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Selective Nontreatment of Defective Newborns: An Ethical Analysis

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In the Oct. 25, 1973 issue of the *New England Journal of Medicine* Raymond Duff and A. G. M. Campbell reported on 299 deaths in the special-care nursery of the Yale-New Haven Hospital from January, 1970 through June, 1972. Of this number, 43, or 14%, were the result of withholding treatment.¹ The report brought public attention and analysis to procedures which previously had been practiced quietly, inconsistently, and not always with careful rationale. In the intervening years, the topic of selective nontreatment of defective newborns has been receiving increased popular and professional attention. The issues raised by this subject are manifold. Answers remain ambiguous, in part because the questions are so new and are not themselves yet clearly formulated. Nonetheless, three issues come forward for special consideration: basic assumptions concerning human life, ethical analysis and formulation, and methods of implementation of policy developed.

Assumptions

Confrontation with death forces concern with life and its meaning. Thus, in the matter of selective nontreatment of defective newborns, we are compelled to bring to conscious examination our basic assumptions about human life. The ethical analysis which follows is built on four premises.

First, defective newborns are human beings. Those who, like Joseph

Fletcher in his statements on the topics,² formulate their discussion around the "humanhood" of the neonate, obscure matters and intensify visceral rather than rational response by abusing the normal sense of words. The neonate can be no other kind of being than human. The discussion is more properly set in terms of the "personhood" of this human life, the quality or potential quality of this human life.³ This distinction is no mere semantic quibble, for while the designation of defective newborns as human does not lead us directly to clear decisions on appropriate treatment, acknowledgement of the humanity of the neonate prevents us from dismissing the infant with little reflection. Human beings merit respect. The obligation to respect requires that careful moral deliberation takes place.

Secondly, human beings have value. Thus, the defective newborn is of value. In the discussion of the possibility of selective nontreatment, there is no necessary implication that such infants are of lesser or no value compared with other newborns. To recognize the value of the neonate is to assert its fundamental worth and indicate a preference for its protection. But once again, the recognition of value does not itself dictate which decisions are to be made with regard to the object of value. Values exist within a context of interrelated values, sometimes subordinate, sometimes superior, sometimes supplementary, sometimes competitive. Thus one is led to ask, valuable in relation to what? This points to my third premise.

Life is valued in relation to the attainment and exercise of other values. Richard McCormick quotes a 1957 statement of Pope Pius XII regarding the moral obligation to use ordinary means of life preservation: "A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, death, all temporal activities are in fact subordinated to spiritual ends."⁴ McCormick proceeds to argue — correctly, I think — that this means that life is valuable in its relation to higher values, in particular to the values of human relationships and relation to the transcendent, through relation to neighbor. On another occasion, McCormick carries his analysis further. We often confuse two meanings of the term "life," he points out. We may mean either "the existence of vital and metabolic processes" or a state of or potential human personhood. The former is not valued for its own sake, but as a foundation for the latter.⁵ To argue to the contrary that the "basic" value of biological life must always take precedence over considerations of "higher values" of personal life is to risk collapsing the wholistic view of man in which both physicality and spirituality are integral to personhood. In analysis of decisions regarding the treatment or nontreatment of defective newborns, therefore, life must be viewed within a wider constellation of personal human values.

Fourth, just as reductionistic vitalism is questioned by an understanding of human being which places highest emphasis on a network

of personal values, so death itself is relativized by the religious perspective. Death, as biological cessation, is not the Ultimate Enemy. Because death is not the final negation, it cannot be reified into a demonic god who is to be avoided at all costs. This has long been recognized in the honoring of sacrifices for higher principles and loyalties. In recent years we have seen increasing acceptance of death as a natural and, at times, suitable part of life. Despite some demur about "the indignity of death with dignity,"⁶ most theologians and philosophers, as well as psychological therapists, have seen the contemporary openness to acceptance of death as a good and appropriate human attitude. Acceptance of one's own death as appropriate appears in the current literature of counseling the dying as a legitimate goal of personal adjustment for the terminally ill person. Acceptance of the appropriateness of the death of another is also proposed when, for such reasons as discussed below, prolongation of the life of the other is seen as meaningless. Thus, the death of defective newborns cannot, *a priori*, be rejected as an absolute evil.

