

August 1984

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Recommended Citation

Riga, Peter J. (1984) "The Care of Defective Neonates, Ethics Committees and Federal Intervention," *The Linacre Quarterly*: Vol. 51 : No. 3 , Article 9.

Available at: <https://epublications.marquette.edu/lmq/vol51/iss3/9>

The Care of Defective Neonates, Ethics Committees and Federal Intervention

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Introduction

As the technological abilities of modern medicine get more sophisticated, the problems of defective fetuses and neonates will become more troublesome.¹ While the idea that a woman may legally and morally abort her children found to be probably defective through amniocentesis enjoys widespread popularity among Americans, now the question to be faced is whether the logic of this mentality has begun to spread to those children who, while defective, manage in some way to be born.²

There are other problems in this delicate area as well. We have had the case of the killing of one of a set of twins found to be defective while the other was permitted to live;³ selection of sex gender with its evident dangers; the development of fetal operations which can correct many abnormalities thought previously to be unavoidable, etc. The latter case poses acute problems for the abortion mentality since now the fetus is treated as an independent patient and to that extent, is considered a human being. And what of the technology of receding the time of viability from six months to five-and-a-half months or even earlier? What becomes of court decisions in the abortion cases and the notion of state interest?⁴ This problem was considered by the minority opinion in the most recent abortion decision of the U.S. Supreme Court (*Akron*).

It should also be noted that the questions which follow are hard questions of law and ethics and no clear and ready answers or solutions will be available for the doctor, other medical personnel, ethics committees, etc. What is imperative, however, is that we approach the question with a profound respect for *all* human life, the parents as

well as the defective children. If we are going to act like God, we should act like God with compassion, justice, and equality. Perhaps a serious dialogue can begin with the widespread use of ethics committees which has now been recognized by the federal government.

The Cases

I

In the case of *In re Mueller*, a set of Siamese twins who were allegedly denied food and oxygen at their parents' request came to the attention of the courts.⁵ The deformed twins were born May 1, 1981, to a Danville, Illinois physician and his wife. The twins were found by a judge on June 5, 1981, to be neglected children but, curiously, the same judge found no neglect on the part of the parents who knew or should have known what was happening to their children in the hospital. Someone was responsible for withholding ordinary food and drink in a situation which was far from ethically clear.⁶

The state took temporary custody of the sons of Dr. Robert Mueller and his wife, Pamela Schopp, when a social worker, acting on an anonymous call, visited Lakeview Medical Center and found evidence of neglect. In fact, what she found was that the Siamese twins were denied food and drink to the point where their ribs were protruding.⁷ In effect, they were being allowed to starve.

The twins were joined at the waist and shared three legs. More ominously for their future, they shared a common digestive system and some vital organs.⁸ While custody was being decided, the children were examined and cared for at Children's Memorial Hospital in Chicago, to determine whether they could be separated. Medical experts gave a negative prognosis for separation. In fact, the final resolution of the case indicated that no one was responsible for the neglect since the parents were finally awarded custody of the twins who were permitted to be taken home.

The ethical and legal issues here are momentous since there are no recorded cases in which either parents or physicians have been held civilly or criminally liable for failure to maintain children born with either defects or conditions such that the parents are unwilling to live with them. In a sense, what we have in these cases is the other side of the coin of the *Phillip Becker* case where a young Down's syndrome 12-year-old boy was refused corrective heart surgery by the parents and this was upheld by the California courts for no other reason than that the boy was retarded.⁹ The difference is that in the *Mueller* case, the defect was detected immediately at birth and the attempted remedy was a sort of post-natal abortion. This practice is not new, as we shall soon see. Involuntary euthanasia on defective neonates has been going on for well over a decade at various university clinics and hospitals. It is only recently that it has been brought to the notice of public authorities. Some legal and moral standards, therefore, must be

set up for treating or not treating such children. The case of *Infant Doe* from Bloomington, Indiana, was factually similar.¹⁰

In this latter case, a severely retarded Down's syndrome child was allowed to die by denying it the elemental human demands of food and drink. It was originally the decision of her parents which the appellate courts of Indiana refused to stay or prevent. The child died of dehydration and starvation before the U.S. Supreme Court could intervene. The legal question is not "moot" but is precedent in Indiana. But because there was no opinion in the case, it is difficult to know exactly for what the case stands.

The facts seem to show that *Infant Doe* was not dying at all. If the child was dying and was beyond the scope of the healing process, as we shall explain, then there would have been no legal or moral problem. As with all the dying, we would then withdraw the useless technology of medicine, make the patient as comfortable as possible, and let nature take its course. The cause of death would be the pathological condition of the patient for which we can do nothing further, not the removal of medicine or technology. The lawyer for the parents at first claimed that the child had only a "50/50 chance of survival" with a simple operation to open a fistula which was blocking the esophagus. In fact, under questioning, he admitted that this figure was incorrect and that *Infant Doe* "could have surgery with more than an even chance of success" according to expert medical testimony. In sum, it seems that *Infant Doe* was allowed to dehydrate and starve to death because she was retarded. Under those circumstances, parents and their doctors decided to "let nature take its course." This was, in reality, a twist in the evident meaning of the English language. If one withdraws food and drink from any child, it will die and the cause will be the refusal, not "nature." As little information as possible was given by all concerned — lawyers, parents, hospital personnel and authorities — which seems strange under the circumstances, given the notoriety which the case received nationally. If, as claimed, there were two acceptable medical procedures open to the parents, one of which was nontreatment why was this fact not made clear from the onset? The reason, however, seems to be clear: for the first time in the history of the United States, an appellate court justified out-and-out euthanasia for the sole reason that the subject was retarded. Since *Infant Doe* died of dehydration and starvation, the withholding of food and drink was the direct cause of death.

In October, 1973, an article appeared entitled "Moral and Ethical Dilemmas in the Special Care Nursery."¹¹ The authors reported that some 43 (14 percent) of the 249 consecutive infant deaths at the Yale University School of Medicine special care nursery were related to withholding treatment. The parents and physicians in a joint decision decided that the infants' prognosis for *meaningful life* was very poor and therefore, treatment was to be rejected. The standards used by the

medical clinic were not explained by the article.

