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# Withholding of Life-Supporting Treatment from the Mentally Incompetent

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The troubling issue of withholding life-supporting medical treatment from dying patients is exacerbated in the case of the mentally incompetent. We need not look to a brain-damaged Karen Ann Quinlan or the even more bizarre Rosemarie Maniscalco case for examples. State hospitals and institutions are ready sources of mentally disturbed or severely retarded individuals who cannot give informed consent for medical treatment and who, when terminally ill, present difficult dilemmas for the hospital staff. One example, that of Joseph Saikewicz, a profoundly retarded 67-year-old man who had been institutionalized in Massachusetts schools for the retarded since 1923, provides a graphic case study of the legal, medical, and moral dimensions of the problem.

In 1976, Saikewicz, whose IQ was 10 and whose mental age was the equivalent of a two year and eight month old child, became ill. The diagnosis was acute myelogenous leukemia, an invariably fatal disease which, though non-curable, may in some instances be slowed down by chemotherapy treatments.

The question facing his physician and the Belchertown State School authorities where he had resided for nearly 50 years was what was the proper treatment. There is no question that the staff was concerned with Saikewicz's welfare. The school physician had sent him to the University of Massachusetts Medical Center for initial diagnosis and then transferred him to the Bayside Medical Center for further consultation with hematology and oncology specialists. As the Belchertown medical director was later to testify: "I'd like to do our best to treat him as a patient; that he deserves like anybody else. . . . Our concern is to find expert people who can guide us as to what kind of treatment he should receive."

Those involved recognized the complexity of the problem: without chemotherapy Saikewicz would probably die within two months; with it there would be a 30-50% chance of a remission that could prolong

his life 2-13 months. Saikewicz was unable to understand the situation and his family did not want to get involved. Furthermore, the proposed therapy had serious adverse side effects. To add to the dilemma, the staff was aware that the overwhelming majority of similarly situated competent patients opt for the therapy.

At this juncture the school appealed to the Hampshire County Probate Court for permission to begin the chemotherapy. The court appointed a guardian *ad litem* to recommend whether the treatment should be commenced. Initially impressed with the fact that nearly all of the "normal" patients with a similar diagnosis elected chemotherapy, the guardian was inclined to favor treatment. Further conversations with Saikewicz's physicians, however, convinced him that the patient's inability to comprehend or cooperate with the treatments would not be normal. That fact led the guardian to change his mind. He recommended that no treatment be given.

On May 13, 1976 the Probate Court held a brief hearing in which several physicians testified that because of Saikewicz's profoundly retarded condition and his inability to understand or communicate concerning his medical disabilities, they advised against treatment. At first the judge was unpersuaded. In part his initial reluctance hinged on his personal assessment that, "If I had a serious disease and with treatment I could live another five or eight or ten years, whatever, I'd rather take the treatment than just take the chance of dying tomorrow or next week."

He shifted his position after one of the physicians reiterated the realistic possibilities and the difficulty of carrying out the protocol. The doctor also noted the deteriorated quality Saikewicz's life would take even if the medication proved successful. The Probate Court, though, was uneasy with its order to withhold treatment and asked for an appellate review of its ruling. On motion of the Attorney General, the Massachusetts Supreme Judicial Court granted direct review.

One index of the case's moral complexity is the fact that the Attorney General's office submitted competing briefs in the case: the Attorney General sought to reverse the decision while the Civil Rights Division supported the order. Additional *amicus* briefs were submitted by several groups interested in the mentally retarded.<sup>1</sup>

On July 9, 1976 the Supreme Judicial Court by divided vote upheld the Probate Court order. It stated that an opinion would be forthcoming. On Sept. 6, 1976 Joseph Saikewicz died peacefully of bronchial pneumonia, a product of his acute leukemia that by court order remained untreated until the end.

Among the multiple issues raised in this case the primary question was, should Saikewicz have been treated? The various briefs and *amici* arguments along with the vast medical, moral, and legal literature now available on the subject of death and dying provide the sources for a tentative answer.

