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LEGAL ISSUES IN MEDICINE

ADDING INJUSTICE TO INJURY

Compulsory Payment for Unwanted Treatment

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A NEW YORK court this year issued one of the most disturbing and aberrant appellate opinions of the past two decades concerning the right to refuse treatment.[1] In my view, the judges ruling in *Grace Plaza* v. *Elbaum* made a series of errors: they assumed that institutions can have ethics apart from those of their physicians; they believed that both institutions and physicians are primarily motivated by money; and they approved the use of legal threats by institutions and physicians against patients and their families. In this court's idiosyncratic view, dying and medical care seem to be not about patients and their families, but about power and money.

THE CASE OF JEAN ELBAUM

In late June 1986, 60-year-old Jean Elbaum was admitted to a hospital with subarachnoid bleeding. Her condition deteriorated quickly, and by the end of July she was in a persistent vegetative state. The attending physician advised the family that he wanted to replace the nasogastric tube with a gastrointestinal feeding tube so the patient could be transferred to a nursing home. In accordance with Jean Elbaum's previously stated wishes regarding such treatment, the family at first refused, but they ultimately agreed after being "told that legal proceedings would result unless consent was given."[2] A gastrostomy was performed on September 2, 1986. Two weeks later Jean Elbaum was transferred to Grace Plaza, a nursing home.

Before the transfer, the patient's husband, Murray Elbaum, and her daughter met with the medical director of the nursing home. They told him that Jean Elbaum had previously stated that if she was ever in a "vegetable-like" state with no hope of recovery, she would not want to be kept alive, and that she had specifically stated that she wanted no respirators, antibiotics, or tubes to keep her alive. These instructions were explicitly transmitted by Murray Elbaum on 6 to 12 occasions. Nevertheless, the following year antibiotics were administered to Mrs. Elbaum at the nursing home. The medical director later testified that this action was necessary to prevent the spread of infection to other patients.[2]

On October 6, 1987, Murray Elbaum told both the medical director and the administrator of Grace Plaza that the gastrointestinal tube should be removed because of his wife's previously expressed wishes, and that only "comfort care" should be provided. The medical director responded by letter three days later, stating, erroneously, "State law prohibits us from allowing a patient to die as a consequence of withholding fluid and malnourishment."[2] Thereafter, Murray Elbaum stopped making payments to Grace Plaza for his wife's care. Four months later the administrator notified Elbaum that he was $18,500 in arrears, threatened legal proceedings to collect that amount, and asserted that no matter what he or his wife wanted, on the basis of New York law gastrostomy-tube feeding would be continued. The letter stated:

> Please be aware that even if irrefutable evidence of the patient's wishes were forthcoming, Grace Plaza is not willing to undertake removal of the gastrostomy tube, and we believe that we have the right under New York law to refuse to do so.[2]

Shortly thereafter the nursing home brought suit for payment of bills, and Murray Elbaum brought suit seeking a court order to remove the gastrostomy tube. Elbaum's suit was heard first. Murray Elbaum, who had been married to the patient for more than 36 years, testified that she first expressed her views about life-sustaining treatment at the time of the Karen Ann Quinlan case. If she were in a similar situation, she had said, she "would not want to be on any respirator or any other mechanical means, she wanted to die." When a family friend suffered a stroke that rendered him comatose, she told her husband: "Murray, I want you to tell me now, I am telling you and I want you to tell me that you will not do anything to sustain my life in the event I am a vegetable. I want it to end, I don't want it sustained." Mrs. Elbaum's sister testified that she and her sister had made a pledge to each other not to permit forced feeding, respiratory assistance, and medication to be used to treat the other "if there was no hope of recovery." Jean Elbaum's two children described discussions they had had with their mother to the effect that "she never wanted any tubes put into her because she wanted to die naturally and quickly."[2]

The trial judge ruled that "none of these [statements] can be said to have taken place in a contemplative manner [and that] Jean Elbaum [did not] contemplate death by starvation or dehydration."[3] The judge accordingly refused to order the gastrostomy feeding discontinued.