In an earlier case, *Maine Medical Center v. Houle*,¹² a male infant was born without a left eye and a left ear, with a deformed left hand and a tracheoesophageal fistula. Without surgical repair (a minor operation), the infant would die. The parents were informed and they directed the physician not to operate on the child and to withhold feedings and intravenous fluids. The Center petitioned the state superior court for a temporary restraining order to maintain intravenous feedings pending the court's ruling on the question of surgical intervention. The child developed seizures which were interpreted as brain damage. The court granted the restraining order and ordered the parents not to interfere with the efforts of the physicians to perform surgery; to do so would constitute child neglect. The pediatrician notified the court of the severity of the prognosis and the condition of the child. The judge ruled that "the issue is not the prospective quality of life to be preserved." *Houle* held that the *evaluation* (i.e., the value to be assigned to this life or any life) is beyond the scope of a physician's medical expertise because "quality of life" judgments are beyond the physician's medical expertise, and that withholding consent to the operation would constitute "neglect" on the part of the parents. In the words of the court: "The most basic right enjoyed by every human being is the right to life itself." The court acted as *parens patriae*, appointed a guardian to consent to surgery, and enjoined the parents from interfering from any future medical treatment. The infant died on Feb. 24, 1974.

In this case, as well as in the *Mueller*, *Infant Doe*, and *Becker* cases, the parents were particularly angered over interference in "a strictly private and familial matter." The matters of family privacy and parental decision-making are, of course, principles of good law and ethics generally. But it seems that the above cited cases, while few, should warn us that more is involved here than just these principles: who speaks for the defective child who has an independent right to life? With regard to these cases, the following remarks are in order.

II

First of all, in each of these cases, we are not in a *Roe* situation since all of these children have been born and, presumably, have met the constitutional requirement for personhood with full rights, including a right to life. Leaving the fate of such persons to the interested discretion of parents and doctors can be seen as an arbitrary denial of due process and equal protection. What is at work, at least in these few cases, is a quality-of-life argument decided by interested parents and doctors, for which there is little legal precedent. We are not dealing here with a "prolongation of dying" of terminally ill patients, but with children who will have a diminished human capacity.

Secondly, any legal response to this question of involuntary euthanasia depends on our expectations of what law can and should accomplish in this situation.¹³ Any such determination in the final analysis can only be made by the broader determination of law as public policy made by a legislature or by the people themselves: Are these defective children a definable class? Are certain instances of withholding treatment morally justified or socially desirable and who is to make this decision fairly and impartially after a consideration of all the facts? What criteria or standards should be established to define such a class? Legal rules must focus on criteria, procedures, and decision-making processes for implementing a *social* policy in this area of involuntary passive euthanasia. These legal-ethical questions must be answered before we can begin to think about a legal or social policy or a juridical determination. Due process is a legal as well as a moral obligation to every person, irrespective of whether he or she is capable of invoking this right. This right exists in the face of government and *every other person*, parents included.

These cases involve hard questions of social policy which must be faced by the legislature. Failure to do so not only makes the work of courts necessary but also confusing, as the case law in this area has clearly shown. Failure by the legislature to establish public policy in this area also contributes to lack of objective standards to be followed by parents, hospitals and medical personnel.

When dealing with defective neonates, it is truly difficult to give general rules and standards. Standards in general there must be, but more important still are the values and intent of the decision-makers. So many of these cases are so borderline, that is, in a gray area, that general rules are inapplicable and some discretion must be left to doctors, parents and other decision-makers for truly borderline cases where refusal of treatment is not due *solely* to the handicapped condition of the child. Herein lies the heart of this problem.

Thirdly, it should also be clear that the right to privacy simply cannot be asserted by a whole group of parents of defective neonates when the rights of other citizens (their children) are possibly being undermined and destroyed without due process. Thus, some general presumptions and objective criteria must be set up to insure a fair and impartial application, where the subjects of rights (children) can give no consent to their own treatment and a substituted consent of some form must be found. We shall try to outline these standards in the final section of this paper.

Substituted consent for these defective neonates is really a misnomer. There is no possibility of finding what they would want, were they able to see and understand their present condition. We are dealing with persons who will lead, at best, diminished lives as in the *Saikewicz* case,¹⁴ but for whom treatment will prolong their lives. Therefore, it is crucial to understand that any election not to treat

defective neonates outside of the "poor medical prognosis" context, is really based on a "quality of life" determination which is essentially a question of social and, therefore, legislative policy. It is also a question of value choice, of the meaning of death and life, a question beyond the competence *per se* of any medical or hospital personnel.

It may well be that, as a society, we will decide not to treat certain, well-defined classes of persons (severely retarded, senile, etc.) but the legal and moral guidelines and standards should be reasonably well-defined and the circumstances rather clear where treatment will not be refused except in the most hopeless medical cases.¹⁵ It may also well be that our society is actually afraid to articulate such guidelines for a variety of reasons and is therefore willing to consign these cases either to the private discretion of some (e.g., parents and doctors) or to the courts. The difficulty with this is that, in the former solution, we are left without clearly defined standards so that neonates are given no fundamental due process which will fairly safeguard their right to life, while the latter solution has led to judicial confusion concerning the standards to be applied in similar cases.¹⁶

Questions Might Be Asked

For example, in the cases of defective newborns, some courts might seek to ask, as the *Quinlan* court did, what the newborn would decide (substitute consent) were he capable of doing so.¹⁷ Yet, we might want to ask why a defective infant might want to die. First of all, this is already a false question because, besides the *miracule dictu* or fanciful nature of the answer, we are in grave danger of imposing our own values upon the child who has absolutely no basis for the fears and horrors we might have for ourselves in a similar state. We project our values onto the child by this quality of life argument. The fundamental error here is that this proposition presupposes, first, a higher level of health, consciousness, awareness, etc., and then a degeneration from this state. By definition, this state is, and has always been, absent from the defective newborn who might well be happy and satisfied to live out his limited human potential, having never realized what he is missing. This can only be realized by those who have, in fact, recognized the higher levels of intelligence and human consciousness and who now project *their* potential lack or loss on those who never had it in the first place. We are in grave danger of confusing *our* suffering (physician, parents, judge, general public) with that of the child who has never known any other existence and who, for all we know, would be perfectly content to live as he or she is. In fact, it is well-known that many of these handicapped children are capable of giving and receiving love and generally taking care of themselves. In protected or sheltered environments, many of them even lead productive lives. But all this becomes a basic question in classical public policy of how far,

as a society, do we wish to revere, treat and protect such people.¹⁸ This fanciful projection in the *Quinlan* and *Saikewicz* decisions made those decisions less credible.