## Arguments for Treatment

Some very strong positions were advanced in the briefs for the state's absolute duty to preserve the life of a mentally incompetent terminally-ill patient. Not to take every measure possible it was argued, would be to devalue the life of the mentally retarded patient. The authors of the Attorney General's brief, fearing "quality-of-life" judgments would devalue the mentally retarded, contend that "treatment decisions should be tailored to the 'medical needs' and not to the 'medical and personal needs' of the incompetent patient."<sup>2</sup>

While there is a serious need to be aware of and to guard against those who would insert rational utility tests for the preservation of life, that position has horrendous implications for the medical treatment of the mentally incompetent. Such a stance is a cruel caricature of the very values its proponents hope to preserve. It fails to accept the fact that under such a standard the patient is reduced from a person to a disease; he is an entity stripped of all meaning save that of "medical interest."

Such critics also discount the difficulty of administering chemotherapy to a profoundly retarded individual. Because he would not understand what was being done to him such a patient tends to pull out the IV's and attack those attempting to help him. To prevent that from happening, the patient would have to be placed in restraints. To the critics of the court's decision these conditions are not sufficient grounds to withhold the treatment: "Such a conclusion would be unwarranted given that the doctors testified that chemotherapy would be difficult rather than impossible to administer."<sup>3</sup>

The assistant Attorneys General who held that view are supported by the Developmental Disabilities Law Project group which maintains that, "It is basic to the human condition to seek life and hold on to it however burdened."<sup>4</sup> For them there is but one guiding principle: "Lives which can be saved must be saved."<sup>5</sup>

The position that the physician must do everything possible to secure maximum patient longevity regardless of the condition of the patient is not a novel one. It is an attitude, though, that is increasingly under criticism in both the medical and ethical communities.

The deontological or rule-oriented standard articulated in that model does have the advantage of guaranteeing consistency in treatment and the avoidance of "quality-of-life" judgments. But the very attempt to treat disparate categories of patients as if they were similar is to introduce differing standards of treatment. Even if 100% of the competent leukemia victims elected chemotherapy, it does not necessarily follow that the same treatment must be administered to others who have substantially diminished capacities to understand and accept the therapy.

The vitalist doctrine of utmost medical care whenever possible,

coupled with the refusal to accept the position that differing conditions sometimes mandate differing care, finds its logical culmination in the Maine Medical Center's handling of *Baby Boy Houle*.<sup>6</sup> That case, which is frequently cited as legal precedent by the critics of the Saikewicz decision, involved a horribly deformed newborn. His entire left side was malformed; he had no left ear, was practically without a left eye, had a deformed left hand; some of his vertebrae were not fused. Furthermore, he was afflicted with esophageal fistula which prevented feeding by mouth and allowed fluids to push up into his lungs. As his condition deteriorated he contracted pneumonia and had several convulsive seizures which led to suspicion of severe brain damage.

The tracheal esophageal fistula, which most immediately threatened the infant's life, is remediable by relatively simple surgery. The attending physician and the boy's father wanted to forego the procedure. Several of the other physicians objected and took the case to court. Superior Court Judge David G. Roberts' opinion forcefully articulates the vitalist position. He stated that regardless of the newborn's condition, "At the moment of live birth there does exist a human being entitled to the fullest protection of the law." Dismissing the attending physician's opinion that the massive deformities and probable brain damage had rendered the life not worth saving because it was beyond the scope of medical expertise, he ruled that the only issue to be decided was the medical feasibility of the proposed treatment. In his view, if the corrective surgery is medically necessary and medically feasible, it must be undertaken. And he so ordered. (The child died shortly after the court mandated surgery.)

### Arguments Against Treatment

From Judge Roberts' perspective and that of the critics of the Saikewicz decision, courts should not consider the "quality-of-life" of defective or retarded individuals when life-saving measures are necessary. The medical and moral literature, though, evidences a more complex and sophisticated approach to the problem. Richard McCormick, S.J. of Georgetown University's Kennedy Center for Bioethics, has provided the most thought-provoking analysis of the issue. In an essay in *The Journal of the American Medical Association*, he writes that advances in medical technology have brought us to the point where we can easily transform yesterday's medical failures into today's successes.<sup>7</sup> Translated into practice this means we must shift the question from, "Can we keep this patient alive?" to "What kind of life are we saving?" Such questions are irretrievably "quality-of-life" judgments and, McCormick argues, there is no avoiding them.

