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The Saikewicz Decision and Patient Autonomy

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With the increased emphasis that has been given to patient autonomy in recent years, it is not surprising that the question should arise as to whether any right to refuse medical treatment extends to incompetent patients and if so, how such a right should be exercised. Indeed, these issues are raised by *Superintendent of Belchertown v. Saikewicz*,¹ a Massachusetts court decision that has attracted a good deal of attention in recent months.

The Saikewicz Decision: An Overview

On April 19, 1976, Joseph Saikewicz, a 67-year-old mentally retarded person with an I.Q. of 10 and a mental age of approximately two years and eight months, was diagnosed as suffering from acute myeloblastic monocytic leukemia. Although the disease is invariably fatal, chemotherapy offered a 30-50 percent chance of a temporary remission; such remissions typically last between two and thirteen months, although longer periods of remission are possible. A usual feature of the chemotherapy is the presence of adverse side effects such as severe nausea, bladder irritation, numbness and tingling of the extremities, and loss of hair. Because the cooperation of the patient over several weeks of time is crucial for chemotherapy and because Joseph Saikewicz, due to his mental retardation, could not be assumed to be cooperative, it was anticipated that it might be necessary to restrain him for extended periods of time if chemotherapy were to be administered.

The superintendent and staff attorney of the Belchertown State School where Saikewicz resided, filed a motion in the probate court

for the immediate appointment of a guardian *ad litem* with authority to make the necessary decisions concerning the care and treatment of Saikewicz. The probate judge appointed a guardian *ad litem* on May 5, 1976. This guardian, supported by the attending physicians, recommended non-treatment. The probate court entered an order permitting non-treatment and immediately appealed the decision. On July 9, 1976, the Massachusetts Supreme Judicial Court affirmed the probate court's order and indicated that an opinion would be issued at a later date. On Sept. 4, 1976, Joseph Saikewicz died (according to the court record, without pain or discomfort). The opinion was delivered Nov. 28, 1977.

Of particular interest in the *Saikewicz* decision is the use of the "substituted judgment" standard which, the court asserted, "commends itself simply because of its straightforward respect for the integrity and autonomy of the individual."² In reaching its decision, the court argued (a) that in appropriate circumstances, there is a general right to refuse medical treatment for a terminal illness, and (b) 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."³ The substituted judgment approach is identified as the means of exercising the right of the incompetent patient to refuse medical treatment. In applying the substituted judgment standard, the court insisted that "statistical factors indicating that a majority of competent persons similarly situated choose treatment" do not indicate what an individual choice in a particular situation might be.⁴ Thus, the court attempted to determine what Joseph Saikewicz himself would have wanted in the situation had he been able to make a decision and express himself. After considering various factors, the court concluded "that the decision to withhold treatment from Saikewicz was based on a regard for his actual interests and preferences and that the facts supported this decision."⁵

Saikewicz and the Substituted Judgment Standard

Is the use of the substituted judgment standard appropriate in a case such as this one? I shall argue that it is not, for the following reasons: 1) the notion of a right to refuse presupposes a decision-making capacity that cannot be said to have existed in this situation, 2) the nature of autonomy is such that it cannot be assumed by someone else (or by a court) without express authorization by the person whose autonomy it is, and 3) attempting to ascribe preferences to others apart from any expression of them is tricky business that places one on very treacherous grounds.

One of the problems that surrounds the use of the language of rights in many discussions, including that of the court in the *Saikewicz*

decision, is the failure to distinguish various types of rights. For example, sometimes the language of rights is used to designate some sort of a guaranteed option, as when it is asserted that someone has a right to vote. A second type of right, which is also negative in nature, is reflected in proscriptions of such things as killing and stealing; the basic notion here is that certain things ought to be declared out of bounds to others in society. Thus, whether the claim refers to life, property or some other consideration, this type of right involves the assertion that whatever is specified is to be reserved for the person who possesses the right. A third type of right suggests that the person who has the right has a legitimate claim to something, e.g., healthy working conditions or a minimum standard of living. In this case, the accompanying notion of obligation is that someone, such as an employer or society as a whole, has an obligation to provide whatever is specified in the statement of rights.⁶

