

NOTE

THE PRESERVATION OF LIFE AND SELF-DETERMINATION

On October 2, 1979, Brother Joseph Charles Fox, an 83-year-old member of the Society of Mary (Chaminade High School, Mineola, N.Y.), underwent hernia surgery. During the surgery he suffered severe cardiorespiratory arrest, which resulted in diffuse cerebral and brain-stem anoxia. Brother Fox lost spontaneous respiration and had to be maintained on a respirator. His physicians concluded that he was in a "permanent vegetative state."

Rev. Philip K. Eichner, president and religious superior at Chaminade High School, after consulting the only surviving relatives (ten nieces and nephews), requested removal of the respirator. Nassau Hospital refused and Eichner sought judicial relief. Three *amici curiae* briefs (New York State Right to Life Committee, Human Life Amendment Group, the diocesan Catholic Lawyers Guild) supported Eichner and Brother Fox's relatives. The District Attorney opposed any such relief.

On December 6, Supreme Court Justice Robert Meade rendered his decision. In brief, the relief was granted—as in our opinion it should have been. Indeed, we are convinced that the appropriate decision is so clear that it need not have gone to court, and ought not to do so in similar cases.

However, it is not the decision itself which is our concern; it is rather its reasoning. In his petition for termination of "extraordinary life support systems," Eichner argued that "to maintain the life support system of an unwilling patient is an invasion of his constitutionally guaranteed right to privacy." In urging the right of privacy, the petitioner was relying on two highly publicized precedents, *In re Quinlan* and *Superintendent of Belchertown State School v. Saikewicz*. In the well-known Karen Ann Quinlan case, the New Jersey Supreme Court recognized the constitutional right of privacy and stated that it is "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances." The Massachusetts Supreme Court argued very similarly in the Saikewicz case,¹ referring to "the unwritten constitutional right of privacy

¹ Joseph Saikewicz, 62 years of age in 1976, was mentally retarded with an I.Q. of 10. He could communicate only with grunts and gestures. He had been in institutions since 1923, and in Belchertown State School (Massachusetts) since 1928. On April 19, 1976 he was diagnosed as suffering from acute myeloblastic monocytic leukemia, an unavoidably fatal disease. The question of chemotherapy for Saikewicz arose. Such treatment results in remission in 30–50% of the cases treated, a remission of two to thirteen months. The prognosis of remission is lower after the age of 60. Without chemotherapy the patient dies in a matter of weeks or months. On May 13 the Probate Court agreed with Saikewicz's guardian *ad litem* that chemotherapy was not in Saikewicz's best interests. Saikewicz died

found in the penumbra of specific guarantees of the Bill of Rights.”

Judge Robert Meade refused to pass on the applicability of the right of privacy to the Fox case. He had misgivings about it. For instance, since the right of privacy is protected by the Fourteenth Amendment's concept of personal liberty and restrictions upon state actions, “is it not necessary to the establishment of a violation of that right that ‘State action’ be involved?”² Furthermore, Meade felt that the right of privacy is so insufficiently defined but so attractively worded that it invites “unrestrained applications.”

Rather than basing relief on the right to privacy, Judge Meade turned to the common-law notion of the right of self-determination. After examining preceding decisions,³ Meade concluded that there is a common-law right to bodily self-determination “which includes the right of a competent adult to refuse life-sustaining medical treatment.” Even though there are limits to this right, Meade concluded that these limits (countervailing state interests) were not germane in Brother Fox's case. For instance, the state interest in the preservation of life is not at stake because Fox's condition is “hopeless” and further treatment “serves only more or less briefly to extend the process of dying.”

Now clearly Brother Fox could not exercise such a right for himself. Eichner was seeking to do so for him, relying once again on the Quinlan and Saikewicz cases. In both cases a substituted judgment was allowed—that is, a judgment made for one person by another. The substance of such a judgment, of course, must be the best interests of the incompetent, what the incompetent would do were he/she able to choose for him/herself.

