

The following is the legal case related to the hypothetical about "Bill" discussed in the Oct. 7 "Thinking Ethically" class in POM 1. It has been edited for the sake of brevity.

Superintendent of Belchertown State School v. Saikewicz

Supreme Judicial Court of Massachusetts, Hampshire, 373 Mass. 728, 370 N.E.2d 417 (1977)

On April 26, 1976, William E. Jones, superintendent of the Belchertown State School (a facility of the Massachusetts Department of Mental Health), and Paul R. Rogers, a staff attorney at the school, petitioned the Probate Court for Hampshire County for the appointment of a guardian of Joseph Saikewicz, a resident of the State school. Simultaneously they filed a motion for the immediate appointment of a guardian ad litem, with authority to make the necessary decisions concerning the care and treatment of Saikewicz, who was suffering with acute myeloblastic monocytic leukemia. The petition alleged that Saikewicz was a mentally retarded person in urgent need of medical treatment and that he was a person with disability incapable of giving informed consent for such treatment.

On May 5, 1976, the probate judge appointed a guardian ad litem. On May 6, 1976, the guardian ad litem filed a report with the court. The guardian ad litem's report indicated that Saikewicz's illness was an incurable one, and that although chemotherapy was the medically indicated course of treatment it would cause Saikewicz significant adverse side effects and discomfort. The guardian ad litem concluded that these factors, as well as the inability of the ward to understand the treatment to which he would be subjected and the fear and pain he would suffer as a result, outweighed the limited prospect of any benefit from such treatment, namely, the possibility of some uncertain but limited extension of life. He therefore recommended "that not treating Mr. Saikewicz would be in his best interests."

[The judge below entered an order that agreed with the recommendation of the guardian ad litem. This appellate opinion reviews that decision.]

. . . The judge below found that Joseph Saikewicz, at the time the matter arose, was sixty-seven years old, with an I.Q. of ten and a mental age of approximately two years and eight months. He was profoundly mentally retarded. The record discloses that, apart from his leukemic condition, Saikewicz enjoyed generally good health. He was physically strong and well built, nutritionally nourished, and ambulatory. He was not, however, able to communicate verbally resorting to gestures and grunts to make his wishes known to others and responding only to gestures or physical contacts. In the course of treatment for various medical conditions arising during Saikewicz's residency at the school, he had been unable to respond intelligibly to inquiries such as whether he was experiencing pain. It was the opinion of a consulting psychologist, not contested by the other experts relied on by the judge below, that Saikewicz was not aware of dangers and was disoriented outside his immediate

environment. As a result of his condition, Saikewicz had lived in State institutions since 1923 and had resided at the Belchertown State School since 1928. Two of his sisters, the only members of his family who could be located, were notified of his condition and of the hearing, but they preferred not to attend or otherwise become involved.

On April 19, 1976, Saikewicz was diagnosed as suffering from acute myeloblastic monocytic leukemia. Leukemia is a disease of the blood. It arises when organs of the body produce an excessive number of white blood cells as well as other abnormal cellular structures, in particular undeveloped and immature white cells. Along with these symptoms in the composition of the blood the disease is accompanied by enlargement of the organs which produce the cells, e. g., the spleen, lymph glands, and bone marrow. The disease tends to cause internal bleeding and weakness, and, in the acute form, severe anemia and high susceptibility to infection. *Attorneys' Dictionary of Medicine L-37-38 (1977)*. The particular form of the disease present in this case, acute myeloblastic monocytic leukemia is so defined because the particular cells which increase are the myeloblasts, the youngest form of a cell which at maturity is known as the granulocytes. *Id.* at M-138. . . . The disease is invariably fatal.

Chemotherapy, as was testified to at the hearing in the Probate Court, involves the administration of drugs over several weeks, the purpose of which is to kill the leukemia cells. This treatment unfortunately affects normal cells as well. One expert testified that the end result, in effect, is to destroy the living vitality of the bone marrow. Because of this effect, the patient becomes very anemic and may bleed or suffer infections, a condition which requires a number of blood transfusions. In this sense, the patient immediately becomes much "sicker" with the commencement of chemotherapy, and there is a possibility that infections during the initial period of severe anemia will prove fatal. Moreover, while most patients survive chemotherapy, remission of the leukemia is achieved in only thirty to fifty per cent of the cases. Remission is meant here as a temporary return to normal as measured by clinical and laboratory means. If remission does occur, it typically lasts for between two and thirteen months although longer periods of remission are possible. Estimates of the effectiveness of chemotherapy are complicated in cases, such as the one presented here, in which the patient's age becomes a factor. According to the medical testimony before the court below, persons over age sixty have more difficulty tolerating chemotherapy and the treatment is likely to be less successful than in younger patients. This prognosis may be compared with the doctors' estimates that, left untreated, a patient in Saikewicz's condition would live for a matter of weeks or, perhaps, several months. According to the testimony, a decision to allow the disease to run its natural course would not result in pain for the patient, and death would probably come without discomfort.