While Karen Quinlan, of course, was not retarded from birth as was Saikewicz, the relation between the two cases is that in both, the patients were incapable of exercising their own right of privacy and courts had to find a way of doing it for them. They used "substituted consent" for this purpose.

In all of this discussion, perhaps it can be stated differently again: the fact is that we have never known what it is to be of such diminished capacity as never to have known any other life. That makes it impossible for *us* to change places with both groups, i.e., those who never had the capacity in the first place and those who, like Karen Quinlan, had it and then lost it.

Fourth, it is noteworthy that there are correlations between parental acceptance of their handicapped children and such factors as religion, social class and the presence of supportive friends and relatives. As one expert put it: "But parents learn to value and love their children as they live with them."¹⁹ In any case, there is no clear or convincing reason why a diminished future should bother the person who has known no other level of life. What it does is disturb other people, such as parents and doctors. There are certainly no convincing arguments for this alternative of dealing with the problem so far advanced by those who want to kill them "for their own good" or, what amounts to the same thing, not to treat them as they would other "normal" children or adults similarly situated and thus "allow them to die."

More to the point, as a society we should be terribly skeptical about a strong group (parents and doctors) who want to kill, or not treat, or do away with a weaker group (defective newborns) "for their own good," simply because they are handicapped. History is too replete with such examples to take this argument very seriously either as a matter of law or of public policy. In the words of P. Foot: "With children who are born with Down's Syndrome it is, however, quite different [than children soon to die]. Most of these are able to live on for quite awhile in a reasonably contented way, remaining like children all of their lives but capable of affectionate relationships and able to play games and perform simple tasks. The fact is, of course, that the doctors who recommend against life-saving procedures for handicapped infants are usually thinking not of them, but rather of their parents, and of other children in the family, or of the 'burden on society' if the children survive. So it is not for their sake but to avoid trouble to others that they are allowed to die."²⁰

Fifth, the easiest cases to decide in this area are those children whose "medical prognosis is wretchedly bad," and who would die in a very short time no matter what we would do. When this basic medical

decision or prognosis is made in good faith and according to accepted medical standards, all support systems, including I.V. (outside of those necessary for the comfort of the child), may be legally and morally discontinued since such a procedure no longer has any human meaning or significance (e.g., anencephalic newborns). One is not obligated to do the futile or to continue the useless; neither are we obligated to take disproportionate measures to continue a life which would be one of constant pain. "Primum non nocere." This was the basic conclusion of the *Quinlan* court as it set up the procedure to be followed in such cases without further judicial intervention and it can be applied to the situation of defective neonates as well.²¹ It should be noted, however, that even in these cases of dying neonates, fundamental nutrients and water are part of the comfort of the patient and should not be removed simply to hasten the moment of death. They may be removed, however, in situations where their administration is part of the pain condition itself or where they plainly prolong death while doing no real good for the patient. Discretion here lies with the medical personnel.

More Difficult Cases Exist

But there are the much more difficult cases of mentally and/or physically defective persons who will live diminished lives, but from whom accepted and comparatively simple procedures have been withheld so that they are "allowed to die," when those procedures could have prolonged their admittedly limited lives, as seems to be the situation in the *Mueller* and *Infant Doe* cases. This was the objective of Public Law 504 (Rehabilitation Act of 1973). What fair criteria can be set up in such cases to distinguish the three cases — the prolongation of dying cases, the refusal of treatment based principally on mental or physical retardation, and the cases in the gray or ambiguous area?

The problem to be faced in these tragic situations is both moral and legal. The moral question is, "What category of patients do we — as a society — simply not wish to treat?" The answer we are beginning to receive, at least in the cases of defective neonates cited above, is that since their "quality" of life is so bad (and since there are no defined standards, this term is anything the decision-maker wants it to mean), they should be allowed to die. We are beginning to see a subtle erosion away from the presumption of life for these children to one against them. Moral questions simply cannot be shirked by a society and these categories of human beings (the senile aged, the severely mentally and physically handicapped neonates) will simply not go away. Given our sophisticated technology, their number will, in fact, increase.

In addition, there is an important legal question here which follows hard on the moral question. What is happening in the courts in the few cases handed down concerning defective persons is: 1) such defective

children are not being treated the same as other "normal" children in the same situation (*Becker, Mueller, Infant Doe* and possibly *Baby Jane Doe*); and 2) the standard used in these cases by those who are basically interested parties is subjective and dangerous ("quality of life") for these groups themselves. It is disturbingly clear in these few cases that it is the courts themselves which are therefore creating great protection difficulties in the way they are treating these people.^{22, 23}

What should be clear at once is that parents and their physicians alone cannot be trusted to make such decisions for such defective human beings. Both of these groups have a significant conflict of interests which impairs their judgment negatively in a life and death situation, such as in the *Mueller* case, where decisions affecting the children must be made comparatively soon after birth. The parents' interest may well be to save their own psychological and economic life as well as that, perhaps, of their own children, past and future. Such children may be a burden to their parents, but in that case, this would make the parents bad decision-makers, under the circumstances. Similarly, the physician is usually more affected by those whose feelings are most visible and tangible — the parents — if he or she is to be a very objective articulator of the child's interest. What physicians are truly capable of doing is to give an honest and complete evaluation of the situation and, if certain agreed upon standards are met (cf. *infra*), then parents and doctors, as fundamental decision-makers, can proceed legally and morally.