In a strongly worded opinion, a unanimous five-judge panel of the appeals court reversed this ruling:

> We find that the record as a whole in this case establishes that Mrs. Elbaum's statements and reflections on the subject of artificial and extraordinary life-sustaining medical treatments were made with . . . resolve and purpose so as to constitute "solemn pronouncements" [and were sufficiently] "clear and convincing" [to apply to her current condition].[2]

The nursing home was chided for ignoring the wishes of Jean Elbaum "while simultaneously insisting upon payment for their undesired services." The court gave the nursing home the choice of acceding "to Mrs. Elbaum's wishes concerning the removal of the gastroin-

testinal tube within 10 days" or transferring her to another facility that would honor her wishes.

The Case Regarding Payment

Jean Elbaum's feeding tube was removed and she died, but the nursing home continued to pursue its claim for payment. The trial judge dismissed the case, stating that "where medical services are provided to a patient over the objections of the patient, the provider of such services is not entitled to reimbursement."[4] This was seen as a victory for patients' rights. The nursing home's appeal, however, resulted in a remarkable reversal. A four-judge panel of the same appeals court that had ruled in the earlier case (although the panel consisted of different judges) ruled three to one that the nursing home was entitled to payment for its unwanted and unauthorized services, a sum in excess of $100,000.[1]

This ruling seems to have been possible only because the court mischaracterized the case as analogous to one in which a family wanted to deprive a child of treatment that would save her life,[5] rather than a case in which a family was transmitting the wishes of an adult patient. The court, for example, characterized the nursing home's actions as saving Jean Elbaum's life, and Mr. Elbaum's expression of his wife's wishes as an attempt by him to be "the final arbiter of [Jean Elbaum's] life or death."[1] The judges also missed the point when they argued that the nursing home could not have known in 1987 what a court would conclude in 1989 about Jean Elbaum's wishes. The question was not what the court's finding would be in 1989, however, but what was known in 1987 about Jean Elbaum's wishes, as transmitted by her family.

The second major problem with the opinion on payment to the nursing home is that it was based on the assumption that facilities such as nursing homes, in contrast to physicians practicing within them, can have ethics and that it would be wrong to force a "nursing home facility" to engage "in conduct which it considered unethical."[1] Hospitals and nursing homes are corporations, legal entities endowed by law with immortality and limited liability. But corporations are not persons, cannot practice medicine, and are incapable of having either moral or ethical objections to medical acts. Instead, their boards of directors and administrators develop policies. Grace Plaza, for example, adopted a policy against removing feeding tubes only after Mr. Elbaum made his request. Was the facility acting unethically before this time? And if so, did the board's vote make the nursing home ethical? Suppose a nursing home adopted a policy that "as a matter of ethics" it would use antibiotics only for viral infections and not for bacterial infections. Should anyone treat this decision seriously? The point is that the court raised an arbitrary and self-serving institutional policy to a higher (and apparently unchallengeable) level by mislabeling it a matter of "ethics."

Finally, the opinion amounts to a vote of no confidence in the medical profession because it implies that doctors cannot be trusted to ascertain the wishes of patients and their families and act accordingly. The court ruled that physicians and nursing homes can ignore the wishes of their patients as expressed by family members, unless the family obtains a court order certifying that the family has accurately ascertained the wishes of the patient. No court had ever gone so far as to grant physicians and facilities, in effect, both legal immunity for continuing to provide unwanted and unauthorized treatment and guaranteed payment for that treatment. The court's ruling ignored almost two decades of decisions to the contrary because, as is clear in its opinion, the court had a profound mistrust of physicians:

> If Mr. Elbaum's conduct in this case were condoned, health care providers would have an additional financial incentive to obey, without question, the orders of those conservators who might prematurely despair of their conservatee's recovery, or . . . whose judgment might be tainted by motives less altruistic than Mr. Elbaum's. The potential evil we see resulting from this, i.e. the possible death of even one patient whose life might have been saved, is infinitely greater, in our view.[1]

No evidence was presented that physicians in New York, in order to ensure they will get paid for everything they do, will discontinue life-sustaining treatment "without question" when continued treatment could save the patient's life. The court seems to believe that the medical ethics of physicians and the business ethics of nursing home administrators are identical, and that it is only by guaranteeing their payment that the lives of patients can be protected.