Paul Ramsey has argued that, viewed religiously, life is a gift and a trust. Thus it is immoral, he claims, to choose death as an end. One may allow death and choose how to live while dying, but should not opt directly for death.⁷ His point should be kept in mind. It reminds us, as will be developed below, that western religious ethics has a bias toward life. Though the conclusions of this essay differ from those of Ramsey, acceptance of death, as described here, is neither refusal of a gift nor violation of a trust. It is a recognition that gifts and trusts are to be acted on responsibly. In the ethical analysis which follows, the nature of this responsibility will be outlined.

Ethical Analysis

Basic to the humanistic ethical analysis which is rooted in the western religious heritage is a bias toward life. While death is not necessarily to be thought of fearfully, life is not to be considered lightly. Human life in all its personal qualities is a value to be maintained. It is to be given up only in carefully considered situations and for proportionate reasons. Like Ramsey, Leonard Weber proposes an ethical viewpoint from which life is viewed as a gift.

When life is viewed as a gift . . . there are limits to what one may do to it and with it. To see life as a gift . . . means to have an attitude of acceptance and protection rather than of control.⁸

This gift analogy, provided it does not lead to a hesitance to question or make decisions regarding experiences which come to us,⁹ provides a useful perspective. Appreciation and cultivation rather than rejection are responses appropriate to gifts. Thus, a bias toward life is a natural corollary of a world view which recognizes the world and human existence as, in a general sense, a gracious bestowal.

Two implications follow from this bias toward life. First, care should be taken that if we err in judgment with regard to selective nontreatment, we err on the side of life. We cannot avoid decisions; and error is an unavoidable part of human decision-making. But we can develop guidelines to fault, when necessary, in conservation of life. A second implication, one to which we shall return later, is that commitment to life logically should entail commitment to provision of means to support and enhance life. As a society we are committing ourselves to the preservation of lives of neonates who, under past circumstances, would have died. We are doing so by furnishing increasingly sophisticated neonatal intensive care and other advanced forms of lifegiving therapy. It is reasonable to assert, however, that to give only existence to defective newborns, without provision for necessary life-long maintenance and life enhancement, is only a partial commitment to life.

Because the choice between maintaining or letting go the lives of defective newborns is of relatively recent origin, moralists have found it difficult to establish specific ethical criteria by which to guide decisions. Assistance has been found, however, in a tradition which has been developed to deal with a closely related issue. This is the traditional distinction between ordinary and extraordinary or heroic means of life preservation. Widely accepted by physicians and philosopher-theologians alike, this distinction provides guidance as to which actions are morally mandatory (ordinary means) and which are elective (heroic means). Although the content of these two designations is not without some ambiguity,¹⁰ most would use a person-centered rather than procedure-centered definition. According to the person-centered approach, two characteristics are central to declaring a proposed means heroic and therefore elective: 1) lack of benefit, and 2) excessive personal or social burden accompanying the attainment or use of these means.¹¹

In his *Ethics at the Edges of Life*, Ramsey argues that, at least in relation to the dying, the ordinary-extraordinary analysis can and in most cases should be reduced to a "medical indications" policy.¹² He concludes that the first characteristic just cited, lack of benefit, is sufficient as a criterion of judgment. When treatment is no longer medically indicated, i.e., beneficial, it may be ceased. One may choose to live until death without this superfluous treatment. Even where death is not imminent and some might talk about a patient's right to refuse treatment, Ramsey prefers to avoid the ordinary-heroic terminology in favor of a medical indications approach. He sees referring the decision-maker to objective elements in the context of the decision to be made as the prime value in not entirely jettisoning the terminology.