In fact, most physicians in various studies tend not to want to treat such infants since they represent a failure for the physicians or at least, most physicians consider such infants better off dead — even though some parents do *not* share views of their physicians, yet they never say so.²⁴ If these studies are correct, then we have a significant problem where some treating physicians believe in the loose thinking of the "quality of life" theory without the guidance of some objective standards. The dangers implicit in such a situation are obvious, particularly for purposes of due process for these neonates.

Who, then, can be trusted with such decisions? The *Quinlan* decision at least provided some protection for incompetents in a prolonged dying situation by a diffusion of decision-making representing a societal consensus (ethics committee). And, by analogy, the same reasoning may be applied to newborn defective children who are in the same situation: while acknowledging the parents as appropriate guardians, and protecting their right to *participate* in the cessation of medically useless treatment, the court stated that such a decision would be legally valid only if it had the approval of a hospital ethics committee. Whatever one thinks of the final function of such a committee, it does introduce the recognition of the impermissibility of physician(s) and family making such important decisions alone, with no protection for the helpless child. In other words, this method of decision diffu-

sion is not to be construed as an unwillingness to assume personal responsibility on the part of parents and physicians, but rather as an incipient effort to reach some form of societal consensus on these edges of life issues and to take them out of *exclusive* hands of those (parents, physicians) who have a negative vested interest in the case. This would fit in well with Professor Robertson's suggestion that, for the most extreme cases, society, through the legislature or courts, should recognize certain objective criteria where treatment can be refused: "But, just as authoritative and specific criteria have eased the physician's determination of when brain death has occurred, the risks of delegating treatment to parents, physicians, or committees can be similarly lessened if specific criteria are developed to describe defective characteristics in the familial or institutional situations in which treatment may be withheld from defective infants."²⁵ If such standards are established, an ethics committee might well prove useful. We shall develop the notion of ethics committees a little further in this study. In any case, what Professor Robertson is arguing for is both objective criteria of what standards are to be used for when to treat and not to treat, at least in general. This would also be in itself a form of due process as well.

Perhaps this is as far as we can go. Perhaps, to openly acknowledge that we are willing to treat the retarded, the senile or severely defective neonates differently from the "normal" patient is so offensive to society's view of the equality of citizens that its explicit knowledge is impossible. We then need to rationalize a way to treat them differently, and the notion of substituted judgment seems to be one such invention by the courts. And yet, if we can establish some minimal standards which will justify refusal or removal of treatment, perhaps this would be as far as we can go with rules. In this sense, ethics committees can be invaluable at arriving at such a societal moral consensus. While it should be noted that a "societal moral consensus" is not necessarily objectively correct, what such a consensus does do in a democracy is to take that decision out of the hands of a few interested parties. The process has, I believe, fewer abuses.

Necessity of Proper Information

Finally, it would also seem part of the legal obligation of informed consent by the parents that they be objectively and fully informed of the possibility of taking many of the defective newborns home and having a wholesome — at least in some cases — familial experience. Recent studies have shown this to be much more prevalent than previously suspected, either by physicians or by the general public. As another expert has put it: "Those who have lived with the handicapped seem to reject any necessary incompatibility between being handicapped and leading a worthwhile life, a conclusion that ought to

be taken into account by those charged with making decisions about the 'right to life' of infants with birth defects."²⁶ The story of such parents has yet to be written and told.

The real problem in this area is how to restrict legally a refusal to treat the extreme cases, which many thoughtful physicians believe do exist.

The AMA Judicial Council has tried to deal with the most extreme of these cases: "A decision whether to treat a severely defective infant and exert maximal efforts to sustain life" should be left to the parents. No one could quarrel with this, as long as the parents are fully informed of all the possibilities, and the decision is restricted to a very narrow category of cases. But this is not what is happening in this field. Outside of "maximal care," we have rather simple medical procedures being refused in order to bring about death and, as in the *Mueller* and *Infant Doe* cases, the withholding of ordinary food and drink for the seemingly sole reason of physical and mental handicap. It is these latter hard cases which cause all the legal and moral problems. We need some clear procedures in this painful area. In fact, the AMA guidelines of 1975 simply abandon the field to the exclusive decision of the parents which, as we have seen, cannot be conceded by any society dedicated to due process.

III

The following legal standards will help minimize the risks to others (e.g., medical personnel, hospitals, the parents themselves), but still, the real danger here is the outgrowth of measures already morally and legally accepted in our society against defective human life which is unborn. It seems only a small but logical step to correct what we missed only a short time before. In fact, this has been suggested by some doctors and experts in the field.²⁷ As we have mentioned, this is not a direct problem of law, but of society's attitude toward defective human life, which then comes to affect the law. Once we start down this road of justifying the taking of any human life, for whatever reason, it is difficult to control its logical application to those who have managed to be born defectively.

Even after the few cases relating to defective neonates are carefully examined, there emerge few clear and sure guidelines for ethics committees, physicians and parents to follow in knowing when to treat or not treat. The following guidelines are legal and moral, garnered from some of the cases, as well as from good medical practice, which can be used as initial starting points:²⁸

(1) As a general rule, parents are, in fact and in law, the principal decision-makers for the health care of their children. This principle is well established, whether in natural or in constitutional law. Outside of the exceptions given below, their desires and wishes are to be

followed by all others as the general rule.²⁹

(2) The physician(s) has (have) a legal and moral responsibility to be open and truthful to the parents of defective neonates, as soon after birth as possible. This calls for full disclosure and informed consent on the part of parents at the earliest possible time after the preliminary diagnosis has been established. All future medical options should be outlined for the parents or guardian, including nontreatment, risks, benefits, chance of success and the consequences of each medical procedure available. The objective of this is to give parents the fullest information and possible options available to them so that they can fully and knowingly consent to treatment or nontreatment.

