

February 1982

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Recommended Citation

Roy, David (1982) "Issues in Health Care Meriting Particular Christian Concern - A Priority Issue: The Severely Defective Newborn," *The Linacre Quarterly*: Vol. 49: No. 1, Article 8.

Available at: <http://epublications.marquette.edu/lnq/vol49/iss1/8>

Issues in Health Care Meriting Particular Christian Concern – A Priority Issue: The Severely Defective Newborn

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Introduction

This paper will concentrate on severely defective newborns and their cluster of problems as well as the debate surrounding the question of how to best care for these children. The issue has been selected as a priority issue because it has generated proposals which cut at the roots of a Christian view of man and poses challenges to Christian communities to move beyond ethical argument to a practical and socially obvious demonstration of the beliefs underpinning Christian ethical positions.

Summary of the Discussion

Contemporary medicine is the scene of an increasingly intense debate which centers on the issue of whether all severely defective newborn babies should be given equally vigorous treatment or whether some should be left radically untreated and allowed to die. This issue has generated more than a debate. Pediatric practice varies widely with respect to these babies. Many have been left untreated and allowed to die. Some, however, have lingered for extended periods of time. This situation has stimulated a series of pleas in favor of humanitarian infanticide. On a more theoretical level, speculation has begun on the doubtful human status of these infants.

The debate has begun to move beyond the boundaries of medicine and medical ethics. It raises broader issues of a social, cultural and economic nature. This issue also promises to be at the center of a debate which could well surpass recent abortion debates with respect to the degree of polarization and acidic confrontation it generates.

A Christian involvement in this debate and a Christian concern with this issue must manifest itself on two interrelated levels. The level of informed, balanced, differentiated, comprehensive, and clear ethical argument is essential. However, a point in argument is reached when fundamental and fundamentally divergent beliefs and value choices are laid bare. At this point Christian ethical argument has to push forward to a living *demonstration* that defective newborns can indeed be given the care they require.

This demonstration will certainly demand the imaginative creation of new ways of caring for those we cannot cure. It may also demand the creation of new communities, analogous to older religious orders, to dedicate themselves to meet crucial needs which surpass the competence and resources of existing social agencies.

Christian belief and the ethical positions it supports demand incarnation in societal activity which makes a cutting difference in the reality of how we care for the weak, the broken, and the incurable. Moral positions and ethical argument are impotent without this social incarnation.

Each of these points now calls for a more extensive development. The preceding reflections summarize the argument this paper is designed to develop.

Seriously Defective Newborns — Selective Treatment, Nontreatment and Euthanasia: Our New Social Debate?

In 1957, Glanville Williams, in his now famous book on *The Sanctity of Life and the Criminal Law*, mentioned toward the end of his discussion of euthanasia that “the proposal to legalize humanitarian infanticide is put forward from time to time by individuals.”¹ An example of the reasoning behind such a proposal appears in Williams’s quotation from Millard E. Everett’s *Ideals of Life*: “My personal feeling — and I don’t ask anyone to agree with me — is that eventually, when public opinion is prepared for it, no child shall be admitted into the society of the living who would be certain to suffer any social handicap — for example, any physical or mental defect that would prevent marriage or would make others tolerate his company only from a sense of mercy. . . . Life in early infancy is very close to non-existence, and admitting a child into our society is almost like admitting one from potential to actual existence, and viewed in this way only normal life should be accepted.”³

Williams follows this quotation and ends his book with the opinion that these proposals are few in number and “may at present be dismissed as politically insignificant.”³

There are many indications available that proposals for "humanitarian infanticide" may no longer be simply dismissed as socially or politically insignificant. This is not to say that such proposals already enjoy wide public acceptability today. In fact, the general public is hardly extensively familiar with these proposals or with the medical situations which are inviting them. It takes time for society at large to become sufficiently familiar with an idea, to get sufficiently "used to" a new and different notion to permit its wide acceptability. But societal attitudes change even with respect to very fundamental human values, sometimes in a very extensive and relatively rapid fashion, as our recent experience with abortion and prenatal diagnosis via amniocentesis cum fetal euthanasia readily demonstrates.

In this respect it is significant that the idea of mercifully terminating the lives of seriously defective newborns is being considered in various fashions with increasing frequency today. The notion of infant euthanasia, in the active sense of deliberately terminating life, is already the center of a debate which is just beginning to gain momentum and capture the attention of the general public. The professional and societal participants in this debate are bound to increase in number.

Selective Nontreatment and Active Euthanasia?

This debate over infant euthanasia will likely become more intense and rival, if not surpass, abortion as a focus of societal moral and legislative concern. The debate over infant euthanasia in that active sense has arisen within the context of increasingly frequent parent-doctor decisions to withhold treatment from seriously defective newborns for conditions which would undoubtedly be treated in an otherwise normal infant, but which, if untreated, generally prove fatal. Selective non-treatment of seriously defective newborns, either on a case-to-case basis or as guided by a selection policy for definite categories of neo-natal defect, is motivated by a variety of judgments and value choices, but always accompanied by the hope and expectation that these babies will die quickly and painlessly. Often they do not. These babies not infrequently survive with varying subsequent life expectancy and with greater physical and mental damage than would be the case had they been given immediate and vigorous treatment.

