

Foreword

MORE ON APPROPRIATE DECISION MAKING FOR THE TERMINALLY ILL INCOMPETENT PATIENT

To many of our readers, it must seem that we are preoccupied with the subject of appropriate decision making for terminally ill incompetent patients, and more specifically with the 1977 *Saikewicz* decision of the Massachusetts Supreme Judicial Court.¹ Indeed, this current edition of the *Journal* contains the fifth and sixth installments in our year-long health-law and public-policy debate over the meaning, the wisdom, and the impact of the *Saikewicz* opinion. For better or for worse, during this past year the *Journal* has become the nation's most active academic forum for scholarly debate of *Saikewicz*.

How and why did this debate come to be? It began when, in my capacity as Editor-in-Chief, I invited Professor Charles Baron of Boston College Law School to publish in the *Journal* some of his thoughts on *Saikewicz*. This he did, in our Summer 1978 edition, and spontaneously there ensued a series of commentaries, expressing a variety of viewpoints on *Saikewicz*, in subsequent editions of the *Journal*. Contributing authors, in addition to Professor Baron, were Dr. Arnold Relman, Professor George Annas, and Professor Allen Buchanan.

But does *Saikewicz* deserve all this attention? Should we have allocated such a large portion of our finite editorial resources to publishing a highly specific and deliberately controversial, albeit much-heralded, series? I think so. In my view, it is hard to imagine at this time a health-law case subsequent to the better-known, although less controversial, 1976 *Quinlan* decision of the New Jersey Supreme Court² that the *Journal* should have examined more closely.

¹ Superintendent of Belchertown State School *v.* Saikewicz, 1977 Mass. Adv. Sh. 2461, 370 N.E.2d 417 (1977).

² *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976). *Quinlan* held, among other things, that life-supporting mechanical ventilation of a patient who, although not brain-dead, is in an irreversible vegetative state (having neither cognition nor sapience), could be terminated without fear of civil or of criminal liability, if a hospital "ethics committee" concurred with the termination decision of the guardian, family, and physicians of the patient.

Because the principles embodied in *Quinlan*, unlike those in *Saikewicz*, generally leave decision making for *Saikewicz*-type patients within the province of their families and physicians

In *Saikewicz*, the Massachusetts Supreme Judicial Court, that state's highest court, decided that a Massachusetts probate court judge appropriately had ordered that potentially life-prolonging (but not life-saving) chemotherapy not be administered to Joseph Saikewicz, a 67-year-old, severely retarded man who had an acute, invariably fatal form of leukemia, and who could hardly have comprehended the meaning of the suffering that chemotherapy entails. The high court also held that, in the future, such "proxy" decisions whether to give or to withhold potentially life-prolonging treatment of terminally ill incompetent patients should be based on an assessment of what the patient would have wanted; furthermore, the high court named the state's probate courts as the appropriate agencies for making such decisions, thereby withdrawing from physicians and families their traditional prerogative of making such decisions without routine judicial intervention.

In this latter aspect of its decision—calling for routine judicialization of decision making in *Saikewicz*-type cases—the court took an unusually firm stand in resolving one of the principal societal questions involved in determining the course—in terms of quantity, quality, and nature—of medical treatment administered to terminally ill patients: *Who* should decide whether or not to provide treatment, in instances where the choice potentially involves life or death? I believe the attention given to this critical question in our *Saikewicz* series has been justified. Such decisions have great importance both in addressing individual cases (from both societal and patient perspectives) and in making the difficult policy judgments (some would say life-rationing decisions) that inevitably must be made concerning the macro- and micro-allocations of our nation's scarce resources, especially its medical resources.

I shall not attempt here to analyze critically the viewpoints expressed on the "Who should decide?" question by the contributors to our series. I plan to join this debate later by writing an Article on sources of authority in *Saikewicz*-type pediatric cases. But, for now, I will refrain from broadening the debate or the number of debaters. Instead, I will use this Foreword to bring you up to date on our extensive discussions of *Saikewicz*, and to share with you my thoughts on the importance of these discussions to the *Journal* and its staff.