Our task, he writes, is to draw lines, develop criteria, and formulate guidelines for handling such cases, not to retreat behind talismanic incantations of "the sanctity of life" and "the worth of every individ-

ual." Such slogans in his opinion are the weapons of ideological battle, not the tools for analysis and enlightenment.

McCormick's own framework is developed from the traditional Judeo-Christian understanding that "It is neither human nor unchristian to say that there comes a point where an individual's condition itself represents the negation of anything truly human." When that point is reached, he asks, is not the best treatment no treatment?

There is, of course, the always lurking danger in these decisions that an individual will be valued for his functional utility, what he can do, rather than who he is. A sad example of that mentality occurred in the famous Johns Hopkins case in which a mongoloid child with an intestinal blockage (duodenal atresia) was allowed to starve to death over a fifteen day period because his parents felt, "It would be unfair to the other children to raise them with a mongoloid."<sup>8</sup> James Gustafson, the University of Chicago ethicist, in a thorough and convincing criticism of that incident, argues that the presumption of life is not qualified by intelligence nor does it yield to inconvenience. There comes a point, however, when inconvenience becomes suffering and suffering becomes unbearable. At that stage, he believes, the individual no longer has an absolute moral duty of sustaining the burden.

### Application to Saikewicz

The McCormick-Gustafson position cuts a middle ground between medical vitalism (preserving life at all costs) and medical pessimism (taking life when it seems frustrating, burdensome or "useless"). It also aids us in a determination of how best to proceed in a case like that of Joseph Saikewicz. Following their guidelines, one neither opts for a medical feasibility test nor the unreflective dismissal of any treatment of profoundly retarded individuals.

In the decision-making process we must begin with a determination of what is going on and the most appropriate response to that reality. In the instant case that involves an understanding of Saikewicz's condition and the effect chemotherapy will have upon it. Only then is one able to make a "risk-benefit" assessment tailored to the specific needs of the individual.

Much useful information for that task is provided in the Mental Health Legal Advisors' Committee's depiction of the mental world of the profoundly retarded:

These people are incapable of communicating on anything but a momentary concrete level. They can experience pain and when they do, they scream and cry and flail about with their arms and legs. More importantly for the purposes of their undergoing painful therapy which might have future benefit is the fact that such individuals have no concept of time, especially future time. They are also aware, but do not comprehend, changes in surroundings and they tend to react to such shifts with fright and insecurity which is frequently expressed loudly and vehemently.<sup>9</sup>

A further analysis of the problem of utilizing chemotherapy treatment on the profoundly retarded is found in the Probate Court transcript where the undisputed testimony of all the physicians involved was that such patients have no ability to understand or cooperate in the treatment. When that fact was coupled with the severe nausea, anemia, bladder irritation and the susceptibility to infection that accompanies chemotherapy, the conclusion of the medical testimony was that, "It is going to be virtually impossible to carry out the treatment."

"The issue," as one of the physicians summarized it, "boils down to the quality of his life now and when he goes through the treatment. If treated, he certainly will suffer. The low probability that he will go into remission has to be measured against that reality." Still another factor is the realization that the treatment might actually shorten his life. A final consideration is the fact that if the leukemia is left undisturbed, Saikewicz will die relatively quickly without pain or discomfort.

Those who subscribe to the proposition that "it is basic to the human condition to seek life and hold on to it however burdened," found support in much of the legal literature until the landmark Karen Ann Quinlan case forced the New Jersey Supreme Court to recognize the incredible hardships medical technology can now exact from a patient. In *Quinlan* for the first time we find a court ruling that "a patient cannot be forced to endure the unendurable."<sup>11</sup>

### Attitudes Toward Death

Stewart Alsop perhaps best summed up the situation in a brilliantly insightful description of his own heroic but ultimately unsuccessful fight against leukemia. "There comes a time," he writes, "when it is both wrong as well as useless to continue to resist. . . . The dying man needs to die, just as the sleepy man needs to sleep."<sup>12</sup> When that time comes further expenditures of effort and expertise are not only futile, they are foolish.