This can and typically does happen in the case of children suffering from spina bifida with myelomeningocele. This situation has urged one pediatric neurosurgeon to raise the question of active euthanasia. "Active euthanasia might be the most humane course for the *most severely* affected infants whom you elect to treat, but it is illegal. . . . I feel that a slow, 'natural' death over weeks, months or years is not

humane for the child, the family, or the staff forced to care for the infant. However, until active euthanasia, with whatever safeguards, becomes acceptable to society, I feel that vigorous treatment should be pursued for *virtually every case*.”⁴

It is clear that nontreatment, especially the radical nontreatment advocated by Dr. John Lorber over the past few years,⁵ generally means death for the baby. However, death does not always come quickly. These babies very frequently linger for months or longer in many cases. So Dr. John Freeman asks, “Is there a right to die — quickly?” and addresses the question to the medical profession and to the general public.

The unoperated infant is being condemned to death, sooner or later, by less than optimal care — what might be termed passive euthanasia. The physician does not take into account the increased pain and suffering to both child and parent attendant to letting nature take its course. If we make that decision for a given child should we not then, as physicians, also have the opportunity to alleviate the pain and suffering by accelerating that death? This conversion from passive euthanasia to active euthanasia is not an easy one for society or for the individual physician faced with the decisions and their consequences. Having seen children with unoperated meningomyelocoles lie around the ward for weeks or months untreated, waiting to die, one cannot help but feel that the highest form of medical ethic would have been to end the pain and suffering rather than wishing that the patient would go away.

It is time that society and medicine stopped perpetrating the fiction that withholding treatment is ethically different from terminating life. It is time that society began to discuss mechanisms by which we can alleviate the pain and suffering for those individuals whom we cannot help.

People will ask: If we are to kill some children with meningomyelocoles, then where will we draw the line? At children with mongolism who may have a long, if impaired life? At children with muscular dystrophy who have a shorter life, but a number of normal years? At the severely retarded child? At the mildly retarded child? At the child with phocomelis, or with a congenital amputation? There are areas where I do not believe euthanasia should be considered, but which physicians and society can and should discuss. However, in those rare instances where the decision has been made to avoid “heroic” measures and to allow “nature to take its course,” should society not allow physicians to alleviate the pain and suffering and help nature takes its course — quickly?⁶

Dr. Freeman is of the opinion that active euthanasia should not be *considered* in the range of cases he mentions in question form, but only in those *rare* instances, where decisions have been made to avoid “heroic measures.” However, the cases where much less than heroic measures have been waived to allow severely retarded children and children with Down’s syndrome to die are not inconsiderable in number. Decisions for nontreatment — with death as a consequence — of defective newborns, where the degree of defect varies considerably, are increasingly frequent. Moreover, the treatment in question is often of a quite routine surgical or medicational nature. Surgical correction of duodenal atresia is not considered to be an extraordinary or heroic

measure of medical treatment for an otherwise normal and healthy child. The same or similarly routine treatment has been withheld, with death as a consequence, in a number of published cases of children with Down's syndrome.

The major point to be made here is that parent-doctor decisions for nontreatment of defective newborns with prolonged dying and death as a consequence, appear to be increasingly frequent and to manifest a trend toward passive euthanasia on the basis of quality of life prognoses for the infants in question.

However, Dr. Freeman's questions and his passionate plea seem to reveal a "logic of the humane-thing-to-do" bridging passive euthanasia, the withholding of life-prolonging treatment, with active euthanasia, the deliberate hastening of defective infant death or the deliberate and immediate termination of defective infant life.

Robert Reid has clearly expressed this logic in an article dealing with policies for selective nontreatment of newborns suffering from spina bifida with myelomeningocele.

There is a blatant inconsistency in the attitudes of doctors who operate a policy of "selection." The whole aim of such a policy, and the hope of all those who are party to the decision to put that policy into operation, is that the child should be allowed to die quickly. Yet, having made this selection, the same doctors, along with the baby's parents, are prepared, or are forced, to stand back, take no further action, and watch the child take three, six, or sometimes as many as nine months to die. In the most unfortunate of circumstances the child will live on, either in an institution, or cared for by its parents.

Most doctors would be prepared to guarantee that the effectiveness of pain-killing drugs and modern nursing care will remove any physical sufferings from the remaining days of life of the infant. The state of affairs is clearly ironical, and verges on the hypocritical. If a designated aim of medicine is that a child should die, why should it not be more humane to make it die?

The question is not an unreasonable one. . . . For there is no doubt, if it is possible to arrive at acceptable criteria which can be reliably used to fulfill the hope that a spina bifida child will die, then the same criteria must be capable of being used to define a situation in which it can be ensured that the child *does* die.⁷

Criteria for Selecting Babies for Nontreatment

Criteria for a selection of which defective newborns will be allowed to die and which will be optimally treated with the hope of prolonging their lives are at the heart of the debate over the seriously defective newborn. The criteria are proposed to bring some degree of rational control into a decision-making process which already shows signs of considerable inconsistency and arbitrariness.