The assertion that there is a right to refuse medical treatment is most coherently interpreted as a claim that involves the first type of right — that of a right as a guaranteed option. The problem insofar as the *Saikewicz* case is concerned is that this type of right, unlike the other two, presupposes the existence of an agent capable of making decisions. Moreover, as is illustrated by the example of voting rights, it is usual to suggest, particularly when the stakes are high, that the presence of a well-developed decision-making capacity is a precondition for the exercise of the right (hence the identification of a minimum age for voting). In short, to say that someone ought to be guaranteed an option doesn't make much sense if that someone is not capable, and never will be capable, of making decisions at a level commensurate with that required for the exercise of the right. As Paul Ramsey observes, "Incompetent patients do not have 'privacy' in the sense of autonomy and self-determination. Competent patients do."⁷ At best, to assert that the incompetent patient has a right to choose is to make a hollow statement. At worst, to so claim is to invite abuse. In all cases, it is to add confusion to the situation.

Violation of Notion of Autonomy

Second, even if the refusal of medical treatment could be said to have been an option for Joseph Saikewicz, to attempt to exercise that option for him, as the court did, does violence to the notion of autonomy. As is illustrated by the provision added to the New York Mental Hygiene Law in 1966, enabling the designation of a Committee of the Person to act on one's behalf should one become incompetent,⁸ it might be possible to delegate autonomy, or at least the right to make decisions justified by appeals to autonomy. And in cases in which patients have expressed treatment preferences prior to becoming

incompetent, it might be the case that autonomy can be respected retrospectively. However, if autonomy is understood as making the decisions relevant to one's own affairs, it is difficult to see how the decision-making process can simply be assumed by someone else without undercutting the very notion of autonomy; quite obviously, if someone else is making the decisions, particularly without express authorization by the person to whom the decisions relate, that person is not in control of his or her own affairs. Thus, contrary to what the court asserted, the substituted judgment standard, as it was applied in this case, cannot appropriately be characterized as respecting the autonomy of Joseph Saikewicz, but rather would seem to stand in contradiction to the notion of patient autonomy.

Third, in cases such as that of Joseph Saikewicz in which no expression of preference has been made or can be made by the patient, can we with confidence determine what the preference of a particular patient might be? In discussing the principle of paternalism, John Rawls asserts, "We must choose for others as we have reason to believe they would choose for themselves if they were at the age of reason and deciding rationally."⁹ But however fine that might sound in theory, in practice is such possible?

The court showed wisdom in not basing its decision on statistical studies of the population as a whole or on the projected preferences of competent persons imagining what they would do in similar situations; rather, as noted above, the court attempted to determine what Joseph Saikewicz himself would have wanted, had he been able to make a decision and express himself. But was there any way of determining this? Granted, it is not unreasonable to conclude that the pain and discomfort accompanying the chemotherapy would have been considerable. But how would he have felt about things in the periods of calm between the storms? As the attorney general of Massachusetts noted in commenting on the case, "There is no way for us to know if this mentally retarded person 'fears' or 'understands' the pain; and there is no way for us to measure his desire to live or his appreciation of being alive."¹⁰ In short, to attempt to ascribe preferences to others is very tricky business in situations in which the patient has not expressed and cannot express a preference. Thus one must seriously question whether responses to situations such as that of Joseph Saikewicz should be based on such uncertain grounds.

The upshot of all of this is that the substituted judgment approach does not seem to be a particularly appropriate way of deciding what ought to be done in situations involving incompetent patients who have not had occasion previously to express treatment preferences. This is not to suggest that incompetent patients don't have any rights; indeed, I insist emphatically that quite the opposite is the case and that the personhood of incompetent patients ought to be defended just

as rigorously as the personhood of competent patients. Rather, it is to protest attempting to justify treatment decisions by making appeals to autonomy when so doing is incongruous and to suggest that we would be well advised to use other concepts of rights and other moral norms when responding to situations such as that of Joseph Saikewicz.