An important facet of the chemotherapy process, to which the judge below directed careful attention, is the problem of serious adverse side effects caused by the treating drugs. Among these side effects are severe nausea, bladder irritation, numbness and tingling of the extremities, and loss of hair. The bladder irritation can be avoided, however, if the patient drinks fluids, and the nausea can be

treated by drugs. It was the opinion of the guardian ad litem, as well as the doctors who testified before the probate judge, that most people elect to suffer the side effects of chemotherapy rather than to allow their leukemia to run its natural course.

Drawing on the evidence before him including the testimony of the medical experts, and the report of the guardian ad litem, the probate judge issued detailed findings with regard to the costs and benefits of allowing Saikewicz to undergo chemotherapy. The judge's findings are reproduced in part here because of the importance of clearly delimiting the issues presented in this case. The judge below found:

“1. That the majority of persons suffering from leukemia who are faced with a choice of receiving or foregoing such chemotherapy, and who are able to make an informed judgment thereon, choose to receive treatment in spite of its toxic side effects and risks of failure.

“6. That such toxic side effects of chemotherapy include pain and discomfort, depressed bone marrow, pronounced anemia, increased chance of infection, possible bladder irritation, and possible loss of hair.

“7. That administration of such chemotherapy requires cooperation from the patient over several weeks of time, which cooperation said JOSEPH SAIKEWICZ is unable to give due to his profound retardation.⁵

“8. That, considering the age and general state of health of said JOSEPH SAIKEWICZ, there is only a 30-40 percent chance that chemotherapy will produce a remission of said leukemia, which remission would probably be for a period of time of from 2 to 13 months, but that said chemotherapy will certainly not completely cure such leukemia.

“9. That if such chemotherapy is to be administered at all it should be administered immediately, inasmuch as the risks involved will increase and the chances of successfully bringing about remission will decrease as time goes by.

⁵ There was testimony as to the importance of having the full cooperation of the patient during the initial weeks of the chemotherapy process as well as during follow-up visits. For example, the evidence was that it would be necessary to administer drugs intravenously for extended periods of time twelve or twenty-four hours a day for up to five days. The inability of Saikewicz to comprehend the purpose of the treatment, combined with his physical strength, led the doctors to testify that Saikewicz would probably have to be restrained to prevent him from tampering with the intravenous devices. Such forcible restraint could, in addition to increasing the patient's discomfort, lead to complications such as pneumonia.

“10. That, at present, said JOSEPH SAIKEWICZ's leukemia condition is stable and is not deteriorating.

“11. That said JOSEPH SAIKEWICZ is not now in pain and will probably die within a matter of weeks or months a relatively painless death due to the leukemia unless other factors should intervene to themselves cause death.

“12. That it is impossible to predict how long said JOSEPH SAIKEWICZ will probably live without chemotherapy or how long he will probably live with chemotherapy, but it is to a very high degree medically likely that he will die sooner, without treatment than with it.”

Balancing these various factors, the judge concluded that the following considerations weighed against administering chemotherapy to Saikewicz: “(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 will cause immediate suffering, and (6) the quality of life possible for him even if the treatment does bring about remission.”

The following considerations were determined to weigh in favor of chemotherapy: “(1) the chance that his life may 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.”

Concluding that, in this case, the negative factors of treatment exceeded the benefits, the probate judge ordered on May 13, 1976, that no treatment be administered to Saikewicz for his condition of acute myeloblastic monocytic leukemia except by further order of the court. The judge further ordered that all reasonable and necessary supportive measures be taken, medical or otherwise, to safeguard the well-being of Saikewicz in all other respects and to reduce as far as possible any suffering or discomfort which he might experience.

It is within this factual context that we issued our order of July 9, 1976.