Judge Meade rejects this approach: “Respectfully this Court is unable to accept the analyses adopted in those [Quinlan, Saikewicz] decisions.” Meade argued that *by its very nature* the right to decline lifesaving treatment can be exercised by the individual alone, for it is “a right of the individual to make up his or her own mind.” Karen Quinlan could not do this, and even less so could Joseph Saikewicz, who had never been competent.

Even though he rejected the analyses of *Quinlan* and *Saikewicz* as involving a fiction (the use of a substituted or proxy judgment as if it

September 4, 1976. The Probate Court cautionarily submitted its own decision to the Massachusetts Supreme Court. The Supreme Court published its full decision on November 28, 1977.

² Citations here and hereafter from Meade's decision are taken from the manuscript (No. 21242-I/79) kindly provided by Rev. Philip K. Eichner, S.M.

³ For instance, *Union Pacific Railway Co. v. Botsford* (1891), *Erikson v. Dilgard* (1962), *Palm Springs General Hospital Inc. v. Martinez* (1971), *In re Long Island Jewish-Hillside Medical Center* (1973).

were the concerned individual's), Judge Meade did not reject the relief requested. Why? He first noted that Brother Fox had clearly indicated that, under the circumstances and conditions that presently surround him, he would not consent to continuation of the life-supporting respirator. Then comes his crucial reason: "If Father Eichner, his committee, were to request the termination of the respirator, then that request would be the decision of Brother Fox which Father Eichner would merely pass on as a conduit. Unlike *Quinlan* and *Saikewicz*, no fiction is created nor is the judgment of Father Eichner substituted for that of Brother Fox."

In other words, Judge Meade feels authorized to grant relief *only because* the decision is that of Brother Fox. It is the decision of Brother Fox *only because* he had seriously discussed the Quinlan case and made his views clear before his predicament. Any other analysis Judge Meade sees as substituted judgments, which must be disallowed because the right in question is that of *self-determination*.

We believe this analysis has great importance with regard to the moral duty of preserving life. We will first suggest its implications and possible consequences, then the broader issues it raises.

The very first implication of this reasoning is that the vast majority of dying incompetent patients will be unable to have respirator (etc.) support discontinued where in balanced human and Christian judgment this is the thing to do. Why? Because most people will not have made their minds and preferences known through prior discussion, or if they have, witnesses of the fact may be lacking. For instance, how many people have discussed the Quinlan case in such a way that their clear preferences would be known and certifiable in their own incompetent, dying hour? If they have not, then there are no grounds for removing them from the respirator. We find reasoning that leads to such a conclusion self-defeating and ultimately very vulnerable.

Secondly, if Judge Meade disallows substituted judgments in cases of perpetual incompetency such as Saikewicz (he refers to any attempt to discern the actual interests and preferences of Saikewicz as "a ritualistic exercise, necessarily doomed to failure"), it is clear a fortiori that he would have to do the same for infants. That would imply that no dying infant could ever be withdrawn from life-sustaining equipment if such equipment could continue to keep that life going—regardless of condition or prognosis. This seems to us at odds with humane medical practice and good morality.

Thirdly, Judge Meade's reasoning clearly is based on the notion of individual self-determination understood, as he says, as "the right . . . to do whatever its possessor desires irrespective of the views of the majority." "Whatever its possessor desires" is not necessarily coincident with the best interests of the possessor. Thus, in deciding what is responsible

medical treatment of the dying incompetent, Judge Meade has driven a wedge between true best interests and personal desires, favored the latter as the basis of treatment, and left certification of these desires in the hands of the nearest of kin. Does this not offer greater possibility for abuse than an analysis which attempts to link more closely personal desires with actual best interests, and allows public opinion ("the overwhelming majority," as *Quinlan* words it) some role in determining, at least broadly, the meaning of best interests?