Many of these proposals involve criteria of a technical, medical nature. They are necessary if selective treatment decisions have to be

taken. One may seriously question, however, whether any list of objectively measurable criteria are a sufficient basis for life-death selection decisions. Robert Veatch has spoken of the "technical criteria fallacy." He has questioned the validity of a set of criteria which are used as automatic selective-decision dispensers. "It is not the precise content of the list which is important. Rather it is the concept that *any* list of objectively measurable criteria can be translated directly into decisions about selection for treatment and nontreatment. Presumably the lists being proposed are meant to be reasonably accurate measures of prognoses. Yet the presumption that treatment or nontreatment rests solely on prognosis is surely contestable. The decision must also include evaluation of the meaning of existence with varying impairments."⁸

This "evaluation of the meaning of existence with varying impairments" is a point where the debate over the seriously defective newborn has already entered its broader ethical and philosophical phase. We deal here with criteria proposals for selective nontreatment and for active euthanasia which are not immediately technical in character but involve estimates of what behavioral capacities are necessary for an infant to be judged human. The general public is already accustomed to this kind of question as a result of the abortion discussions over the last years. A great number of people have grown accustomed to the idea or now hold that the fetus, at least up to a certain stage of development, is not human. Can a similar evolution of attitude be expected with respect to the seriously defective newborn? Were such an evolution of attitude to take place, would it not be a significant determinant of societal readiness for merciful infanticide?

What merits serious consideration with respect to the title question for this preamble is that euthanasia proposals are already being made or at least suggested as justifiable on the basis of a classification which relegates certain types of defective newborns into the category of the nonhuman.

Registers of indicators, observable and measurable, have been established to facilitate and regulate the selection of defective newborns for optimal, vigorous treatment or for nontreatment and death, as the case may be. Joseph Fletcher has already attempted a similar register of indicators of humanhood, a tentative profile of man. "Synthetic concepts such as *human* and *man* and *person* require operational terms, spelling out the which and what and when. Only in that way can we get down to cases — to normative decisions. There are always some people who prefer to be visceral and affective in their moral choices, with no desire to have any rational, critical reflection (encephalic and not merely visceral) about the problems of the moral agent — in biology and medicine as much as in law, government, education or anything else.

"To that end, then, for the purpose of biomedical ethics, I am suggesting a 'profile of man' in concrete and discrete terms."⁹

One, of course, is perfectly justified in asking whether any set of discrete terms is capable of grasping and mapping the integrated reality we are attempting to indicate or express with *synthetic* concepts, such as man, human, person. Do these synthetic, integrated and systems concepts not perform a function which no array or summation of analytic and subsystems concepts is capable of doing? If it is possible, while being very encephalic and nonvisceral, to wonder whether "any list of objectively measurable criteria can be translated directly into decisions about selection for treatment and nontreatment," then it is equally mandatory to question whether *any* list of indicators can directly issue in judgments about the nonhumanhood of any being born into the human race.

Nevertheless, ways are being suggested to arrive at such judgments. The purpose is presumably to facilitate decisions for selective nontreatment, for allowing certain categories of defective infants to die, as well as decisions regarding the most *humane* way of managing these infants after the selection has been made.

In June of 1977, the Anglican Church Task Force on Human Life in Winnipeg, Manitoba, produced an interim report, *Considerations Concerning the Passage from Life to Death*. The report considers the newborn infant with severe neurological defects and raises the question as to whether certain categories of such infants are to be treated as human.

An earlier section of the report discusses "What it means to be human." The discussion presents a range of opinions and concludes:

There is, however, a common thread in the foregoing comments. They all speak about man's ability to relate. The capability to relate to himself, with his neighbor, and with God encapsulates all the minimal criteria set down by theologians and scientists alike. It would follow, therefore, that without any of these criteria, actual or potential, a living body is not human. It is true that we are bound to emphasize the quality of another's life or to know completely their ability to relate. One can really distinguish, however, between human life and mere biological existence by using the foregoing criteria.¹⁰

One of the many difficulties with this paragraph is that one does not have to go through the problematic exercise of labeling very defective babies as human or nonhuman to know what to decide about their treatment or nontreatment. Ethical and moral theological criteria have already been elaborated which cogently argue for the wisdom of withholding heroic and even ordinary treatment, for instance, surgical treatment when medical interventions of this kind will only fix the baby at a primitive stage of biological, neurological, psychological and human development. These nontreatment decisions can be justified in carefully circumscribed situations without turning the curve into that arbitrary morass of human/nonhuman labeling.

Efforts at such distinctions are bound to produce only arbitrary norms and establish very dangerous precedents. These are arbitrary norms because "human" encompasses a complex developmental process and we really do not know what a defective baby's future will be. There are arbitrary norms which are also unidimensional in character, because a baby, defective or not, is part of our reality, not just a physiological system with this or that chance of being salvaged. We, the entire human community surrounding the child, are part of this baby's reality; the baby, an integral part of ours. "Human" is not a discrete kind of label of the type we attach to objects and things. To say this particular baby is nonhuman is arbitrary and isolates the baby from the entire human community.

Such isolation and the criteria upon which it is based set up very dangerous precedents. The criteria can be applied to many categories of persons suffering from severe trauma or deterioration, not just to severely defective newborns. When this label is applied, we are also affected. These persons no longer belong to *us*. We have changed. We are no longer the ones charged with their human care. We can behave toward them as though they were not human, because by hypothesis and by labeling, we have decided that they are not. But what happens to *our* humanity when *we* so behave?