Saikewicz died on September 4, 1976, at the Belchertown State School hospital. Death was due to bronchial pneumonia, a complication of the leukemia. Saikewicz died without pain or discomfort.

. . . The question what legal standards govern the decision whether to administer potentially life-prolonging treatment to an incompetent person encompasses two distinct and important subissues. First, does a choice exist? That is, is it the unvarying responsibility of the State to order medical

treatment in all circumstances involving the care of an incompetent person? Second, if a choice does exist under certain conditions, what considerations enter into the decision-making process?

We think that principles of equality and respect for all individuals require the conclusion that a choice exists. For reasons discussed at some length [above], we recognize a general right in all persons to refuse medical treatment in appropriate circumstances. The recognition of that right must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both.

This is not to deny that the State has a traditional power and responsibility, under the doctrine of *parens patriae*, to care for and protect the “best interests” of the incompetent person.

. . . The “best interests” of an incompetent person are not necessarily served by imposing on such persons results not mandated as to competent persons similarly situated. It does not advance the interest of the State or the ward to treat the ward as a person of lesser status or dignity than others. To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons. If a competent person faced with death may choose to decline treatment which not only will not cure the person but which substantially may increase suffering in exchange for a possible yet brief prolongation of life, then it cannot be said that it is always in the “best interests” of the ward to require submission to such treatment. Nor do statistical factors indicating that a majority of competent persons similarly situated choose treatment resolve the issue. The significant decisions of life are more complex than statistical determinations. Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the unique perspective of the person called on to make the decision. To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.

. . . We believe that both the guardian ad litem in his recommendation and the judge in his decision should have attempted (as they did) to ascertain the incompetent person’s actual interests and preferences. In short, the decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.

. . . The two factors considered by the probate judge to weigh in favor of administering chemotherapy were: (1) the fact that most people elect chemotherapy and (2) the chance of a longer life. Both are appropriate indicators of what Saikewicz himself would have wanted, provided that due allowance is taken for this individual’s present and future incompetency. . . . With regard to the second factor, the chance of a longer life carries the same weight for Saikewicz as for any other person, the value of life under the law having no relation to intelligence or social position. Intertwined

with this consideration is the hope that a cure, temporary or permanent, will be discovered during the period of extra weeks or months potentially made available by chemotherapy. The guardian ad litem investigated this possibility and found no reason to hope for a dramatic breakthrough in the time frame relevant to the decision.

The probate judge identified six factors weighing against administration of chemotherapy. Four of these, Saikewicz's age,¹⁷ the probable side effects of treatment, the low chance of producing remission, and the certainty that treatment will cause immediate suffering were clearly established by the medical testimony to be considerations that any individual would weigh carefully. A fifth factor, Saikewicz's inability to cooperate with the treatment, introduces those considerations that are unique to this individual and which therefore are essential to the proper exercise of substituted judgment. The judge heard testimony that Saikewicz would have no comprehension of the reasons for the severe disruption of his formerly secure and stable environment occasioned by the chemotherapy. He therefore would experience fear without the understanding from which other patients draw strength. The inability to anticipate and prepare for the severe side effects of the drugs leaves room only for confusion and disorientation. The possibility that such a naturally uncooperative patient would have to be physically restrained to allow the slow intravenous administration of drugs could only compound his pain and fear, as well as possibly jeopardize the ability of his body to withstand the toxic effects of the drugs.

The sixth factor identified by the judge as weighing against chemotherapy was "the quality of life possible for him even if the treatment does bring about remission." To the extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it. A reading of the entire record clearly reveals, however, the judge's concern that special care be taken to respect the dignity and worth of Saikewicz's life precisely because of his vulnerable position. The judge, as well as all the parties, were keenly aware that the supposed ability of Saikewicz, by virtue of his mental retardation, to appreciate or experience life had no place in the decision before them. Rather than reading the judge's formulation in a manner that demeans the value of the life of one who is mentally retarded, the vague, and perhaps ill-chosen, term "quality of life" should be understood as a reference to the continuing state of pain and disorientation precipitated by the chemotherapy treatment. Viewing the term in this manner, together with the other factors properly considered by the judge, we are satisfied 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. . . .

¹⁷ This factor is relevant because of the medical evidence in the record that people of Saikewicz's age do not tolerate the chemotherapy as well as younger people and that the chance of a remission is decreased. Age is irrelevant, of course, to the question of the value or quality of life.