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Saikewicz: Nontreatment Decisions for Incompetents

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Should we provide chemotherapy for leukemia for Joseph Saikewicz, an incurably ill, elderly, severely retarded resident of a state institution, whose life may be prolonged for up to a year by such care? The case of *Superintendent of Belchertown v. Joseph Saikewicz*,¹ which discusses this question, seems destined to become a classic for debate among lawyers, physicians and philosophers.²

I find the decision by the Supreme Judicial Court of Massachusetts, which affirmed the probate court's decision not to treat Saikewicz, open to speculation. First, I question that the number of considerations for nontreatment exceeded the considerations for treatment. I examine and reject some of the court's considerations for nontreatment, and argue that the court overlooked a consideration for treatment. Secondly, I doubt that the substituted judgment doctrine, a procedure which the court used to discover Saikewicz's wishes, was rigorously applied. Finally, I argue that the court did not establish a criterion for determining when life is worth living for Saikewicz. Hence, the court had no decision procedure for deciding Saikewicz's fate when there were an equal number of considerations for and against treatment.

A. Saikewicz's Situation

Joseph Saikewicz was a 67-year-old, profoundly retarded (I.Q. of 10 and mental age of approximately two years and eight months), long-term inmate (54 years) of state institutions in Massachusetts. Although he could not communicate except for gestures and grunts and responded only to gestures and physical contact, Saikewicz

enjoyed good health until April, 1976, when doctors learned he had acute myeloblastic monocytic leukemia — a fatal cancer of the blood.

The superintendent of Belchertown State School, where Saikewicz had resided for the last 48 years, petitioned the probate court for a determination about medical treatment. Treatment would involve the use of powerful drugs to kill not only leukemia-affected cells, but in the process, normal body cells as well. Because of massive, indiscriminate, blood-cell destruction, the onset of chemotherapy usually makes the patient much sicker. Side effects of treatment include nausea, vomiting, bladder irritation, numbness and tingling of the extremities, and hair loss. Finally, even if successful in inducing a remission, chemotherapy does not cure the underlying disease, and so after a period of two to 13 months, the leukemia usually returns and kills the patient.

Although there was medical controversy as to whether Saikewicz's age would impair the effectiveness of chemotherapy, facts before the court indicated that Saikewicz had a 30 to 40 percent chance of remission.³ The court also noted that chemotherapy would require the cooperation of Saikewicz over a period of several weeks and this raised speculation that he would need to be physically restrained during treatment and constantly supervised. Finally, the court remarked that Saikewicz was not presently in pain and within weeks or months would die a relatively painless death without chemotherapy, but that such treatment would probably lengthen his life. The court decided against treatment and Saikewicz died in September, 1976, from bronchial pneumonia, presumably a complication of his leukemia.

B. Substituted Judgment Doctrine

Since the court modeled the legal treatment of an incompetent patient after that of a competent one, and competent patients have the right in appropriate circumstances to refuse medical treatment, Saikewicz also had a right to refuse medical treatment. The court construed its decision for nontreatment as being what Saikewicz would have done in an exercise of his right to privacy and self-determination. But, of course, Saikewicz himself could not have made a decision to refuse treatment, because he was incompetent. The court resorted to the substituted judgment doctrine to solve this difficulty.

The substituted judgment doctrine is the court's attempt to "don the mental mantle of the incompetent" and "to substitute itself as nearly as may be for the incompetent, and to act upon the same motives and considerations as would have moved (the incompetent)."⁴ Using this doctrine, the court tried to place itself in Saikewicz's position and act as he would if he were competent to make decisions about his medical care. In doing this, the court had to

consider how Saikewicz would act while knowing that he would live out his life as an incompetent. In other words, the court tried to see Saikewicz's situation through his eyes as an incompetent, if competent to assess his situation, and this necessitated taking into account his continuing incompetency. There is no presumption that Saikewicz must be subjected to what rational and intelligent persons decline, since this placed a lesser value on his life. Evidence that most people would accept chemotherapy had no direct bearing on Saikewicz's case.

While I have no criticism of using the substituted judgment doctrine, I question whether the court rigorously applied substituted judgment to Saikewicz so that it viewed considerations about nontreatment from his perspective. In my discussion of the arguments against treatment and in presenting an additional argument for treatment, I present examples of the lack of rigor in applying substituted judgment.