Two of the points just mentioned demand a moment's reflection.

The Winnipeg document, mentioned above, draws the conclusion as to how we may, even should, behave toward severely defective newborns once we decide they are not human.

The severely defective newborn infant which has no chance of gaining a modicum of spiritual or intellectual life deserves special consideration. The medical attendants may hope that the infant will contract some infection which, without treatment, will cause death, but if such a merciful outcome does not occur, the parents and society may acquire a sad burden for 20 or 30 years. Nobody wants to assume the responsibility of taking direct action to end the infant's life because of the paralysis of thought which so easily immobilizes those who have to make life and death decisions about the infant.

An infant with severe neurological defects may not be "human" as defined earlier in this paper and it is a fundamental error to treat it as human. It is natural to trust what we see rather than what we know from the evidence of experience and medical science. We see that the creature looks like a human being and it was born of woman, though we know that it cannot possibly develop "humanhood." Our eyes carry the day and we treat the creature not only in a humane way but as if it were human.

We are obligated to treat all sentient beings in a humane way, not causing them pain and, if they are in pain, endeavoring to relieve it. This obligation to treat animals humanely does not mean to most of us that we should treat them as if they were human. Our senses and emotions lead us into the grave mistake of treating human-looking shapes as if they were human although they lack the least vestige of human behavior and intellect. In fact the only way to treat such defective infants humanely is not to treat them as human. ¹¹

Without doubt, the severely defective newborn with no chance of gaining a modicum of spiritual or intellectual life deserves special consideration. But the above proposal is very clear: special consideration in the circumstances means the desirability or justifiability of terminating such a baby's life, of killing such a baby. That kind of "special consideration" itself — frequently contemplated, let it be emphasized, beyond the boundaries of the particular document being quoted — deserves special consideration.

One consideration will suffice for the moment. What could conceivably happen to the fragile web of our civilization if we decide that certain babies are not human and that we may kill them, humanely for their own sake, perhaps very selfishly for someone else's sake?

What is at stake is whether the thin edge of the wedge of euthanasia will be a catastrophe or a civilizing influence for mankind. The argument, reinforced by the spectre of a Hitler, that the law will be abused by dictatorial monsters is easily dispensed with. Hitlers will abuse the spirit of the law whether it exists or not. What is more important is whether civilized people will be tempted to misinterpret the law and commit infanticide where it ought never to have been contemplated.¹²

This is a good point, but it comes too late. We must really ask whether infanticide should ever be contemplated, let alone performed. If the answer is no, and we will briefly argue in favor of that negative below, then opting for infanticide and performing it with a rationale, not just out of desperation, will inevitably ask for further arbitrary extensions of this procedure.

Quality of Life Judgments and Letting Babies Die

Some newborn babies suffer from such serious neurological defects that one can have little hope for their survival and equally little hope of their developing beyond the physiological level of functioning they have already achieved. Such is the case with an anencephalic child. However, many other babies are born with very serious defects, yet have chances of reaching levels of development which will permit them to give and receive love, even to take their own lives into their own hands, often to a very significant degree. This is the case with many Down's syndrome babies and with babies suffering from spina bifida with myelomeningocele. Of course, to reach these levels of development these babies will require extensive and complex medical treatment. Decisions are now being regularly made to withhold such treatment and let the babies die. Indeed, this is being done on the basis of policies with criteria for selective nontreatment for potentially lethal defects which would otherwise be treated in normal babies.

One pattern of reasoning underlying a specific policy of selective nontreatment of babies suffering from spina bifida with myelomen-

ingocele merits particular attention and debate, if not critique. The pattern of reasoning, not the specific policy proposals, is the focus of attention here.

Dr. John Lorber is widely known for his forthright and clear positions on the treatment of myelomeningocele and associated multi-system defects. The criteria he now uses to select babies for nontreatment are also widely known and quite as widely debated. A number of hospitals have adopted his or similar criteria. Others have not.

What is under scrutiny here is the reasoning he employs to face the results of vigorously applying his criteria of selection. One of the results is that some babies die who would otherwise have reached the levels of intelligence necessary to the levels of communication and human life mentioned earlier.

It may be feared that selection for treatment may lead to the early death of an infant who has at least a chance of normal intellectual development. The data presented here indicate that with modern advances in treatment this is possible in a minority of even the most severely afflicted infants. Twenty percent of all 110 infants with major adverse criteria at birth were of normal intellectual development at 2-4 years of age, though all have severe physical handicaps and their life expectation is short.¹³

Allowing such infants to die is worthy of debate, has been and will continue to be debated. However, it is the reasoning in favor of permitting these results which calls for inquiry here.

