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The Role of Judges in Life/Death Decisions for the Neurologically Impaired

H. Richard Beresford, MD, JD

The Massachusetts supreme court has recently ruled that decisions about withholding care from hopelessly ill, legally incapacitated patients must be made by judges. It clearly rejected the view that families and attending physicians should be empowered to make such decisions. In this respect, the ruling contrasts with that of the *Quinlan* case and highlights the issue of whether judges or physicians and families are better able to make medically and morally sound decisions respecting this class of patients.

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The Massachusetts Supreme Judicial Court recently ruled that judges have the final authority to make life/death decisions for legally incompetent patients [8]. The ruling has greatly perturbed the Massachusetts medical community because it seems to bar attending physicians and families from agreeing among themselves to withhold care from hopelessly ill persons who are legally incapacitated [2, 7]. The ruling contrasts with that of the *Quinlan* case, in which the New Jersey supreme court empowered family, attending physicians, and a hospital "ethics committee" to act jointly to remove a respirator from a severely brain-damaged adult [5]. Both courts agreed, however, that it is lawful to withhold therapy from hopelessly ill patients if the treatments promise nothing more than to prolong a noncognitive or minimally cognitive existence.

The Saikewicz Case

The focus of decision in the Massachusetts case was Joseph Saikewicz, a profoundly retarded (IQ, 10; mental age, 2½ years) 69-year-old man who had spent most of his life in state institutions. When he developed acute leukemia in 1976, his attending physicians recommended against chemotherapy. But because he was incapable of participating in decisions about his care, the confining institution asked a probate judge to appoint a guardian to act for him. When notified of the situation, his two sisters declined to participate in the guardianship hearing or to assume any role in his care. A guardian was then appointed and promptly recommended that Saikewicz not be treated because he had an incurable illness for which treatment offered little prospect of benefit and was likely to cause great discomfort.

The probate judge ordered that chemotherapy be withheld, although he conceded that it might prolong life and that most competent and informed persons with analogous leukemias elect to receive it. He considered that the pa-

tient's age, his inability to cooperate in treatment, the likelihood of distressing side-effects, the low probability of remission, and the dubious quality of life if remission were obtained outweighed any possible therapeutic benefits. The judge then asked the state supreme court to determine if a probate court has general authority to issue such an order and if the order in the instant case was correct. The high court answered both questions affirmatively but withheld its written opinion for over a year. In the interval, Saikewicz died of pneumonia, having received no treatment for his leukemia.

The belated written opinion of the Massachusetts supreme court reasons that because legally competent persons have a constitutional right to refuse medical care, incompetents should be accorded a similar right. Although incompetents have no decision-making power, the doctrine of substituted judgment enables lawfully appointed guardians and judges to act on their behalf. The guardian's role is to try to ascertain the incompetent's preferences; but, if these preferences are unknowable, the guardian should determine what choice a reasonable person in the incompetent's situation would make. In the court's view, the medical evidence supported the guardian's conclusion that a reasonable person in Saikewicz's position would decline treatment. It cautioned, however, that its ruling should not be read as a devaluation of Saikewicz's life, even though his impaired cognition was a factor in weighing the reasonableness of treatment.

Having concluded that withholding life-prolonging care may be appropriate in some cases, the court prescribed a judicially oriented procedure for making decisions. Thus, in the event a question arises as to whether to withhold care from an incompetent person, a petition must be filed with a probate court for appointment of a guardian. Once appointed, the guardian must make a thorough investigation

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and present to the court "all reasonable arguments in favor of administering treatment to prolong the life of the individual involved" [9]. The court then decides whether treatment shall be administered or withheld. In reaching its decision, the court may avail itself of the opinions of medical experts or "ethics committees," but it is not required either to seek or to follow such advice. To emphasize that the power of decision rests firmly with the probate judge, the state supreme court noted that it takes "a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts . . . to any committee, panel or group, ad hoc or permanent" [9].

Considerations

The court's ruling raises several challenging questions, but perhaps the most immediate is this: Does the court really mean that probate judges must make all decisions about all life-prolonging care for all hopelessly ill incompetents, be they brain-damaged or minors? If so, one can anticipate a sharp expansion of the dockets of probate courts in Massachusetts and a contraction of the activities of hospital committees [6] established to assist in decisions about care of the hopelessly ill. As noted by Dr Relman [7], the number of cases potentially subject to the court's ruling is not inconsiderable, and only a well-staffed, medically sophisticated, highly efficient probate court system could effectively handle them. If the Massachusetts supreme court envisions a narrower scope for its ruling, then at some future time it will need to spell out more precisely when the jurisdiction of the probate court must be invoked. In the meantime, Massachusetts physicians and families must either go to court if they wish to withhold care from hopelessly ill and legally disabled patients, or else quietly evade the mandate of the court's decision and risk civil or criminal liability.

As with the *Quinlan* decision, the impact of *Saikewicz* in other states is unpredictable. A striking aspect of the *Saikewicz* opinion is the court's distrust of private decision-making by attending physicians and families, whether or not it is buttressed by the opinion of an "ethics committee." Why the court thinks that judges are more likely to make correct decisions than those most intimately concerned with an ill person does not clearly emerge from its opinion. Perhaps it believes that judges have more refined ethical sensitivities than physicians, or that families may have nonaltruistic motives for withholding treatment from a hopelessly ill person. The "gravitational effect" [3] of *Saikewicz* may therefore depend on how lawmakers elsewhere weigh the comparative abilities of judges, on the one hand, and physicians and families, on the other, to arrive at medically and morally defensible decisions. As Professor Goldstein has suggested, because no objectively right or wrong answer exists in these cases, there is no compelling reason to prefer judicial decisions to private agreements [4].

Both *Quinlan* and *Saikewicz* assume a societal consensus about the rightness of allowing some hopelessly ill persons to die. Where they differ is in the choice of decision-maker. *Quinlan* would leave the decision to family, physicians, and a committee; *Saikewicz* places the responsibility on a probate judge. Other alternatives are to make physicians the primary decision-makers, to allow physicians and families to decide without the intervention of a committee or a court, or to allow families alone to decide once they have received an unequivocally hopeless prognosis from an attending physician. If the *Quinlan* and *Saikewicz* courts accurately interpret the public will, it would be unthinkable to issue a blanket prohibition against withholding presumptively futile treatments from the legally disabled.

Because more litigation about withholding care from the hopelessly ill is likely, legislation may be helpful [1]. Such legislation might specify the types of cases in which withholding care may be considered and establish a procedure for decision-making. It could identify the decision-makers, define the role of committees or panels, and provide for access to the courts in the event that a prescribed procedure fails to produce agreement on the level of care. If the legislation permits private decision-making, it could explicitly protect the participants from any civil or criminal liability.

The alternative to legislation is more judge-made law. If *Saikewicz* is any portent, the trend may be to increase the role of judges in specific decisions about levels of medical care. If this pattern indeed develops, one would hope for judges who are both skilled evaluators of medical data and good moral philosophers. One would also hope that they are capable of exercising these talents in situations which call for very prompt decisions. But even if such judges are abundant, the question will remain why they are better suited to decide when to stop medical care for the hopelessly ill than persons who are more knowledgeable about prognosis or more passionately involved in the ill person's fate.

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