(3) While it is difficult to determine always what "accepted medical standards" are at any one time (what is extraordinary today may be ordinary procedure tomorrow), the presumption is that the physician is acquainted with the ordinary standard of the profession. Indeed, this is his obligation under the law as minimal competence. If nontreatment or treatment is within that range, the doctor may comply with the parents' wishes. If the doctor is uncertain as to prognosis, he should consult another independent doctor, who is to perform an independent examination of the child. (By independent I mean disinterested in the outcome, whether for research, transplantation, or for any other reason.) It would also be of great value in any area of doubt for the doctor to have an ethics committee which he could consult, for decision diffusion, dispassion, and some expert input in this delicate matter. Such a committee could be composed of a cross-section of prominent legal, medical, ethical and religious talent.³⁰

(4) If the parents decide not to treat, and to permit the child to die, it is imperative that the doctor seek the independent evaluation of another disinterested doctor before he acquiesces in the desire of the parents (presuming, of course, that the course of action is supported by good and accepted medical standards). These standards will be discussed more in detail in section 6.

(5) If the doctor and the independent examining doctor conclude that nontreatment by the doctor is not in conformity with accepted medical procedure, then the attending doctor must point out this situation to the parents and explain the reasons why this is so. If the parents insist on nontreatment, nonetheless, the doctor or hospital administrator should not hesitate to petition a court of competent jurisdiction for the appointment of a guardian to consent to treatment.

(6) What are the standards to be used not to treat? This is a difficult question because these standards are always evolving. Indeed, it is the very nature of medical progress that they do evolve, for the better. But, lacking any absolute legal standards, the following may be safely followed:

- Where death will come about imminently, no matter what we do, there is no legal or moral obligation to treat or to continue to treat, outside of basic procedures, to make the child comfortable.³¹
- Where there is no probable medical possibility — given our present knowledge of medicine — of the child ever achieving any cognitive or sapient stage of conscious realization, no treatment need be given (or commenced) nor need treatment be continued, except to make the patient comfortable. The treatment is withheld here, not because the child is retarded (the Equal Protection Clause of the Constitution applies to them as well) but because the treatment is medically and, therefore, humanly useless. Such a judgment is for the doctor(s) to make as good medical practice. Morally and legally, we are held to what is humanly possible *now*, not to what can or will happen sometime and somewhere down the historical road.
- Where there is no probable medical possibility — given our present knowledge of medicine — of the child ever achieving any cognitive or sapient stage of conscious realization, no treatment need be given (commenced) nor need treatment be continued. Once again, we are held to what is humanly possible, not to what can or will happen sometime and somewhere down the historical road.
- Many eminent authorities argue — and the author is in agreement on this point — that where the child has no reasonable possibility of ever being able to participate to *any* degree in human relationships with others, no treatment need be commenced nor treatment continued, beyond basic comfort of the child. One should carefully know the limitation here: *any* degree of human relationship. This is an admittedly difficult concept to deal with because it has been so manipulated by the "quality of life" arguments for nontreatment of otherwise defective neonates. To erase all ambiguity, we must insist on this almost absolute "any" and this should be read in conjunction with the paragraph immediately preceding the present one. There will be close cases and, as we shall point out later, all presumptions should and must be resolved in favor of life and in favor of the young patient. With this said, there remain true cases of defective children where the brain is so under- or nondeveloped, that we can say, with a great deal of medical certitude, that this child has little or no hope of any human interaction. Once again, the judgment is a medical one and all presumptions should and must be resolved in favor of the patient-child.
- Where there is no medical possibility or probability of alleviating what reasonable medical judgment would consider to be an intolerable level of continued suffering, the same judgment should obtain as in the above cases. Human intervention must be for the good of the patient (*primum non nocere*), and if there is little probability that good will come about, then it is both futile and cruel to act further on this human being.

However, in this last condition, precisely because there is a dimension of the subjective involved, another doctor, an independent doctor, should examine the case along with, if possible, the hospital ethics committee, if one exists. This condition should also be seen in the light of good and accepted medical standards.

(7) To alleviate the intolerable decision-making in such a charged and painfilled atmosphere, parents should be told that the question of long-term custody of the child can be settled later. This would allow them to consent to care at a crucial juncture, rather than force them to participate in the child's death by nontreatment as the price of not assuming long-term custody. By emphasizing that the appropriateness of custody must be assessed continuously throughout the child's life, the parents could more comfortably commit themselves to the child, one day at a time, without feeling boxed into the situation.

(8) If the doctor concludes that treatment will be ineffective, but the parents insist that it be undertaken, the doctor should acquiesce to these desires, as long as the treatment does no further harm nor causes any further suffering to the child. If it does, the doctor should, in conscience, refuse to perform, and speak to the parents about obtaining a different physician.

(9) Under no circumstances should an active agent, or otherwise legal procedure, whose direct object is to either kill or help terminate the life of the child, be administered. Much here depends on the *intent* of the doctor and medical personnel. No court of law can really control or regulate this. For instance, it is certainly legally and morally permissible to administer a large quantity of a pain-killing drug, if the direct intent of the doctor is, in fact, to alleviate pain, even though it has, as an indirect effect, the shortening of the life of the patient.

(10) In all cases, basic comfort and care should be given. This should include food and water in all but cases where it is actually painful for the child to receive even those. This should include warmth, loving, touching, sanitation.

(11) Above all, the major rule in the area is that treatment is to be withheld only in the clearest and most compelling cases of hopelessness, using the above-mentioned safeguarding criteria. If there is *any* doubt of this, it should be resolved in favor of the child, for his life, and for his best interests. In other words, the presumption is always in favor of life and treatment and all doubts should be resolved in the child's favor.

Conclusion

The case of *Baby Jane Doe* of New York is important because it shows so clearly the pitfalls in this whole area of defective neonates. The child was born severely retarded and with an operable case of spina bifida. The prognosis was uncertain, but doctors seemed to agree

that with an operation, she might live to age 20; without it, to age two or less. The difficulty here is that the parents invoked privacy and have been able to block the federal government's request that it view the records to determine whether the operation is being denied *because* she is retarded or for other reasons extrinsic to her retardation. This would seem to be a quite normal case of civil rights investigation (since Baby Jane has no independent voice) on the part of government under the law (Section 504, Rehabilitation Act of 1973) were it not for the strange attitude of the parents, medical personnel and the courts, which prevents the government from determining facts of the case which it has a legal obligation to do.