The first statement of this reasoning follows immediately upon the above quotation: "It must be remembered that, after early childhood, the suffering of a person with such severe physical defects and so few opportunities in life is likely to be greater in those with normal intelligence."¹⁴

Dr. Lorber amplifies on this reminder in his 1975 Milroy Lecture: "Using our criteria, some children who would have survived with normal intelligence will be excluded from treatment and will die. Nevertheless, it is my experience, as it is that of psychologists, social workers, teachers, and parents, that those young people who are severely handicapped by multi-system defects suffer far more if they have normal intelligence than if they are retarded. Only the intelligent realize fully what they have been through, what they have missed and will miss. Only the intelligent will worry about the frustrations of employment, loneliness, lack of opportunity and of normal family life. Only they will worry about their future and who will look after them when their parents are too old or are no longer alive."¹⁵

This reasoning represents a level of paternalism which is insufferable and merits the sharpest rejection. The entire thrust of our admittedly unevenly developing civilization, has been to assure that individual human beings have the *chance to work out and master their own personal destinies*. We have a position here which says that medicine is justified in determining that the working out of some destinies will be

too difficult for some persons. Before they have the chance and before they have to face their challenges, they may be left untreated and allowed to die.

This is the sort of hubris which casts a pall of suspicion over even the very justifiable instances of selective nontreatment. And a judgment in favor of not treating a given infant *can* be ethically justified. Ethically justifiable guidelines for selective nontreatment *can* be established, as will be indicated below.

From Selective Nontreatment to Euthanasia

It is clear that nontreatment, especially the radical nontreatment advocated by Dr. John Lorber over the past few years, generally means death for the baby. However, death does not always come quickly. In fact, these babies may frequently linger for quite awhile. So Dr. John Freeman asks the medical profession and the general public, "Is there a right to die — quickly?"¹⁶

With respect to the decision for selective nontreatment the question, more specifically, is:

If we make that decision for a given child, should we not then, as physicians, also have the opportunity to alleviate the pain and suffering by accelerating that death? . . . In those rare instances where the decision has been made to avoid "heroic" measures and to allow "nature to take its course," should society not allow physicians to alleviate the pain and suffering and help nature to take its course — quickly?¹⁷

Dr. Freeman is quite aware that his question, affirmatively answered, implies a conversion from passive euthanasia to active euthanasia. Though he believes this conversion "is not an easy one for society or for the individual physicians faced with the decisions and with their consequences," he also holds that society and medicine should stop "perpetuating the fiction that withholding treatment is ethically different from terminating life. It is time that society began to discuss mechanisms by which we can alleviate the pain and suffering for those individuals whom we cannot help."¹⁸

Dr. Freeman has raised a question, taken a position and issued a plea. We shall return to these below.

This paper opened with a quotation of Glanville Williams that proposals for humanitarian infanticide could, at the time of his writing, be dismissed as politically insignificant. This is no longer the case. Decisions not to treat babies and to allow them to die are now being made on a regular basis in hospitals with respect to babies who have genuine chances for human development. A body of thought which is also emerging to support these decisions and to prepare the way for a still more active and direct termination of the lives of these babies, works with four fundamental concepts and assumptions:

- 1) If we cannot prognosticate a future life of sufficient quality for a baby, then this life need not be preserved.
- 2) If a baby, despite the possibility of achieving significant levels of human development, will foreseeably have great burdens of pain and suffering to endure, then we need not — some will argue, *should not* — preserve this baby's life.
- 3) Decisions with respect to treatment or nontreatment of severely defective newborns will be less difficult and more efficient once we accept the doubtful or certain nonhuman status of these babies.
- 4) Humanitarian infanticide, i.e., directly, swiftly and painlessly killing a seriously defective newborn when we have decided, perhaps justifiably, not to treat may at times be the most *humane* thing to do.

Admittedly, many who would accept 1) and 2) would not be prepared to accept 3) and 4).

A clarification of oversights and a sharp drawing of lines with respect to these four assumptions and to their implications is obviously necessary. We now turn to the sketch of an ethical argument and several ethical positions on the care of the severely defective newborn.

The Severely Defective Newborn — Selective Nontreatment, Quality of Life and Euthanasia: The Outlines of an Ethical Argument

We shall state below that ethical argument is not sufficient to assure a social policy of care for defective newborns which will be consonant with the highest canons and ideals of Western civilization. Nevertheless, clear, sharp and profound ethical argument, though not sufficient of itself, is absolutely indispensable. What follows is only an outline of how such an ethical argument should proceed.

The Ethics of Selective Nontreatment

1. The Situation

Contemporary pediatric medicine is the scene of an increasingly intense debate centering on an issue which in its crudest and most unqualified form, lends itself to a paraphrasing of the logic Shakespeare captured so memorably: to treat or not to treat seriously defective newborn babies. At an earlier period, many or even most of these babies would simply have died, indeed, quite quickly. Because little could then be done, little had to be decided.

That is not where we are today. Medicine has advanced. Much more can now be done. Many of these babies now need not die as a direct and quick result of their defects at birth. Their lives can be "saved" or at least prolonged for a very significant period. Of course, in so many of these cases, the babies remain severely handicapped. And so we ask whether what we can now medically do to these babies is really for them, i.e., in their favor and contributing to their well-being. What modern medicine can do for these babies so often seems far from being enough.

Enough for what? It is most frequently enough to prolong their lives. But many — and this group begins with the parents of defective newborns as well as their doctors — feel that the lives salvaged will really not be worth living. So whether to treat these defective newborns very vigorously or not to treat them at all — and this most frequently means allowing the babies to die — has become a set of real alternatives. This set is real because both options are being taken and argued. The second option is being taken ever more frequently, it would seem, and argued ever more publicly.