The first piece in this series, authored by Professor Charles Baron of Boston College Law School, appeared in Volume 4, Number 2 (Summer 1978) of the *Journal*. Titled *Assuring "Detached but Passionate Investigation and Decision": The Role of Guardians Ad Litem in Saikewicz-type Cases*, this Article (the first of Baron's two contributions to the series), focuses upon the

(through so-called "ethics committees"), *Quinlan* is the more widely accepted of the two opinions, particularly by the medical community.

portion of the *Saikewicz* opinion that states that the type of “proxy consent” question arising in that case requires for its decision “the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created”—more specifically, that *Saikewicz*-type treatment decisions should be decided by probate courts, not by *Quinlan*-type “ethics committees,” by attending physicians, or by patients’ families or guardians.

In his Article, Baron agrees with *Saikewicz*’s general direction, but argues that the Massachusetts Supreme Judicial Court did not go far enough in the judicialization of the resolution of *Saikewicz*-type treatment decisions, since it failed to lay down guidelines that would assure a truly adversary process in all such instances. Baron proposes guidelines designed to overcome this failure, including a requirement that patients in *Saikewicz*-type cases be represented in probate court by two guardians ad litem, one whose task it is to make the strongest possible argument for providing treatment, and the other whose task it is to argue with equal vigor against providing treatment.

Based upon the argument that it erroneously embroils the identification and resolution of a medical question in the adversarial process of the Massachusetts judicial system, the *Saikewicz* decision has drawn considerable criticism and open hostility from the Massachusetts medical community. It is not surprising, therefore, that the second contribution to this series is a strong retort to Baron authored by Arnold S. Relman, M.D., the Editor of *The New England Journal of Medicine* and a leading scholarly spokesman for the United States medical community. In his Article, which appeared in Volume 4, Number 3 (Fall 1978) of the *Journal* under the title *The Saikewicz Decision: A Medical Viewpoint*, Relman strongly disagrees with *Saikewicz*’s call for judicial resolution—instead of resolution by patients’ families and physicians—of *Saikewicz*-type medical treatment decisions. This policy, he asserts, violates both common sense and clinical tradition, and its application necessarily will result in serious problems, such as the unnecessary prolongation of the suffering of many seriously ill patients.

As an alternative to *Saikewicz*’s routine-judicialization approach, Relman suggests that judicial input should occur only when there is disagreement, concerning treatment, among next of kin, or between next of kin and attending physicians, or when there is a complaint, by a relevant party, of injury or of wrongdoing. In all other situations, he states, resolution of even the most significant treatment decisions by attending physicians with the informed consent and guidance of next of kin should be sufficient. Finally, Relman proposes that adequate protection of the interests of the incompetent patient could be achieved by a requirement that the physician in charge document, by detailed entries in the medical record, that the treatment decision—either for or against the administration of significant

therapy—received (1) the concurrence of the patient's family, and (2) the advance approval of a group of the physician's professional colleagues who have no vested interest in the outcome of the decision.

The third work in this series is a rejoinder by Baron to Relman that further engages and focuses the debate between them. This Article, titled *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman* and published in Volume 4, Number 4 (Winter 1979) of the *Journal*, challenges Relman's statement that *Saikewicz* was incorrect in calling for routine judicial resolution of medical treatment decisions in *Saikewicz*-type cases. First, Baron argues that Relman's belief that physicians should make such decisions unaided and unencumbered by the courts is based upon an outmoded, paternalistic view of the physician-patient relationship. Second, Baron addresses the importance of guaranteeing to *Saikewicz*-type patients the kinds of procedural safeguards that characterize decision making by courts and that are not necessarily present to any significant degree when treatment decisions are made by attending physicians. Finally, Baron argues that Relman has overestimated the social costs of bringing *Saikewicz*-type cases before the courts, and that such costs as exist are offset fully by the social benefits of the procedural safeguards that only the courts can provide.

The fourth piece in this series, also appearing in Volume 4, Number 4, is titled *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*. In this Article, Professor George Annas of Boston University School of Medicine attacks Relman's assumption that *Saikewicz*, by virtue of its judicialization approach, directly contradicts *Quinlan*.