The limited purpose of rule 45 CFR Part 84 to be posted at the nurses' station, restricts itself to cases in which nutrition and customary medical care are discriminatorily withheld from certain infants *solely* because they are handicapped. This rule was made to enforce the clear intent of law 504 under which it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition *solely* because he/she is handicapped and the handicap does not render treatment medically contraindicated. In other words, both the law and the rule are consubstantial to the same end of safeguarding the civil rights of a helpless group of humans-in-being. For the reasons given *supra*, while the parents and doctors are normally the ones to make medical decisions for their children in life-threatening situations where the child is defective in some serious way, the history of the past 20 years has shown clearly that such a child needs added protection to safeguard its basic civil rights.

The argument of the medical community against the new rule is that it intrudes unnecessarily into the privacy of parents and doctors in proper medical decisions. Yet, given the history of abuse which we have outlined *supra*, the rule is a long overdue response to abuses by some doctors who have exceeded their own professional authority by allowing the withdrawal of medical treatment for nonmedical or ideological reasons (a life of a "quality" not worth living). These instances have been too well documented and too widely practiced to take this complaint by doctors and parents seriously. The law and the rule are urgently needed.

Furthermore, and in the same vein, the AMA's guidelines for defective infants and their treatment (1981) effectively deny the physician's traditional role as advocate on behalf of his patient in such cases. They make him a mere consultant, allowing parents unlimited authority to refuse life-saving treatment for their handicapped children. These guidelines do not even intimate the legal and moral obligation of the physician to take legal action when the parents' decision would lead to neglect. Public Law 504 simply steps into a vacuum created by the medical profession itself which has shown itself to be

widely and seriously negligent in protecting these patients. This author has great difficulty in understanding the reasoning of the courts for striking this simple rule, posted in the nurses' station of federally funded hospitals. In fact, in this area of law, courts have been only compounding or condoning the crucial problem.

The case of *Baby Jane Doe* contradicts many of the standards we have established *supra*. Yet, if such standards were, in fact, followed by the medical profession, they would obviate the necessity of rule 54 of Public Law 504. As the situation exists presently, with the decision of the courts not to enforce the rule, children such as *Baby Jane Doe* have no independent advocates and are left to the arbitrary vagaries of parents and a medical profession which have already proven themselves quite neglectful in this delicate area. Legally, we have not seen a group of humans so powerless since *Dredd Scott*.

Further Developments

More recently, the government has further modified its proposed rules.³² In these last suggested rules, the government has attempted to modify criticism of rule 54 by mandating or encouraging the creation of hospital ethics committees. Such committees were originally encouraged by the New Jersey Supreme Court in the *Quinlan* decision³³ with which the guardian of *Karen Quinlan* had to consult before the removal of her life-sustaining equipment. Moreover, the American Academy of Pediatrics, in its response to the federal rule 54, recommended the establishment of a version of hospital ethics committees in place of hotlines and investigators:

The Academy believes the creation of infant bioethical review committees constitutes a direct, effective, and appropriate means of addressing the existing education and information gaps.³⁴

In fact, the most recent study on these legal-ethical problems recommends the establishment of such ethics committees.³⁵ The most recent literature in the field,³⁶ as well as national conferences on the subject,³⁷ have taken up the theme as well.

Can such ethics committees substitute adequately for rule 54 in living up to Public Law 504?

The arguments against the hotline and government agents descending on health facilities have been well aired.

Intervention by the government is always retrospective and does not by itself set up any standards for treatment or nontreatment. Such an information procedure is erratic at best and can easily be used to harass and punish unpopular personnel. Such intervention causes consternation and has a chilling effect on physicians and the hospital and could easily poison the atmosphere of the unit as everyone begins to suspect everyone else.

Thus, in principle, we are reduced to three choices.

— First, we could permit the status quo, letting the physician and the parents make these critical decisions. Yet, as we have seen, there have been too many cases where defective neonates have been deprived of simple medical procedures (*Infant Doe*) simply because the child was retarded. If there are two universally accepted standards in this area, they are that 1) the principle that such decisions must be made in the best interest of the child and 2) that Down's Syndrome is *not* a justification for not treating an otherwise correctable, life-threatening condition in a newborn. As we have also seen *supra*, in general, family autonomy and parental burden (it is parents who must bring up the child) must enjoy a presumption of decision-making. But the presumption should give way, particularly in situations like defective neonates, where the emotionality of the rapid decision can cloud judgment. In these edges-of-life decisions, parents and doctors need help.

— Second, we could take these cases to court. Besides the inundation of cases which they would have to hear, courts are not particularly better decision-makers in this area than anyone else. Of course, this does not rule out the role of courts — particularly in ambiguous areas where there is a clear disagreement between the doctor who considers a particular procedure standard medical care under all the circumstances, and the parents. Intervention by the court in such a situation is actually mandated.

— Third, we could espouse direct governmental intervention with some of the drawbacks which we have cited *supra*. Can an ethics committee act as a *tertium quid* to respect parental autonomy while protecting the civil rights of these children which the government is, by law, obligated to do?

The answer is uncertain because ethics committees have not been employed to any large extent.³⁸ Such committees would be staffed by a cross section of the community to represent as much as possible the moral sense of the community itself. The ethics committee should be composed of personnel mostly independent of the institution so as to avoid any conflict of interest or conflict of loyalty (even, perhaps, one's employment). The purpose of the committee would not be to make decisions on its own, but to be there on a consultative basis for the crucial ethical decisions to be used by all concerned.

In other words, the committee's function would be to help others make these crucial decisions or, in a real exception, to recommend to the health care facility, court action itself. The help of the committee could be used *prospectively*, that is, could be assembled and consulted by anyone having an interest in the case: medical or hospital personnel, parents or guardian, the administration of the hospital or any member of the committee itself. Its records and testimony would be

confidential and could be turned over to third parties only by court order.

The function of the committee would also be in *retrospective* review of morally problematic decisions (there was some doubt about whether nontreatment was morally justifiable). This kind of review provides a forum to discuss how decisions could have been made better and how future cases could be better handled. In this sense, the committee's function logically leads to establishing *institutional policies* for treatment/nontreatment decisions; it can also support the growth of good ethical decision-making in the hospital itself for future cases.