Thus, contemporary pediatric medicine questions the ethics of selective nontreatment of defective newborn babies. Most people familiar, whether in a casual or professional way, with the plight of defective newborns would not hold that *all* such babies should be left to die. Only *some* babies. But which ones, precisely? Of course some, perhaps many, would vigorously assert that *no selection whatsoever* should be made. All defective babies should be treated with every possible element in medicine's instrumentarium. Every effort to prolong every infant life should be made. On the contrary, those who hold this absolutist policy to be medically unwise and morally insensitive are faced with the intricacies of devising effective and justifiable guidelines or, more specifically, criteria of selection — a tricky and often tragic business.

The question of selective nontreatment necessarily raises a host of serious considerations.

When total cures or restorations to significant levels of health are just possible, what is the function of medicine? To prolong biological life at all costs and for as long as possible? A debatable proposition. However, with a somewhat greater degree of nuance, is it not medicine's function to aid human beings — babies, in our discussion — in every possible way to achieve those levels of development and achievement which *are* open to them, given and accepting the often highly impoverished physical and related mental conditions with which these babies have to begin their lives?

Perhaps. In fact, it would seem so. But what if a baby's multi-system defects are so severe that levels of development and achievement higher than those minimal biological ones already attained are

out of the question? Are medical interventions permitted, let alone mandatory, when their only foreseeable results can be to prolong a baby's fixation at a point of development short of anything we can agree to be humanly worthwhile?

2. A Basic Consideration

Life, biological life, is sacred, but not in abstraction from the other values and possibilities to which it is ordained. "Life" is, of course, a difficult word. But it surely seems to be the case that any level of life is associated with a level of communication of some sort. At the lowest levels, life is associated with levels and complexities of chemical and biochemical exchange, communication and transformation. Every communication affects a transformation of a definite sort. At some of the highest levels of life — the ones we call human — another pattern of communication dominates and quite a different kind of transformation takes place. Promises, commitments, encouragements, esteem, genuine declarations of support, affection, friendship and love are given, accepted. Bonds are forged. Transformations of the high order we call interpersonal are achieved.

3. A Position

The basis for selecting babies for nontreatment has a great deal to do with whether we should make any distinctions whatsoever as to whether certain babies should be treated medically, others not treated and allowed to die. *On the basis of rights*, no distinctions should or can be morally justified. However, *on the basis of chances for development*, distinctions and selections grounded in judgments as to what medical treatment is really doing or failing to do for defective babies may well be an imperative of medical and ethical responsibility.

To withhold treatment from an infant who has a chance, albeit a fighting chance, of reaching the levels of life, the levels of communication and transformation mentioned above, is to make a drastically mistaken value judgment. In fact, many very severely defective newborns have gone on to reach these levels of human life and they have transformed the lives of many around them, partly because of the transformation which took place within themselves. Others, one could say, have not. They have lived miserable lives, plagued by depression and frustration.

However, the same "differentials of happiness" apply to the community of those born normal and without severe defect. To judge that an infant should not be treated, should be allowed to die, because of the obstacles he will have to face or even because of our assessment of the likelihood of his not being able to master these obstacles and achieve the human transformation mentioned above, is indeed to cease practicing medicine in favor of playing God.

pure form
of pessimism

4. An Overview

The ethics of selective nontreatment begin to take shape with reference to the following *canons of medical practice*.

Canon 1

The first canon would dictate that when medicine cannot cure, i.e., cannot restore the patient to full and normal functioning, its equally fundamental purpose is to aid the patient in every therapeutic way to live with his disability, i.e., to develop personally as fully as possible despite and with this disability. Medicine stands in the service of nature to the extent that it *can* unfold and develop.

Canon 2

To *assure* happiness and to *eliminate* suffering from the lives of human beings goes beyond the functions and competence of medicine. Medicine has a far-reaching contribution to make in restoring and buttressing so many of the conditions required for the kind of development a person needs to attain happiness. That attainment necessarily encompasses the ability to integrate varying degrees and modalities of suffering into the whole fabric of one's person and life. But this integration is the achievement of autonomous, free persons. It is also, as is everything of human worth, partially the gift we receive from the people we believe in, trust and love. This is the human drama. It is not medicine's function to close that drama in the first act.

Canon 3

The third canon deals more explicitly with the limits of medicine. When biological damage is so extensive that curative, restorative, and corrective medical interventions cannot aid the patient's development but only succeed in perpetuating or prolonging a patient's fixation at a level of development which is not meant to be final and is far short of the variety of purposes and levels of life to which biological human life is ordained — when this obtains, then, so the canon states, medical intervention has reached its limits, works contrary to its calling in perpetuating such fixations, and should not be employed.

Canon 4

There is a critical and decisive difference between humanely killing when we cannot cure and withholding medical treatment when the purposes of that treatment cannot be obtained. The latter represents a responsible acceptance of medicine's limits. The former assumes an extent of responsibility which cannot be justified. The premise for a logic of human infanticide is false and the conclusion of that logic over time would be unbearable.

5. Conclusion

These canons, combined with the central point made above about the ordination of biological life to higher purposes and values, permit — at times demand — judgments for the nontreatment of certain severely defective newborns and for allowing them to die. These reflections do not assume that anyone can judge that someone else's life is not worth living. What they do accept is that some lives cannot be lived.