Finally, if these indeed are the implications of Judge Meade's reasoning, they constitute a nearly unavoidable stimulus toward legislation of living wills. Judge Meade adverted to this when he noted that "some form of such legislation may perhaps be required if the cessation of artificial life-support systems is to be possible under other circumstances." Contrarily, we believe that most current laws legislating living wills may be unnecessary and even dangerous.⁴ Furthermore, we believe that if any such legislation is called for, the most acceptable and least dangerous form is that whereby a person, in good health, deposes a proxy who will have decisive say in stating his best interests during incompetency. But this is precisely what Judge Meade denies can be done if the right in question is individual self-determination.

And that brings us to the substantive issue raised by his decision: the meaning of self-determination in this context and its relationship to guardianship.

We believe that the principle of individual self-determination is, at best, a limited, partial basis for an understanding of the appropriate resolution of conflict over decisions about the withdrawal of treatment from seriously or terminally ill persons. It perhaps provides an adequate basis for a policy of nonintervention on the part of the state, the medical community, and the family. Any adequate understanding of the moral basis for decisions in cases like that of Brother Fox, however, must move beyond the principle of individual self-determination. It is a sufficient but not necessary condition for decisions about the incompetent.

First, although the competent patient in a liberal society may have the legal right and even the ethical right of self-determination, this principle does not provide any moral basis for that individual to reach his or her own moral decision about whether it is appropriate to refuse or accept medical treatment. For that some fuller moral basis for decision must be provided. Traditionally many moral frameworks have acknowledged two justifiable grounds for treatment refusal: the burdensomeness of treatment or the uselessness of treatment. Some such positive moral guidance beyond the principle of individual self-determination will be required for

⁴ Cf. Andre E. Hellegers and Richard A. McCormick, S.J., "Legislation and the Living Will," *America* 136 (1977) 210-13.

an individual to determine whether medical treatment is morally to be refused or accepted.

But for the incompetent patient there must also be some moral foundation beyond that of individual self-determination. Judge Meade is correct in his recognition that incompetent patients cannot at the time of incompetency exercise self-determination. We think he is also correct in recognizing that the clearly expressed and demonstrated views of formerly competent patients such as Brother Fox provide an acceptable basis for making decisions for such patients, provided there is no evidence that the patient has rejected those views. Occasionally such cases may have to be adjudicated when there is doubt about the expressed wishes of the formerly competent patient or disagreement about whether those wishes remained in effect at the time of the patient's lapse into incompetency. In such cases the next of kin, other family members, or family surrogates such as Father Eichner are important and legitimate sources in reconstructing the formerly competent patient's actual wishes at the time of his/her lapse into incompetency.

Many patients, however, have never been competent or, if competent, have not formulated and expressed a consistent position about their treatment if seriously or terminally ill. Here individual *self-determination* is out of the question, but a fuller understanding of the principles of autonomy and benefit to the patient may still provide a basis for making responsible decisions about the care of such patients. In fact, we maintain that some decision simply must be made for such patients. To fail to make a decision seems impossible or at least morally irresponsible.

We suggest two principles that can replace the principle of individual self-determination as a basis for forming social policy regarding the care of patients like Joseph Saikewicz, Karen Quinlan, and others who have either never been competent or have not expressed themselves adequately while competent. The first principle is the principle of patient benefit. Incompetent patients and formerly competent patients who have not expressed themselves adequately while competent must be accorded full dignity as human beings. We must affirm the moral obligations placed upon others that this implies. Someone must have the responsibility of determining what is in such a patient's best interest. By confining withdrawal or withholding medical treatment within actual individual self-determination, Meade makes it impossible (unless he says more) to get incompetents who have not expressed themselves or those who have always been incompetent off useless or gravely burdensome life-extending machinery. In other words, he makes it impossible for the best interests of many patients to be served by disallowing the only judgment (substituted, guardian) that could possibly serve such interests. In this we disagree. If some medical interventions are not in the best interest of the

patient, it would be irresponsible to permit them to continue. The patient-benefit principle thus leads to the conclusion that someone ought to have the responsibility for deciding both to provide and to withhold medical intervention.