At such a point Paul Ramsey states, "We must cease doing what was once called for and begin doing what is called for now: caring for the dying."<sup>13</sup> That care involves comforting and accompanying with the dying person, not for useless struggles at extending his temporo-spatial existence. As Ramsey reminds us, it is the person, not his disease, who calls for our ministrations. In such circumstances the most the physician can promise is care, not a cure.

Ramsey's suggestions find reinforcement in Elizabeth Kubler-Ross' well-known studies on death and dying. These reveal that the most important problem for the dying is not death itself, but how he dies.<sup>14</sup> For her the patient's chief fear is being isolated or abandoned or being placed in a situation where people with untreatable diseases are "kept alive indefinitely by means of tubes inserted into their

stomachs, or into their veins, or into their bladders, or into their rectums — victims of massive and unwarranted medical intervention upon their own particular death.”<sup>15</sup>

In reference to a terminal cancer case one compassionate physician has written, “It is inhuman to drag the dying patient to radiation therapy, to transfuse him repeatedly, or to give massive toxic and nauseating chemotherapy to relieve one tiny facet of an intolerable existence, thereby dragging it out for a few more agonizing days or weeks.”<sup>16</sup> To do so to an incompetent patient is simply an added cruelty.

One might ask how we get ourselves into such a plight. In part it is because death is perceived not as a natural function of life, but as an enemy to be overcome. Thus begins the application of all available medical resources, regardless of the cost, to the patient or his family. That position, of course, has always been contrary to Catholic moral thought where the saving of a life has never been viewed as an absolute or inflexible norm. Unfortunately, that vision is not always shared by the medical profession.

The medical and moral communities frequently do not even share a common understanding of such traditional distinctions as “ordinary/extraordinary” means of saving a life. Physicians have tended to translate “ordinary” into “customary” or what is readily available. “Extraordinary” is then understood as “heroic” or experimental treatment. With such an interpretation the “state of the art,” not the state of the patient, is the major determinant of usage. To the moralist, non-medical features are equally dispositive and must be factored into the treatment calculus.

Paul Ramsey calls for a “reformed” medical understanding of the terms so that depending on the condition of the patient even the simplest and most easily applicable medication, if offering no reasonable hope of benefit to the person, is deemed “extraordinary” and thus elective. Using his focus on “the person in whom the diseases inhere” and not on the disease itself, it is possible to understand why the dying patient should be treated differently from an otherwise healthy individual stricken with the same disease. For one, the treatment, painful and costly though it be, is endurable for the promise of restored health it holds; for the other the suffering is but an added and unnecessary burden.

Seen from this perspective, the administration of chemotherapy which would inexplicably change the character of Joseph Saikewicz’s life from a peaceful routine into a bewildering nightmare of pain, fear, and physical restraint, would surely constitute “extraordinary” treatment. And if he has no obligation to undergo such treatment — common though it might be for other patients — neither has the physician any moral obligation to provide it; nor the judge to order it.<sup>17</sup>

One last rationale for treatment must be noted. The Attorney Gen-



eral's office was justifiably sensitive to the potential for devaluing the lives of the mentally incompetent implicit in state-sanctioned withholding of medical treatment. To obviate that danger, its brief argued that "allowing a leukemia victim to live a bit longer, although in pain, certainly seems reasonable to preserve the principle of 'the sanctity of life'." The danger warned of is real enough,<sup>18</sup> but it is one that a vigilant court and a watchful public must guard against, not one that a non-competent individual must involuntarily suffer to ward off. Any treatment the profoundly retarded leukemia victim undergoes must be premised on protecting his "best interests" not on upholding some abstract principle.

Given the choice between a peaceful "natural" death and an incomprehensibly painful prolongation of the dying process, courts should not overrule guardian-physician-family decisions that withholding of treatment is the least detrimental alternative for the patient. That decision, reluctantly arrived at to be sure, far from degrading life or devaluating the social worth of such patients is an expression of the highest respect for life and individual dignity. As the New Jersey Supreme Court observed in the *Quinlan* case:

Physicians . . . have sometimes refused to treat the hopeless and dying as if they were curable. . . . We think these attitudes represent a balanced implementation of a profoundly realistic perspective on the meaning of life and death and that they respect the whole Judeo-Christian tradition of respect for human life.<sup>19</sup>

### Supreme Judicial Court Ruling

On December 5, 1977 the Supreme Judicial Court released its long awaited opinion on the Saikewicz case. The Court chose to focus on three issues: the right of any person, competent or incompetent to decline life-prolonging treatment; the legal standard for non-competents; and the procedure to be followed in arriving at such a decision.