Ethical Reflections on Euthanasia and Humanitarian Infanticide

As mentioned earlier, Dr. Freeman has raised a question, taken a position and issued a plea with respect to the justifiability of humanitarian infanticide, of active euthanasia, for certain categories of defective newborns.

The plea is for a discussion of mechanisms to alleviate the pain and suffering of those individuals we cannot cure. The language is soft, but what is being sought is clearly societal approval for doctors to hasten the death or even more quickly terminate the lives of those babies medicine cannot cure. The individuals in our present discussion are babies, severely defective newborns.

The assumption behind this plea would seem to be that modern medicine cannot effectively alleviate the pain of incurable, severely defective newborns without killing them. We are being asked to accept "putting them out of their misery" as the only available alternative to leaving those babies in pain once we have, perhaps justifiably, decided to leave them untreated for specific kinds of defect.

This assumption — and there may be *other* assumptions behind the plea — merits simple rejection. It is simply false. Modern medicine can alleviate and control the pain these babies would otherwise have to bear. It can do so effectively without killing them. This is, at least, the view of a special panel appointed by the Board of Science and Education of the British Medical Association to study the problem of euthanasia.

For those who are dying from painful conditions, doctors can and do provide relief by means of analgesic drugs. . . . It is possible to give opiates to ease pain for many weeks or months, without killing the patient. Newer drugs may increase the margin of safety, but the skillful use of older remedies can still provide satisfactory treatment. Sleep and freedom from pain can be achieved by modern therapeutic measure.¹⁹

Killing incurable and severely defective newborns to control and alleviate their pain is absolutely unnecessary and for that reason, as well as many others, utterly unjustifiable.

A similar reflection is in order with respect to accelerating a baby's death. If the pain can be controlled, then no measures designed specif-

ically to accelerate the baby's death are ethically or medically acceptable. If a hastening of death comes about as a by-product of drugs administered in sufficient dosages to alleviate pain, one cannot speak of euthanasia or of accelerating the baby's death or of having killed the baby. This language would be in demand with respect to an administration of analgesics or sedatives in doses *greater* than those required to relieve pain. "The administration of *those dosages required to relieve pain* belongs to the sphere of actions that are an integral part of living and is not an *overdose* termination of life. The death of a patient in these circumstances simply means that his diseased or deteriorated or deteriorating physical condition can no longer support the activities which are an integral part of living."

If a baby's pain can be alleviated with doses of analgesics which do not kill him or accelerate his death, then the administration of higher dosages must have some other motivation and this motivation should be openly declared, identified, and justified. This paper argues that procedures specifically designed to accelerate the baby's death are not necessary to alleviate pain and, for this reason as well as others, are unjustifiable.

One may seriously question, however, whether the alleviation of these babies' pain is the really determining motivation behind a plea for societal approval of mechanisms which would be equivalent to an approval of killing these babies. Mention has also been made of suffering. Whose? The baby's? Do babies really suffer, over and above the experience of pain which, let it be emphasized again, can be alleviated and controlled?

Suffering involves more than the neurological experience of pain. Suffering involves the perception of a terrible gap between what is and what should or could have been the case with respect to one's own or someone else's life. Babies do not suffer in this sense. But adults can and all too frequently do suffer in this sense. One suspects that both parents and doctors must suffer when they look upon a baby lingering on through a dying curve after they have decided, perhaps justifiably, to withhold medical treatment for specific defect from this baby.

If the decision to withhold treatment has been short-sighted, motivated by a distorted sense of human values, in short, has been unjustified, then full treatment of the infant, not killing the infant or accelerating his death, is in demand and utterly imperative. If, on the other hand, a nontreatment decision is justifiable, then the only really justifiable subsequent behavior toward the infant will consist of alleviating the baby's pain and caring for him with love as *we*, perhaps with courage and mutual support, suffer this baby's demise and the limitations of our own powers to cure and renew life. Accelerating the infant's death or killing the infant is an unacceptable way of escaping the suffering *we*, not the baby, are called upon to bear.

The Position

Dr. Freeman has also taken a position. He believes that ethical differences between withholding treatment and directly terminating life are simply fictional. There are no real ethical differences, at least nothing decisively different, between withholding treatment when we cannot cure and killing once we have decided to withhold treatment. This is Freeman's claim.

Of course, if one focuses exclusively on the defective newborn and *upon his life span*, there is indeed little difference between killing the infant, accelerating his death, and allowing him to die after a decision for nontreatment. In most cases the life span difference is reduced to a matter of days or several weeks.

But Freeman's position centers on ethical differences. Such differences have to do primarily with the canons of our responsibility vis à vis these newborns, with the canons of our responsibility and with our mandate of care. On this level, at least — not exclusively, there are utterly crucial ethical differences between withholding treatment and "humanitarian infanticide."

One of these differences is defined with respect to those who do the withholding or the killing. When we withhold treatment from defective babies because we cannot cure them and because treatment would at bottom signify our initiative in prolonging a dying process or in fixing a baby at a biological stage of development he is meant to transcend, then we admit the limits of what we are able to do medically for this child. We at the same time admit the ethical limits of what we should do to this child.