Annas's thesis is that *Quinlan* and *Saikewicz* are in fundamental agreement with one another and can be reconciled by the next state supreme court that is confronted with a case involving life and death medical decision making for a terminally ill incompetent patient. Both courts, he states, articulate a constitutional right of incompetent patients to refuse life-sustaining treatment, based upon a right to privacy; the two courts also agree, he says, that incompetent patients should be given the opportunity to exercise this right of privacy through proxy decision makers, and that there are few state interests that properly can supersede this exercise. Furthermore, Annas states, the *Quinlan* and *Saikewicz* courts agree that physicians should be permitted to make medical judgments, and that societal judgments belong more properly in the courts. The *Quinlan* court, he believes, simply viewed Karen Quinlan's situation as one in which a hopeless medical prognosis left no doubt that she would have wanted her treatment terminated. Annas states that the *Saikewicz* court, on the other hand, felt that Mr. Saikewicz's situation was such that there existed legitimate doubts concerning what he would have wanted, doubts that could be resolved best by a probate court through an adversary proceeding. Together, the *Quinlan* and *Saikewicz* courts delineate, in Annas's view, the appropriate spheres of medical and legal decision making.

The fifth piece to be published by the *Journal* in this series is the feature Article in this edition. Authored by Professor Allen Buchanan, a member of the Philosophy Department of the University of Minnesota, this piece is titled *Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Saikewicz-type Cases*. As will be seen in the pages that immediately follow this Foreword, Buchanan disagrees to a large extent with everyone who has preceded him in this debate. His thesis, in a nutshell, is that each of his predecessors has overlooked the fact that solution of *Saikewicz*-type problems necessarily requires the resolution of a distinct third class of relevant issues—the ethical class—in addition to the resolution of relevant medical questions and legal questions. In Buchanan's view, the patient's family normally should be the decision maker in such cases, because of the special moral relationship that exists between the family and the patient. Furthermore, he feels that a "genuine" ethics committee (as distinct, he says, from a *Quinlan*-type ethics committee) that is in effect independent of the hospital should set forth, in writing, a set of standards for such decision making by families, and should periodically review the use of such standards.

The sixth piece in this series is a brief rejoinder by Relman to Buchanan, titled *A Response to Allen Buchanan's Views on Decision Making for Terminally Ill Incompetents*. It, too, appears in this edition of the *Journal*, immediately following the Buchanan Article. In this rejoinder, Relman, besides defending himself against Baron's and Buchanan's assertions that he is a medical paternalist, takes strong issue with Buchanan's position that a "genuine" ethics committee should be an essential element of society's approach to *Saikewicz*-type cases. Relman reaffirms his faith in the traditional approach to such cases that he articulated in his earlier contribution to the debate.

I think that you will find the Relman-Buchanan debate in this edition to be a stimulating and enlightening addition to our series on the *Saikewicz* case.

In closing, it seems to me that through this *Saikewicz* series, the *Journal* had made solid progress toward achieving its primary objective: to provide an unbiased forum for expert opinion aimed at clarification and solution of important medicolegal problems. The *Journal*, of course, has published other articles on death and dying,³ but the *Saikewicz* series is especially noteworthy because it brings together—in an organized, sharply focused format—viewpoints of specialists from the separate but related disciplines of law, medicine, and philosophy.

I hope that our readers have learned as much from the *Saikewicz* series

³ For example, van Till, *Diagnosis of Death in Comatose Patients Under Resuscitation Treatment: A Critical Review of the Harvard Report*, 2 *AM. J. L. & MED.* 1 (1976); Kaplan, *Euthanasia Legislation: A Survey and a Model Act*, *id.* at 41.

as have those of our editors and staff who worked so hard to produce it. Our experience of evaluating and editing the *Saikewicz* materials has given us a fresh sense of purpose. We have been forced to think about and to write about a fundamental human question: determining when to cease allocating society's scarce medical resources to a dying human being. It is paradoxical that so much good—in terms of conscientious exploration of this problem—has flowed from the tragic illness of Joseph Saikewicz, a ward of the state whom most of us knew only through the legal rituals that surrounded his dying.

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