Interestingly, the opinion, which is destined to be influential, controversial, and widely debated, began with the admission that existing legal doctrine was unable to resolve the novel issues raised in the case. The Court, admitting that the law necessarily lags behind the most advanced thinking in every area, turned to the reflections of health care, theology, moral ethics, and philosophy for guidance and insight on how to deal with terminally ill patients.

One positive result is that for the first time in a major court opinion we find an acceptance of the distinction long used in medical ethics between ordinary and extraordinary means: "We should not use *extraordinary* means of prolonging life or its semblance when, after careful consideration . . . it becomes apparent that there is no hope of recovery for the patient."<sup>20</sup>

Further, the Court concurred with the *Quinlan* court in adopting the Ramsey/Kubler-Ross thesis that we can and ought to distinguish between "curing the ill and comforting and easing the dying." It

accepted the stand that physicians ought not treat the hopeless and dying as if they were curable. They ought rather, in the Court's view, recognize that the dying are more in need of comfort than of treatment.

These positions, buttressed by recent developments in the law on informed consent and respect for the right of privacy, were the basis for the Court's authorization of the withholding of chemotherapy for Saikewicz. The Court acknowledged the state's interest in preserving life, but where that preservation is tendentious at best and attained only at traumatic cost, the Supreme Judicial Court recognized the right of an individual to forego that cost.

In an interesting turn of the argument, the Court reversed the thesis that the value of life is lessened or cheapened by a decision to refuse treatment. It ruled that the value of life is diminished by the failure to allow a competent human being the right of choice and the right of privacy, i.e., the right to be left alone.

The more difficult problem is the attribution of these rights to the incompetent. As was seen earlier there are those who argue strenuously that the state must always provide treatment of the incompetent or risk devaluing their dignity and worth. The Supreme Judicial Court rejects that proposition and in a precedent shattering contribution to the developing trend in the law, ruled that "the principles of equality and respect for all individuals require that a choice exist for incompetents as well as competents." To do otherwise," it states, "would be to treat wards of the state as a person of lesser status or dignity than others."

Having recognized the right of an incompetent to refuse life-prolonging treatment, the Court is faced with the awesome task in a case of first impression of framing an adequate rationale to explain how that right may be exercised. It does so with an interesting yoking of the long-standing legal doctrine of substituted judgment with a Rawlsian reconstruction of the mental world of a "rational" incompetent.

Substituted judgment, a doctrine first articulated in English law over 150 years ago,<sup>21</sup> deals with authorization of gifts from the estate of incompetents. The English court reasoned this could be done by "donning the mental mantle of the incompetent," i.e., what we might reasonably conclude the individual would do if he could understand his present situation.

That theory of respect for the integrity and autonomy of all persons finds renewed vigor in John Rawls' highly influential *A Theory of Justice* where he writes that maintaining the integrity of the person means that we act towards him "as we have reason to believe he would choose for himself if he were capable of reasoning and deciding rationally."<sup>22</sup> This does not mean that we can impute preferences to him that he never held. But, as is true in the case of Saikewicz, where no

preferences have been made, our task is to ask how we would act for ourselves if we were in a similar position.

Applying the substituted judgment theory to Saikewicz, the Supreme Judicial Court concluded that the Probate Court, the guardian *ad litem*, the physicians, and the school staff all operated in the best interests of Joseph Saikewicz, i.e., they chose what appeared to be the least detrimental alternative available for the patient. It also observed that none of the parties used "quality-of-life" judgments as a value of the patient's life and that great care was taken to respect the worth of Saikewicz's life precisely because of his vulnerable status.

The Court was particularly careful in its fashioning of the "quality-of-life" statements to dispel any possible interpretation that the low quality of life of a mentally retarded individual was a determining factor in this case. It announced its regret that "the vague and perhaps ill-chosen term" had crept into the testimony. It also made explicit its understanding that the phrase as used referred to "the continuing state of pain and disorientation precipitated by the chemotherapy treatment" and not to a "value of life" judgment.