We are left with the question of who this "someone" might be. There are two reasons why family members or family surrogates are in a good position to make the initial determination. First, the family is normally in the best position to judge the real interests of the incompetent patient. They know his or her life style, preferences, and values. The family knows those treatments that might be particularly disturbing and those that the patient may have accepted without distress in the past.

Second, however (and we think this is the more important reason), our society places great value on the family. The family is a basic moral community affirmed to have not only rights but responsibilities in determining how best to serve the interests of its incompetent members. In fact, the principle of self-determination can best be understood to extend beyond the individual to encompass the notion of familial self-determination. This familial autonomy or self-determination is a value highly treasured. While it perhaps should not take precedence over individual autonomy or self-determination in cases where patients are or were competent, it certainly justifies a prominent role for family members in helping to assess what is in the best interest of the incompetent one. Family members are given enormous responsibility for moral nurture, theological and secular education, and decisions about the best interests of their incompetent members throughout the lifetime of the family unit. It should be no different in the case when the incompetent family member is seriously or terminally ill. Occasionally this may lead a family to decide that the incompetent one's interests can best be served by declining a medical intervention.

Even though the courts will approach the matter in a more secular way, there are sound theological warrants supporting the principle of familial self-determination. In Christian tradition the family is seen as a tightly bound unit with a sacramental ministry to the world. It is to mirror forth, by its own cohesiveness and solidarity, the love of Christ for his people. It is the school of love and caring, of nourishing and growth. It shares and deepens its values and spiritual life together as a unit. It determines what is to be its Christian life style. It is the Church in miniature and therefore, like the Church, has its own inner dynamics, priorities, and ideals. Since it lives and grows as a unit, its decisions in many important matters are, or ought to be, corporate decisions, directions taken as a result of its own familial self-determination.

Of course, the principle of familial self-determination cannot ride unchecked. Society's responsibility to assure that the interests of its

incompetent members are served will place some limits on familial autonomy. In cases, however, where a family is willing to make such decisions, and they act to fulfil their responsibility in this regard, the state should intervene only when the familial judgment so exceeds the limits of reason that the compromise with what is objectively in the incompetent one's interest cannot be tolerated.

When there is no family member or family surrogate willing to be appointed guardian for an incompetent one, then the principle of familial autonomy no longer has any significance for the specific case. The principle of patient benefit remains and becomes the exclusive principle for determining the case. Even then, however, when the only principle is that of choosing the course that will best serve the patient's interest, someone will have to make that determination. In these most tragic cases often a public official such as a judge may have to be called upon. By this method due process will be provided to protect the interests of a most vulnerable group in our society. In some cases the choice of the single course that is most objectively in the patient's interest may be so obvious to all concerned that official judicial involvement may not be necessary. There will be a real risk in permitting such decisions to be made outside of public scrutiny for such patients, but our faith in the wisdom and objectivity of those providing care may justify such a risk.

In any case, for such patients standing outside the arms of a loving and caring family structure, the goal must be to choose the single most objectively determined beneficial course.

A decision must be made in these cases. Apparently Meade's rejection of *Quinlan* and *Saikewicz* has led him to reject all substituted and guardian judgments. We disagree. There must be a principle for determining the best interests of the incompetent. The principle cannot be that of individual self-determination. When family members are available to lead in the decision, the principle of familial self-determination should grant them some discretion. They must determine what they consider to be in the best interest of their incompetent member based on their own system of familial beliefs and values. As long as those judgments do not deviate too far from what is most reasonably in the patient's interest, the family's wishes should be controlling. If they do deviate so far that the principle of patient benefit is unacceptably compromised, then others involved—medical professionals, friends of the patient, or any others significantly associated with the patient—must seek review to determine the limits of familial autonomy.

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