C. Arguments Against Treatment

In arguing against treatment, the court listed six factors favoring nontreatment and two favoring treatment. It concluded that the weight of the evidence favored nontreatment. As reasons against chemotherapy for Saikewicz, the court listed: (1) his age, (2) his inability to cooperate with the treatment, (3) probable adverse side effects of treatment, (4) low chance of producing remission, (5) the certainty that treatment would cause immediate suffering, and (6) the quality of life possible for him even if the treatment did bring about remission.⁵ Of these six factors, only (2), Saikewicz's inability to cooperate with treatment, and perhaps (6), quality of life judgment which the court interpreted to mean the continuing pain and disorientation subsequent to chemotherapy, were particularly relevant to an incompetent. As considerations favoring treatment, the court listed (1) the chance that his life might be lengthened thereby, and (2) the fact that most people in his situation, when given a chance to do so, elect to take the gamble of treatment.⁶ While I do not dispute the first and sixth considerations for nontreatment, I have questions about the others.

First, the list of reasons for nontreatment is redundant. Consideration (3), probable adverse side effects of treatment, includes (5), the certainty that treatment will cause immediate suffering. Immediate suffering is just one of the adverse effects of treatment, not some new category.⁷ There are, then, only five distinct considerations for nontreatment.

By (4), the court meant to say that Saikewicz had a 30 to 40 percent chance of remission. The court imported a value judgment into this consideration when it called a 30 to 40 percent chance of remission low. There is nothing wrong with this value judgment except

that I see no accompanying argument justifying the application of "low" to this remission rate. These figures are low in the sense that they are less than 50 percent, but higher than if the remission rate were 10 to 15 percent. The judgment one makes about these figures is also a function of whether or not one is afflicted with the disease. Until the court gives an argument why such figures are a reason for nontreatment, it is unclear that they count as evidence for nontreatment.

Consideration (2) against treatment was that Saikewicz would have been unable to cooperate with chemotherapy. This means, the court contended, that he would have experienced confusion, disorientation, have been unable to anticipate and prepare for side effects of treatment, and consequently, would have suffered more from chemotherapy than a competent patient. No real evidence was given, however, that Saikewicz's pain would have been worse than a competent person's pain. While it may be true that a person who understands the reasons for pain is better able to endure it, it is possible that Saikewicz would not have suffered more than a competent patient. Moreover, since pain perception varies among individuals and may be related only indirectly to incompetency and the factors which the court cited, Saikewicz may not have suffered unduly.

Good evidence about how painful treatment would have been for Saikewicz could have been obtained from a trial treatment for his leukemia. Treatment could have been stopped if he became uncontrollable or uncomfortable. It should also have been possible to sedate him to reduce or control pain which may have been intermittent. Such a strategy would not have been cruel, particularly in view of the court's frequent mention of Saikewicz as a unique individual and the lack of good evidence that his pain would have been worse than that of a competent individual.

A decision on the part of Saikewicz to try out chemotherapy also would have been consistent with the substituted judgment doctrine. Since he had never been in this situation previously, he may have reasoned that some experience with chemotherapy might make him better able to judge its risks and benefits. He could also have reasoned that this decision was reversible since treatment could be stopped. While a decision to begin a trial treatment requires additional discussion, the failure of the court to consider this alternative demonstrated a lack of rigor in applying the substituted judgment doctrine to determine how Saikewicz might have reasoned about his circumstances.

But suppose it were true that Saikewicz would have fared worse on chemotherapy than a competent patient. What would such a comparison show, keeping in mind that the majority of competent patients who are informed of the side effects of chemotherapy, choose this treatment? If the majority of competent patients rejected such treat-

ment (and we knew that Saikewicz would have fared worse than a competent patient), then it is clear that we should not have subjected Saikewicz to treatment. But given that competent patients choose treatment, why should it have been a persuasive consideration for denying Saikewicz treatment that he would have fared worse than competent patients? This comparison tells us only the outcome of Saikewicz's treatment relative to another group, but it does not tell us how poorly — or how well — he would have fared. It is possible that treating Saikewicz still would have been indicated, even though treatment would not have been as beneficial for him as for competent patients.