### Procedure for Decisions

The third item of the Court's concern, the procedure by which decisions to withhold life-prolonging treatment for non-competents is to be made, is of great interest to both the legal-medical community and to the public at large. It is also, perhaps, the least satisfactory and most controversial section of the opinion.

The Court mandates that in questions of providing or withholding life-prolonging treatment from all alleged incompetents (not only state wards), a probate court determination of competency must be made. If the individual is adjudged incompetent, a guardian *ad litem* must be appointed who will represent the patient at a full adversarial hearing and he must defend the proposition that the treatment should be administered. The Court requires this procedure so that "all viewpoints and alternatives will be aggressively pursued and examined."

The effect of this ruling is to add full adversarial hearings with competing witnesses, opposing counsel, and the trauma of courtroom drama to the already stressful decision-making process involved in the withholding of treatment from the terminally ill non-competent patient. What this means at the practical level is that every time a patient suffering from a terminal illness lapses into disorientation, senility, or unconsciousness the family and physicians will be plunged into the unwelcomed, cumbersome, and costly arena of litigation if they determine that further treatment is unwarranted. The predictable result will be the unnecessary continuation of the treatment by the physician and suffering for the patient and his family.

The New Jersey Supreme Court foresaw that result and sought to obviate it by locating the decision-making mechanism within the

guardian-family-physician group subject in difficult or novel cases to ratification by a hospital ethics committee. It did so because it believed decisions on "the nature, extent, and duration of care" are primarily the physician's responsibility. Shifting that role to the courts was judged to be "a gratuitous encroachment upon the medical profession's field of competence. It would also prove to be a time consuming and cumbersome process that would overburden already clogged courts.

The Massachusetts bench feared no such results. In very specific terms it declared: "We reject the approach adopted by the New Jersey Supreme Court." In doing so, it appropriated to the courts the role of making all life and death decisions for every incompetent in the Commonwealth. It did this because in its phrasing "that responsibility is not to be entrusted to any other group purporting to represent the 'morality and conscience of our society,' no matter how highly motivated or impressively constituted."

### Conclusion

The Supreme Judicial Court's disposition of the Saikewicz case has produced a landmark opinion that will influence both the substantive and procedural aspects of all future cases involving the withholding of medical care from terminally ill incompetent patients.

On the substantive level the Court has definitively rejected the vitalist approach to medical treatment and has provided a legal framework for the adoption of Christian moral attitudes on death and dying. It has also strengthened the trend of the law in according to incompetents the same rights exercised by all others.

The procedural aspects of the case are more troubling. Since no distinction was made between long-term incompetents or state wards and those who because of age or illness are no longer able to make informed decisions for themselves, a large category of cases that would formerly be handled at the family-physician stage are now the subject matter of court deliberation.

Despite the Court's distrust of other groups, judges are not gods nor philosophers' kings. Moreover, they are little equipped by training or experience for the type of decision-making they are now called upon to perform. Yet, now it will be only after a full scale judicial hearing that the family and physician of a terminally ill incompetent patient may effect what the Court itself acknowledges as the duty "of (only) caring for the dying." Such is the strange and strained legacy of a case begun to ease the burden of a dying Joseph Saikewicz.

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- In an analysis of *Saikewicz* written before the Massachusetts Supreme Judicial Court issued its opinion, Ramsey was somewhat ambivalent as to how to proceed. He was adamantly opposed to any quality-of-life judgment that would facilitate the dispatch of mentally retarded patients by isolating the fact of retardation and elevating that condition into the decisive consideration. Yet he recognized that a legitimate "medical indications policy judgment" for withholding treatment could be made.
- Such a judgment would be that the very treatment itself, and not merely *Saikewicz's* diminished mental capacity, imposed unacceptable hardships. If that were true, and Ramsey concedes that there were probably such medical indication in this case, then he agrees that "one is not obliged to continue the efforts" to treat the patient.
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  19. *In re Quinlan*, 70 N.J. at 43; 355 A. 2nd at 667.
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