Though medical indications, as Ramsey defines them, are integral to the analysis which follows, especially at the first level of applying the ordinary-extraordinary distinction, it is too narrow a base for the

topic as described here. This is seen even in Ramsey's presentation. He recognizes some right to refuse treatment by conscious persons not imminently dying. He acknowledges in this regard that the traditional ordinary-heroic distinction has been applied to those persons "whose lives could not be *meaningfully* prolonged. . . ." ¹³ Further, to speak as Ramsey does of the possibility of refusing "life-prolonging" as contrasted with "life-saving" treatment when no more "curative" treatment is indicated does not avoid the quality of life considerations he obviously wishes to turn aside. Life quality factors are surely a part of life-prolongation decisions, and unless "cure" means only thorough or substantial recovery, such considerations may be part of the definition here as well. Finally, it is not entirely accurate to call a medical indications policy solely a *medical* indications policy. Strictly speaking, there is medical benefit to treatment which, though it cannot cure, can extend life even briefly. To choose, in one's way of dying, to refuse such treatment is to do so not because it lacks benefit, but because it lacks *sufficient* benefit. This matter of *sufficient* benefit opens the door once again to indications which are not strictly medical. Ramsey's argument cautions us to define terms carefully. But the traditional ordinary-extraordinary categories are still useful in consideration of the topic at hand and can be followed as proposed below.

Ordinary-Heroic Distinction

The traditional context for the application of the ordinary-heroic distinction differs in some ways from the problem faced by those considering treatment of newborns. The guidelines have been developed to assist judgment regarding persons both seriously and terminally ill. They have come to be applied to those imminently approaching death. Though this may be true of some defective newborns, it is not always so. Procedures, sometimes sophisticated, sometimes rather common, which reverse or significantly postpone drawing near to death, can often be carried out. But the question may be raised as to whether the procedures *should* be employed. Thus, the question with defective neonates is not *can* death be postponed without significant burden, but *should* it be? Can the ordinary-extraordinary distinction be useful as a moral guide in that question? The answer appears to be yes, with varying degrees of precision and certitude, at three levels.

At one level the analysis can be applied directly in a more traditional form. Some infants may be born with such extreme physical defectiveness that death is imminent. Any procedures of life preservation followed would simply be a matter of prolongation of dying, rather than restoration to living. In such situations, treatment would clearly fall under the category of heroic, and therefore elective, means. Ramsey's identification of extraordinary with "not medically indicated" would be most applicable here. The "benefit" of such treatment is negligible. Selective nontreatment of newborns in that context

would generally be morally acceptable.¹⁴

The ordinary-extraordinary reasoning can be extended to a second level, suggested by Leonard Weber. He raises the questions: when does the *treatment* of an infant impose an excessive burden on the child? on the family? on society? When possible benefit to the infant can be obtained only by means in which the burden imposed by the treatment becomes excessive, he argues, such means may morally be omitted.¹⁵ Applied to the child, this would appear to mean that when the treatment itself brings extended subjection to pain beyond that of the underlying condition, or so concentrates all energies on the sheer struggle to survive that personal qualities are minimized, or would result in severe treatment-induced disability or disease,¹⁶ such treatment may not necessarily be mandated.

This application is more difficult to use in the case of a possible burden imposed by the treatment on family or society. Weber himself recognizes this and is certain that in many instances the family could be, at least in part, relieved of the burden by external assistance and support. He also sees little likelihood of society being totally bereft of resources. Such considerations have led David Smith to come to an almost total prohibition of selective nontreatment when family or social burden is the prime factor of deliberation.¹⁷ Nonetheless, given the lack of accessibility to sufficient assistance to all families and given the competition for scarce monetary and manpower resources in society, the application of the principle under consideration cannot be absolutely set aside. Severe strain and dislocation can be brought on families. And minimal provision of resources may not be sufficient to assure extensive and adequate care. This concern with the burden on family and society is important not so much with a view to its effect on them, but insofar as it reflexively creates a burden on the infant as well. Thus, concern with the effect of treatment can properly be considered in the case of the neonate, the family, and society. The further one proceeds from the immediate burden placed on the infant, however, the more caution is called for.