Another problem with claiming that Saikewicz would have fared worse on chemotherapy than a competent patient is that we have no firm standard for the benefit of chemotherapy on competent patients, except that the majority of competent patients choose it. With any patient, a physician evaluates the benefit of chemotherapy by how well a patient responds. And a patient does likewise. In many cases chemotherapy is of questionable benefit, even for competent patients. We need to remember, then, that the court drew a comparison between something which is sometimes of questionable benefit (chemotherapy for a competent patient) and chemotherapy for a congenital incompetent. The question is, what can we learn from such a comparison? I do not think that this comparison gives us good evidence that chemotherapy would or would not have been beneficial for Saikewicz. Therefore, it is not a satisfactory consideration for denying Saikewicz chemotherapy.

I have argued that there were only three considerations for nontreatment of Saikewicz since (5) is a special case of (3). I have also questioned (4) as a reason for nontreatment, because the court presented no argument to justify the application of "low" to Saikewicz's chance of remission. Finally, I disputed (2), a comparison which claimed that Saikewicz would suffer more than a competent patient. Thus there remain only three considerations for nontreatment from the court's original list. Are there any additional reasons, other than the two which the court listed, in favor of having treated Saikewicz? There is at least one.

D. An Additional Reason for Treatment

An important consideration in favor of treating Saikewicz was that the decision to treat was reversible, whereas the decision not to treat, particularly with Saikewicz's leukemia where treatment had to begin immediately for any hope of success, would be irreversible. Treatment could have been discontinued if Saikewicz had shown avoidance behavior or behavioral signs of severe pain and stress. For example, if there was always a struggle when nurses came to take him for treat-

ment, it could have been concluded that he was suffering unduly and treatment could have ceased. As I suggested earlier, beginning treatment would have shown respect for Saikewicz and his individual situation and given him an opportunity as best he could to express himself to us.

Many may argue that a trial treatment of Saikewicz would have created difficult problems and it should not have been considered. Presuming that treatment would not set in motion irreversible side-effects and biological processes in Saikewicz, there may still remain objections. First, how much pain and suffering, on substituted judgment of Saikewicz, was too much so that treatment should have been ended? Second, did treatment create aesthetic problems? Third, did beginning treatment of Saikewicz make it more difficult to stop when it was no longer in his interests?

In answering questions about how much pain and suffering justifies ending treatment, we need to recognize that the measures for pain and suffering are imprecise. Uncontrollable behavior by Saikewicz at the sight of tubes and needles or the treatment area should have been sufficient, however. "Uncontrollable behavior" means behavior which cannot be managed by analgesics. The general issue here is when continued life is an injury to a patient. There is no positive duty to treat when the prospects of continued life are poor and the amount of pain and suffering is high.

In dealing with aesthetic considerations about treating Saikewicz, we must remember that aesthetics may, but should not, cloud our assessment of whether to begin treatment. For example, there is the possibility that we may have to suspend a trial treatment and it *feels* different to suspend treatment than never to begin. Additionally, seeing an incompetent in restraints as intravenous tubes drip chemicals which cause toxic side effects would be dreadful. Saikewicz was not the kind of patient who satisfied our need to be healers. The emotional strains which such a patient places on doctors and nurses are possibly greater than in the case of a competent patient. None of this, however, is relevant to what might be the wishes of someone like Saikewicz, if competent, or what might be in his best interests.

The final concern with beginning treatment is that we may mistakenly continue to treat someone like Saikewicz when it is no longer in his interest. We may come to feel, for example, that we can justify the previous pain and suffering of treatment only by continuing efforts to treat. Having criteria for suspending treatment and understanding that continuing treatment may be an injury to a patient should help to prevent a slippery slope. More important, however, to argue that the possibility of making a mistake is a reason for not beginning treatment would justify our never attempting any trial treatments. The objections to a trial treatment, then, do not seem persuasive.

Adding the consideration that the decision to treat is reversible to the court's reasons for treatment would give us three considerations for treating Saikewicz. Earlier I had argued that there are only three considerations for nontreatment. Although now there is an equal number of considerations for and against treatment, there is additional evidence which helps weaken arguments for nontreatment.