Thus, the ethics committee, upon presentation of all the facts, can make an ethical decision on those edges of life which could aid and strengthen the various parties who must make the essential decision. The decision is not made by the committee, since its function is to help others make that vital decision.

Of course, if treatment is clearly called for (e.g., a simple procedure to open a fistula in an otherwise healthy Down's syndrome child who is being allowed to starve because he/she is retarded), the committee should not hesitate to recommend court proceedings if the parents refuse treatment.

And if the child will die, no matter what aggressive treatment is given, the parents' wishes not to treat further except to make the child comfortable, should be respected by all concerned.

Problem Becomes Crucial

The problem for all (ethics committee, medical personnel, parents, hospital administrators) becomes crucial when the situation is ambiguous or in the "gray areas," already described in the body of this article. We have mentioned some principles already accepted universally as good medical procedure: best interest of the child, parental autonomy and family privacy and its presumption, and the right to treatment for the physically and mentally handicapped in an otherwise treatable situation. It is this gray area which causes difficulties and the ethics committee should provide all the help and enlightenment it can in these difficult areas when the situation does not otherwise clearly indicate treatment. If the committee believes that treatment is otherwise morally obligatory because it is consistent with ordinary or accepted medical procedure, and the parents refuse treatment, the committee should not hesitate to advise the hospital to take the case to court, where the ultimate decision can be made in an adversarial process.

While the function of such committees could be expanded to other areas of ethical decision-making (comatose and dying patients, nursing home care, cost analysis in the final stages of death, allocation of

scarce health resources), it should be noted that with such committees on hand and consulted, this would significantly reduce the dangers of malpractice. The reason is that such committees represent not only a cross section of the community ("moral sense of the community"), they also tend to increase the level and standard of care which must be clearly shown to be absent in negligence actions. This is said only in passing, but it could be a practical incentive for "practical headed" administrators to at least give such committees a chance.

Under appropriate circumstances, a bioethical hospital committee can therefore render value assistance to a health facility. The very least that can be said about them is their implacement would be better than what is presently available.

The arguments for hospital ethics committees cited *supra* are only a beginning; as a society, we grapple together with these terrible problems of life and death which modern technological medicine has bestowed on us. The question, like war, is too important for all of us to be left *exclusively* to the interested parties of parents (guardians) and doctors. Some independent person in these tragic situations must speak for the child who cannot speak. Hospital ethics committees can be the beginning of a badly needed dialogue between a worried public and the medical community. This in turn will come, in its own way, to influence "accepted medical standards," at least in the long run. After all, medicine is as much an art as it is a science and therefore moral and ethical values are crucial in medical decision-making. A wider moral and ethical input can only help the medical community morally, psychologically, and legally.

REFERENCES

1. See Robertson, "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," *Stanford Law Review*, 27 (1975), pp. 213, 214; for further insights, see President's Commission, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: Government Printing Office, 1983).
2. Duff and Campbell, "Moral and Ethical Dilemmas in the Special-Care Nursery," *New England Journal of Medicine*, 289 (1973), p. 890.
3. "When Doctors Play God. (Medicine's gains nullify its ethical quandaries: Who lives, who dies — and who decides?)" *Newsweek*, Aug. 31, 1981.
4. The detection and prevention of genetic diseases are becoming ever more advanced. Genetic diseases such as Rhesus disease, spina bifida, German measles, sickle cell anemia, can all be detected three months into pregnancy and can be treated prenatally for the abortion mentality of solving problems by eliminating the victims as well as the fetus as patient and therefore as person. See "Genetic Diseases Can Now Be Detected, Treated Before Birth," *Houston Chronicle* Nov. 26, 1982, sec. 4, p. 44.
5. *In re Jeff Schopp Mueller*, 81-300; *In re Scott Schopp Mueller*, 81-J-301.

6. An entry on the twins' hospital chart read: "Do not feed, in accordance with parents' wishes." Some nurses attempted to feed the babies in spite of the orders.

7. For a more complete summary, see *Commercial News* (Danville, Va.), Oct. 25, 1981, p. 3.

8. *Ibid.*

9. Riga, "Phillip Becker: Another Milestone," *America*, July 12, 1981, pp. 8, 9.

10. For a detailed account see Meyers, *Medico-Legal Implications of Death and Dying*, Cumulative Supplement, 1982, pp. 44, 45. The basis of this "opinion" (there really was only a judgment upholding the parents' decision not to treat) seems to be because of insurmountable medical problems and not because of the existence of Down's syndrome. This is highly suspicious. Medical and hospital personnel, as well as the courts themselves, refused to elaborate in any significant way. Since the case was highly publicized and the public outcry very great, there was a duty to the public on the part of these authorities to explain these "insurmountable problems." In fact, what little we know points to the opposite conclusion.

11. Duff and Campbell, "Moral and Ethical Dilemmas," *op. cit.* See also Campbell and Duff, "Deciding the Care of Severely Malformed or Dying Infants," *Journal of Medical Ethics*, 5 (1979), p. 65; Shatten and Cabon, "Decision-Making and the Right to Refuse Lifesaving Treatment for Defective Newborns," *Journal of Legal Medicine*, 3 (1982), p. 59; Fost, "Counseling Families Who Have a Child With a Severe Congenital Anomaly," *Pediatrics*, 67 (1981), p. 312; Johnsen *et al.*, "Critical Issues in Newborn Intensive Care; A Conference Report and Policy Proposal," *Pediatrics*, 55 (1975), p. 756; Robertson, "Discretionary Non-Treatment of Defective Newborns," in *Genetics and the Law*, ed. by A. Milunsky and G. Annas (1976), p. 451.

12. No. 74-145 (Superior Ct., Cumberland City, Ma.), Feb. 14, 1974.

13. This ability of the law is severely restricted, and, in general, it should be. The law is a blunt instrument in trying to decide the delicate medical-moral problems involved in these cases. Only in the most blatant cases, e.g., where a child is allowed to die simply because he or she is retarded, should courts intervene and investigate.