The Right to Die in Current Law

In 1976 Karen Ann Quinlan became a symbol of medical technology applied without regard for the patient and the patient's family. Most Americans responded to the news of her persistent vegetative state, thought to be ventilator-dependent, by saying, "I never want to be like Karen Ann Quinlan." The New Jersey Supreme Court ultimately issued the most influential decision to date on the right to refuse treatment, ruling that she had both a common-law right and a constitutional right to refuse treatment, and that her family could exercise that right on her behalf.[6] Since 1976 virtually every appellate court in the United States that has considered this issue has arrived at the same conclusion. However, courts in two states, Missouri and New York, have developed idiosyncratic rules permitting families to speak for their incompetent loved ones only if they can produce "clear and convincing evidence" that the patient himself or herself made the decision to refuse treatment. This stance has, in turn, spurred the groups promoting the use of living wills and durable powers of attorney for health care into action. Nevertheless, the Elbaum case was not a difficult one, and Jean Elbaum's wishes should have been honored even under a conservative reading of New York law. If the discussions reported by her

family were not sufficient evidence of her wishes, it is unlikely that any oral statement would be considered "clear and convincing."

Both the medical and the legal systems failed the Elbaums. In retrospect, the only way the family might have avoided years of expensive and invasive treatment that Mrs. Elbaum did not want would have been to refuse to agree to the placement of the gastrostomy tube in the first place. This would have forced the hospital to seek a court order (an order that probably would not have been granted, given Jean Elbaum's wishes, although in the case of Mary O'Connor the New York Court of Appeals ordered tube feeding to be begun in similar circumstances[7]).

Health care providers have a legal and ethical obligation to know and follow the law. It is unconscionable to require patients to seek court orders to force physicians and health care facilities to respect the legal rights and human dignity of their patients. If the hospital or physician really is uncertain of the law in a particular case, the hospital or physician should seek competent legal counsel. If there continues to be genuine uncertainty (physicians may be uncertain or just wrong about the law, even when the law is clear), court review may be reasonable.

The presumption, however, should always be that what the family says about the patient's wishes is correct, since the family is much more likely to know and care about the patient's wishes or best interests than the hospital administrator. In rare cases in which family members cannot in good faith determine the patient's wishes or their motives seem suspect, court review may be appropriate. It should be initiated and expedited by the health care facility. Payment for services rendered while a good-faith effort is made to determine the patient's wishes is appropriate. But no payment is justified to an institution that seeks to thwart or ignore the patient's wishes.

The real issue is almost never who should go to court, but what decision must be made, who should make the decision, and on what basis. In this case the question was whether Mrs. Elbaum would have wanted a feeding tube if she was in a persistent vegetative state. Her next of kin should have been able to make that decision, based on her previously expressed wishes.

Implications for Physicians

It should be underlined that this decision applies only to New York, and even there, New York hospitals have been advised by legal counsel for the New York Hospital Association not to change any existing policies designed to honor patients' wishes on the basis of the decision in the Elbaum case.[8] That is good advice. On the other hand, unless this opinion is soundly overturned on appeal, a legislative solution to the problems created by New York's unusual law is in order. In March 1992 the New York State Task Force on Life and the Law recommended legislation to authorize surrogate decision making for incompetent patients; the proposed law would, among other things, designate a relative or close friend as the decision maker for patients who have not named their own surrogate in a health care proxy.[9] Murray Elbaum would have been Jean Elbaum's designated surrogate under the proposed legislation, and he would have been legally authorized to make the decision to withhold further tube feeding without resort to the courts.

The task force's proposed statute would also deal directly with the issue of payment: no hospital or attending physician who failed to follow the decision of a designated surrogate would be entitled to compensation for services. With the exception of its provisions permitting bioethics committees to make decisions with legal immunity for patients who have no known relatives or friends, the proposal is a reasonable and responsible approach to surrogate decision making. It is also consistent with a trend toward naming surrogate decision makers by statute.[10] Until the proposal becomes law, however, New York physicians should strongly urge everyone over the age of 17 to designate another person as his or her health care surrogate by following the current New York health care proxy law.[11,12]

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