Saikewicz's familial, social and economic circumstances might have made treatment less of a burden for him than for a competent, non-institutionalized patient. Since Saikewicz's sisters chose not to become involved when informed of his leukemia, Saikewicz may have reasoned that prolonging his dying by chemotherapy would not have placed emotional burdens on loved ones. Moreover, since he was a state ward, he may also have reasoned that his treatment would not be a financial burden to himself or his family, an important consideration for many noninstitutionalized patients.

Additionally, since Saikewicz was institutionalized, his life was simpler than the lives of many competent leukemia patients who must severely restrict their activities. They also feel a deep change of body image as skin tone alters and hair falls out. Saikewicz, presumably, would not have felt these same restrictions of bodily activities, since he had not engaged in many of the activities of competent patients and it is doubtful that he would have anguished over a change of body image. Again, these considerations do not indicate how well Saikewicz might have done on chemotherapy. But by failing to consider these unique features of Saikewicz's situation, the court not only neglected to apply substituted judgment rigorously, but also neglected to see the weakness of its arguments for nontreatment.

My analysis of the *Saikewicz* decision shows an equal number of considerations for and against treatment. With this balance — and probably even when the number of considerations is relatively close for treatment versus nontreatment — the court's method of considering the weight of the evidence to decide Saikewicz's fate failed. What, then, should have happened to Saikewicz?

I think a treatment decision needed to be made in terms of a criterion for when Saikewicz's life was worth living. The *Saikewicz* court lacked such a criterion and simply talked about the weight of the evidence. This procedure works only when the evidence is unquestionably in favor of treatment or nontreatment. Moreover, the consequences of error in assessing the number of considerations for and against treatment loom large when the numbers are close.

A proper criterion for treatment was that Saikewicz should have been treated if, and only if, the benefits of prolonged life outweighed the pain and suffering of chemotherapy. In assessing the burden of pain and suffering we need to consider the familial, social and economic circumstances as I earlier suggested. This criterion entails that we should have ceased treatment if Saikewicz were having pain-

behavior unmanageable by analgesics, when bad days began to outnumber good ones and there was little hope for more good future days. If he were living a vegetative existence, maintained by tubes and needles, and there was little prospect that he would ever live again without such intensive care, then we should have found that the benefits of prolonged life do not outweigh the pain and suffering and ceased treatment.

E. Conclusion

While I do not think that the court's arguments supported nontreatment, my arguments do not claim without qualification that we should have treated Saikewicz. In such cases, we should begin treatment, always being ready to stop when we think that the benefits of continued treatment do not outweigh the pain and suffering of the chemotherapy. Beginning treatment is an attempt to go between the horns of the dilemma of either treatment or nontreatment and to give the patient an opportunity to express himself to us as best he can.

Before closing, I would like to point out that I am not arguing in this paper for or against the sanctity of human life nor for a position that human life must be defended at all costs. I think there are many instances where dying is preferable to living with a body wracked with pain in the final stages of a fatal disease. But I do not see that Saikewicz would have become this kind of patient or that we would have needlessly maintained him with a trial treatment of chemotherapy.

REFERENCES

1. *Superintendent of Belchertown v. Saikewicz*, Mass. 370 N.E. 2d 417 (1977): 417-435.
2. The forward to a recent issue of *American Journal of Law and Medicine* 2 (Summer, 1979), pp. 1-v1, points out that the *Journal* has become a forum for Saikewicz discussions. This issue contains three Saikewicz articles, and earlier issues also discuss this case. An interested reader might also consult the *Hastings Center Report*, especially 8 (Feb., 1978), pp. 21-23 and 6 (Dec., 1978), pp. 36-42. A longer article is the Saikewicz chapter in Paul Ramsey's *Ethics at the Edges of Life* (New Haven: Yale University Press, 1978).
3. *Superintendent of Belchertown*, p. 421. The trial judge was unaware of this controversy.
4. Quoted from John Robertson's "Organ Donations by Incompetents and the Substituted Judgment Doctrine," *Columbia Law Review*, 1 (Jan., 1976), pp. 48-78, at pp. 57, 58.
5. *Superintendent of Belchertown*, p. 422.
6. *Ibid.*
7. Dr. Norman Foster suggested this criticism to me.