When we kill such a baby, we assume a mandate to eliminate suffering by eliminating the sufferer. This mandate assumes a total power and dominion over the sufferer because it assumes a total responsibility for the sufferer's life. The least that can be said for such a mandate is that it carries the burden of its proof. The next thing to be said is that such a mandate *requires justification*. The existence of such a mandate has to be demonstrated.

However, the demonstration that medicine has such a total mandate has never been delivered. In fact, the cardinal beliefs and positions of Western civilized thought on the uniqueness and autonomy of every individual human being have consistently rejected the totalitarian premises of such a mandate. If there are technical limits on what we can effectively do medically for a defective newborn, there are also definite ethical limits on what we can ethically do to such a child in his own name and on the basis of our interpretation of what is in his own best interests.

It is the premise for humanitarian infanticide which is rejected here. The premise is admittedly complex in structure. It would, among other things, hold that:

- when we cannot cure, we may kill to eliminate suffering;
- suffering is a problem which can and has to be technically solved;
- medicine is responsible for delivering this technical solution to the problem of suffering with respect to those who cannot be cured;
- there are no limits to medicine's mandate to intervene in a human life.

This totalitarian view of medical responsibility is a determinant of the plea for humanitarian infanticide. This is the concept we emphasize for the moment as meriting rejection and a 360 degree transformation. The premise for medical practice should be that we intervene as little as possible in any human life. Every such intervention has to be justified, even if this justification is usually smoothly implied in the initial contacts which establish a given doctor-patient relationship.

Decisions for nontreatment may, in a range of circumstances, signify precisely a respect for this fundamental principle, the combined principle of individual autonomy and human interdependence. What is intolerable is that a further step and a further intervention — the step of humanitarian infanticide, which claims a totality of responsibility and an absolute imperative to intervene — are the very points denied by the nontreatment decision. In a word, the pattern of reasoning which links nontreatment decisions in medicine with a plea for humanitarian infanticide suffers from a profound and intolerable contradiction. This contradiction centers on the limits of medicine's responsibility and medicine's mandate.

If the premise for humanitarian infanticide has to be rejected, we must also emphasize that the logic set up by this premise would permit a societal conclusion which would, over time, be absolutely intolerable. There are many kinds of suffering and there are sufferers of all ages. If we assume a mandate to kill one group of sufferers to eliminate their pain, how can we in a *non-arbitrary* fashion stipulate that other groups of sufferers may not be killed to relieve them of their suffering? If we have no non-arbitrary canons to govern "humanitarian killing," then limitations on this peculiar mode of benevolence will indeed be arbitrary and subject to removal by those who mean well toward other patients, just as pleaders for humanitarian infanticide mean well for the incurable and defective newborns.

Conclusion

These reflections are only the beginning of an argument which must end with a rejection of the position Freeman has taken. There are ethically critical differences between withholding treatment when we cannot cure and killing when we know we should not treat. When

these differences are ignored, decisions beginning in benevolence will end in a most terrible despotism of the healthy over the weak and incurable.

For these reasons and others still calling for development, it would seem necessary to answer Dr. Freeman's question as to the justifiability of active euthanasia with an unqualified negative.

From Ethical Argument to Existential Demonstration that Care of Defective Newborns Is Possible

We no longer live in a society which is culturally, philosophically, religiously, or ethically homogeneous. In a society which is, homogeneity settles many issues. Debate is unnecessary. Consensus is a given, however fragile this consensus may become at a later date. In a society as pluralistic as our own, careful, ongoing debate is essential to preserve the fabric of fellowship necessary to preserve and enhance the most cherished ideals of our civilization.

The point of debate, of course, is to search for consensus, at least until the nondebtable roots of basic beliefs and their conflicts are laid bare. And then what? Can we reach consensus in policy without a consensus in belief, for example, on what is really humanly worthwhile? On what is humanly really most important? And if we in our society do not at the moment agree on what is humanly worthwhile, what do we then do? We must come to realize that a point is reached when argumentation and debate have to give way to a richer existential demonstration of our beliefs and corresponding ethical positions.

This existential demonstration is absolutely essential to give body and credibility to our ethical argument that the defective, weak, retarded and suffering can be loved into a life which is worthwhile. Correct ethical positions are not enough. We have to demonstrate realistically that these positions *can* be lived.

This demonstration will certainly demand the imaginative creation of new ways of caring for those we cannot cure. This is the moment for the Christian churches, for the Roman Catholic Church, to demand *the establishment, for example, of a new order, a new community* to specifically and effectively care for all those whom others in our society consider as candidates for euthanasia.

There is a crying need for such an order, for there are many defective, disabled and handicapped babies and persons. Many families cannot, in fact, bear the burden of caring for these babies. Were we to succeed in establishing such an order — and I cite this as only *one* example of what we, the Church, should be doing — we would not only be caring for those in the most dire need, but would also be creating a living proof and symbol in our society that euthanasia is not necessary. In the process, we would also be demonstrating that Chris-

tian belief makes a difference and gives a definite shape to a society. As a byproduct we would gradually have to spend less time running around asking why people, young people, are leaving the Church.

Over the past few years, I have strongly argued the case for care and treatment of defective babies whenever there is hope for development. What we must realize is that neonatal medical treatment is only the *beginning* of the care these babies will need, probably all their lives. Are we ready, as Christians, to effectively demonstrate that this care can and will be given?

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