no family, then the patient representative would help make decisions, acting as an officer of the court. Any questionable cases would still go to court. But the patient representative would, by the legal act of certification, allow life-support systems to be discontinued when everyone agrees that is the most desirable course of action.

For all the open discussion of what role the courts should play, it still is not clear what role the Massachusetts court, at least, thinks it is playing. The court's function will only be clarified by other court cases. Relman says things are quiet now in his state. "People are hunkering down, hoping that the whole thing will go away." Yet the Saikewicz decision, he thinks, is like a time bomb. "Sooner or later it will go off. Some family, some nurse, some prosecutor will decide that a doctor violated the law. As long as the [Massachusetts] Supreme Court decision stands, the situation here is very uncomfortable."—GINA BARI KOLATA