It should be noted that some states have adopted legislation authorizing withdrawal of further medical care from infants in irreversible coma. The Louisiana statute allows parents and physicians to discontinue treatment where competent medical judgment has concluded that there is no reasonable chance of recovery from a "continual profound and comatose state." La. R.S. 40: 1299.36 1 A,B,C. Moreover, the Louisiana Supreme Court has upheld the constitutionality of this statute. *In re W.* (1982, La.), 424, S. 2d 1015:

... a permanently comatose child has an independent right to discontinuance of artificially sustained life through the mechanical invasion of the child's body and that an appropriate representative may juridically assert that right on behalf of the child either after the event in civil or criminal proceedings or before the event in a declaratory judgment action.

The same conclusion was arrived at in still another case where the prognosis was hopeless as a good medical judgment. Such a terminal patient need be given nothing except comfort. *In the Matter of Baby F* (1983), Coos County (Oregon), Circuit No. J 928, the child was born on April 10, 1983 with a neural tube defect, known as occipital encephalocele. A mass of brain tissue and fluid was located outside the skull. The child had a small head, a lack of facial expression, poor response to stimulation, an abnormal cry, slow respiration, no suck reflex, no swallow and no grasp. The decision of physician and parents was not to actively

treat the child. No nourishment by I.V. or nasogastric tube was offered. Upon petition by the state, the child was moved to the University of Oregon Medical Center, where it appeared that the prognosis was hopeless, whether or not I.V. or other care was undertaken. The state moved the Court to withdraw custodial petition which was denied while the trial court ordered feedings, including I.V. At trial, the physician testified that the child would die, regardless of whether I.V. feeding was administered or not. The judge dismissed the petition and dissolved the temporary injunction.

14. 373 Mass. 728, 370 N.E. 2d 417 (1977). See Relman, "The Saikewicz Decision: A Medical Viewpoint," *American Journal of Law and Medicine*, 4 (1978), p. 233.

15. See note 28.

16. Various criteria have been used to determine when "extraordinary" measures are to be discontinued. One of these, suggested by Richard McCormick, is that quality of life means to be able to live a life of loving and being loved. If one's potential for that is ended or is so burdened with the mere struggle for survival, then, he argues, it has reached its fullness and all procedures — outside of those to give basics or make the patient comfortable — should be discontinued. "To Save or Let Die," *Journal of the American Medical Association*, 299 (July 8, 1974), p. 172. For an analysis of the confusion in the cases, see *In re Spring*, Mass., 405 N.E. 2d 115 (1980) and its analysis in "Decisionmaking for the Incompetent Terminally Ill Patient: A Compromise in a Solution Eliminates a Compromise of Patients' Rights," *Indiana Law Journal*, 57 (1982), p. 325.

17. Courts have asked for legislative standards but have been forced to set up their own: *Lovato v. District Ct.*, 198 Colo. 419, 601 P2d 1072 (Colo. 1979); *Staz v. Perlmutter*, 326 So 2d 160 (Fla. App. 1978), *approved* 379 So2d 359 (Fla. 1980); *In re Storer*, 52 N.Y.2d 363, 438 N.Y.S. 2d 266 (1981).

18. Riga, *op. cit.*, p. 9.

19. Cf. Zuk, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," *American Journal of Mental Deficiency*, 64 (1959), p. 139.

20. Foot, P., "Euthanasia," *Philosophy and Public Affairs*, 6 (1977), p. 87.

21. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976). See Relman, "The Saikewicz Decision," *op. cit.*; Schram, *et al.*, "No Code: Clarification in the Aftermath of Saikewicz," *New England Journal of Medicine*, 299 (1978), p. 875.

22. See Gustafson, "Mongolism, Parental Desires, and the Right to Life," *Perspectives in Biology and Medicine*, 16 (1973), pp. 529-533, 542. For a contrary view, see Silverman, "Mismatched Attitudes About Neonatal Death," *Hastings Center Report*, 11 (Dec., 1981), p. 12.

23. The literature and cases in the aftermath of the Saikewicz decision are abundant in this respect. See notes 11, 17, and 24.

24. See "Termination of Medical Treatment," *Journal of Legal Medicine*, 3, pp. 233-238.

25. Robertson, "Involuntary Euthanasia," *op. cit.*,

26. Darling, "Parents, Physicians and Spina Bifida," *Hastings Center Report*, 7 (Aug., 1977), pp. 11, 13.

27. Editorial, "A New Ethic for Medicine and Society," *California Medicine*, Sept., 1970, p. 68.

28. The following criteria are garnered in part from the articles already cited in these footnotes. While not definitive in nature, they may continue a dialogue begun in the medico-legal literature. An authoritative commission of medical and legal experts has recently pointed out the lack of, and need for, clear nonjudicial decision-making standards and procedures in arriving at nontreatment decisions for defective newborns. President's Commission, *op. cit.*, pp. 222-229.

29. For a concurring conclusion, see *ibid.*, pp. 224-228.

30. This is explicitly called for by the President's Commission, *ibid.*, p. 227, 228.

31. "When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates [parents or guardians] and providers not to try predictably futile endeavors is ethically and legally justifiable." President's Commission, *ibid.*, p. 219.

32. "U. S. Issues Revised 'Baby Doe' Rulings," *Houston Chronicle*, Jan. 10, 1984, sec. 1, p. 6.

33. *In re Quinlan*, *op. cit.*

34. American Academy of Pediatrics, "Comments of the American Academy of Pediatrics on Proposed Rule Regarding Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants," undated ms.

35. President's Commission, *op. cit.*, p. 227.

36. Fleishman, A. R. and Murray, T. H., "Ethics Committees for Infants 'Doe'" *Hastings Center Report*, vol. 13 (Dec., 1983), pp. 5-9.

37. See the national conference being presented all over the country on various dates by experts in the field: "Institutional Ethics Committees: Their Role in Medical Decision Making," April 21-23, Washington, D.C. as reported in "Are Ethics Committees Alive and Well?" by J. Randal, *Hastings Center Report*, vol. 13 (Dec., 1983), pp. 10-12.

38. Randal in her article cites the study of S. Younger from Case-Western Reserve Medical School who examined larger medical facilities, excluding free-standing psychiatric and rehabilitation institutions. The study showed that less than 1% of these facilities had any ethics committees. *Hastings Center Report*, *ibid.*, p. 11.