The third level of application of the ordinary-extraordinary moral reasoning is the most problematic in current discussion. It is at this level that the most obvious questions of "quality of life" arise. Unlike the second level, at which the *procedures* of life preservation are questioned, it is the *quality of life* itself which is at issue here. Weber, who avoids committing himself to the quality of life ethic, notes the difficulty of dismissing the issue. His answer, as we have seen, is to focus on the treatment rather than the underlying condition. Yet clearly it is the negative quality of life to which the treatment leads that causes him to admit such procedures as non-obligatory.

Ramsey's preference for a medical indications policy for treatment of the dying is in part based on his suspicion of quality of life judgments. This is amplified when he distinguishes between the dying and

those who are perhaps incurable but not yet terminal. "Sometimes . . . infants are not born dying. They are only born defective and in need of help."¹⁸ As pointed out above, one of the implications of a life-biased ethic is the obligation to provide such help. But one needs to consider the possibility that not all help will be helpful. Ramsey acknowledges this in the case of "non-curative" treatment of the dying. He also considers the possibility of the "exception" of those who are inaccessible to care, in states in which "care cannot be conveyed."¹⁹ Perhaps to such possibilities there needs to be added another — the infant who, through treatment, could be kept from imminent death but whose life quality is so minimal that it renders "help" not helpful and therefore extraordinary.

The argument of Richard McCormick is helpful.²⁰ He proposes a line of thought which sees quality of life judgments as an appropriate implication of traditional ordinary-heroic moral analysis. Examining past applications of this tradition, he finds that the *type* of life a person would have to live was often determinative of whether certain actions were morally obligatory or not. He argues further that the moral tradition within which the ordinary-extraordinary analysis is set assumes that biological life "is a value to be preserved precisely as a condition for other values, and therefore insofar as these other values remain attainable."²¹ It is the quality of life which finally renders means ordinary or heroic. Discussion of selective nontreatment must therefore take this issue under serious review.

Quality of Life Considerations

Recognizing the need for quality of life considerations is far easier, however, than actually providing specific content to that formal criterion. Attempts at definition have varied. Joseph Fletcher's 15 positive human criteria build out from neo-cortical functioning to include such variables as minimal intelligence, a sense of time, concern for others, curiosity, and idiosyncrasy.²² James Nelson points to socialness, capacity to experience limitation and freedom, and religiosity or intentionality.²³ Michael Tooley focuses on self-consciousness.²⁴ The debate among these moralists and others indicates the need to proceed with caution in this matter.

The line of reasoning proposed by McCormick provides such a cautious but useful starting point. As seen earlier, McCormick places special emphasis on relational potential. Life is a good insofar as it affords access to higher goods, in particular to the goods of social relatedness and relationship to the transcendent through relationship to neighbor. Thus, this relational potential would be the touchstone of quality of-life judgments. McCormick argues, "It is neither inhuman nor unchristian to say that there comes a point where an individual's condition itself represents the negation of any truly human — i.e., relational — potential. When that point is reached, is not the best

treatment no treatment?" He answers his own question: "When in human judgment this potential is totally absent or would be, because of the condition of the individual, totally subordinated to the mere effort for survival, that life can be said to have achieved its potential."²⁵

Absence of minimal relational potential could probably be ascribed to the anencephalic neonate. Such infants currently cannot ultimately be kept from dying. Should technical means beyond those now available be developed which would sustain their lives, indefinitely or for an extended period of time, these newborns would be rather clear cases of appropriate candidates for nontreatment. On the other hand, as Gustafson argues,²⁶ it is the capacity for relationship that is one of the strong reasons for the life preservation of Down's Syndrome infants. The judgment for other infants is not so clear. Early diagnosis and, even more so, prognosis²⁷ are difficult. Moralists can point to the criteria. Medical and psychological science will have to help fill out these criteria with specificity. Individual decisions will be made with risk, but cannot be avoided. Caution and courage are called for.