Concluding Considerations

It should be noted that the critique presented in the preceding paragraphs has focused on the appropriateness of the substituted judgment standard in this particular case, not on the question of treatment versus non-treatment. To argue that the use of the substituted judgment standard is inappropriate does not automatically lead to the conclusion that treatment is the only defensible course of action. It might be possible to argue (a) that priority ought to be given to maintaining quality of life in situations in which treatment intended to prolong life would be exceedingly burdensome, (b) that compassion mandates that certain terminally-ill patients be allowed to die peacefully rather than be subjected to intrusive forms of treatment of questionable value, or (c) that society's obligation to provide medical treatment is not unlimited and that providing for chemotherapy in the case of Joseph Saikewicz would have been beyond the call of duty. But if any or all of these arguments are to be made, the issues that they address ought to be addressed head-on. Cloaking non-treatment decisions in language that does not fit the occasion obscures the real issues that underlie many such decisions.

Finally, in criticizing the use of the substituted judgment standard in the *Saikewicz* decision, I do not wish to imply that the expressed preferences of previously-competent patients should not be taken into consideration when making treatment decision. It is surely not unusual or absurd to suggest that the preferences of a person should be respected even in situations in which the person is no longer able to give active expression to them. When there is a track record clearly indicating treatment preferences, a strong case can be made for giving recognition to previously expressed preferences of an incompetent patient. Situations where such might be appropriate could include cases in which there is a recently affirmed living will and cases in which treatment refusal options such as that provided by the California Natural Death Act have been exercised.

In summary, to speak of a right of refusal when no capacity for choice has ever existed, to make decisions in the name of autonomy when no authorization to do so has been extended by the patient, and to ascribe preferences to a patient when there is no track record on which to base these preferences is to over-extend the notion of patient autonomy and the accompanying notion of the right to refuse medical

treatment. To misuse a conceptual framework that has come to play an important role in discussions of medical ethics can only damage the cause of patients' rights. The irony of *Saikewicz* is that it undercuts the very values which it purports to affirm.¹¹

REFERENCES

1. *Superintendent of Belchertown v. Saikewicz*, Mass., 370 N.E. 2d 417.
2. *Idem*, at 431.
3. *Idem*, at 423.
4. *Idem*, at 428.
5. *Idem*, at 432.
6. The confusion surrounding the use of the language of rights is accentuated by the fact that many statements about rights involve more than one type of claim. For example, both the second and third types typically underlie the assertion that there is an obligation to preserve human life, a statement that usually involves asserting (a) that one ought not destroy the biological dimensions of human existence necessary for personhood, and (b) that steps ought to be taken to prevent life from unnecessarily expiring — providing sustenance, administering medical treatment, etc.
7. Ramsey, Paul, "The *Saikewicz* Precedent: What's Good for an Incompetent Patient?," *The Hastings Center Report*, VIII (Dec., 1978), p. 37.
8. For a discussion of this provision, see Daniel C. Maguire, *Death by Choice* (New York: Schocken Books, 1974), pp. 169-171.
9. Rawls, John, *A Theory of Justice* (Cambridge, Mass.: The Belknap Press of Harvard University Press, 1971), p. 209. The passage is cited by John A. Robertson in "Organ Donations by Incompetents and the Substituted Judgment Doctrine," *The Columbia Law Review*, LXXVII (1976), p. 63. Robertson in turn is cited by the Massachusetts court in the *Saikewicz* decision.
10. Quoted by Paul Ramsey in *Ethics at the Edges of Life: Medical and Legal Intersections* (New Haven, Conn.: Yale University Press, 1978), p. 305.
11. I am indebted to Ann-Dudley Goldblatt and Edward Langerak, who read a previous draft of this paper. The dialog in which we have engaged has contributed greatly to sharpening the focus of the arguments present here.

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