It may be more difficult yet to determine when the condition of the individual subordinates all else to "the mere effort for survival" and thereby minimizes the capacity for relationship. Constant severe pain, incapacitating response to treatment, or enduring non-consciousness may be elements of such a condition. Some moralists have drawn upon the established maxim of medical ethics *primum non nocere* (first do no harm) in this context. H. Tristram Engelhardt, Jr., for example, proposes the concept of "the injury of continued existence" to apply where conditions of continuing life would not be tolerable.²⁸ In the same fashion, participants in a conference sponsored by the University of California, San Francisco, included as one ethical proposition of their moral policy,

Life-preserving intervention should be understood as doing harm to an infant who cannot survive infancy, or will live in intractable pain, or cannot participate even minimally in human experience.²⁹

The interaction of human potential and the level of care and support provided are demonstrated in prognosis of the infant's future relational ability within the context of subordinating all else to the effort for survival. Relational potential may be kept at a low level if initial and life-long support is not adequate. This fact in turn directs us toward a closer look at the inference drawn earlier from the ideal of "bias toward life." Commitment to life logically entails commitment to provision of means to support and enhance life. Our assessment of quality of life potential is based in part on our expectation of benefits from treatment we are willing or able to provide. John A. Robertson points out that the low quality of life expectation of some defective newborns is due to the absence of provision made by society to bring these children to their fullest capability. This lack of provision, which is "the fault of social attitudes and the failings of healthy persons,"

rather than congenital defectiveness in the infants alone, is often a subtle factor in the judgment that the neonate has little potential.³⁰

Two implications can be drawn from these observations. First, in following out the bias toward life, we must be assured that those whom we keep alive are given full opportunity to maximize their potential. Continuing research and development in neonatal, pediatric, and adult medical care of persons with defects should be supplemented with provision of extensive social support services. If children are now kept alive who would previously have died, we are obliged to help them achieve their highest quality of life. Families who care for these children need the assistance of such services as special education, physical therapies, and family counseling. Financial relief and respite care may be necessary. Institutions for raising such children need to be fully funded and staffed so as to be compassionate rather than custodial care. It is not fair to the newborn to choose a life he would not otherwise have to suffer and not choose to allocate the resources to make that life livable.³¹

Thus, a second implication which could be suggested is that some possible criticism of selective nontreatment is unjustified unless we provide the personal life enhancement to follow the biological life preservation. The more we provide for life support and enhancement, the less appropriate will selective nontreatment be. The converse may also be true. The less often means of increasing life quality are made available, the more choices not to maintain life may be justified. While ethical and/or medical decisions ought not simply reflect current structures of social justice, neither ought they be made without any reference to them. Recognizing that financial and personnel resources are not inexhaustible, allocation decisions will have to be made and consequences faced honestly.

We have seen, then, that life-biased ethics will incline us toward caution in judgment about selective nontreatment and that it urges us to expand life-enhancing services, thus increasing the number of neonates for whom a life preservation decision is appropriate. Recognizing that avoidance of death is not always the most suitable stance, we have found help in decision-making in the tradition of the ordinary-extraordinary means analysis. This has led us to see that selective nontreatment may be a moral decision when dying is irreversibly proximate, when the means of life maintenance themselves create excessive burden, and when relational potential is negligible or unable to be exercised.

Implementation

Although a complete analysis is beyond the scope of this essay, directions of thought regarding implementation of the foregoing moral analysis are offered. Issues are complex here, especially in light of excesses which are to be avoided. Two major concerns come to mind: who

is to make the decision? What legal status should such decisions have?

There is little moral or legal question over the necessity or propriety of proxy consent in the treatment of defective newborns. Paul Ramsey has recently focused attention, however, on the parameters of the acceptable range of decisions to be made as he questions the criteria used in the deliberation process. He states that both covenant loyalty to others and familial, medical, and legal obligations "require that a medical indications policy alone be applied where another, voiceless, human life is at stake."³² To do otherwise, he argues, is to open the door to quality of life judgments, to risk circularity of reasoning in the "reasonable man" approach to proxy consent, and to chance ascribing rather than discovering the best interest of the patient. Although the caution which prompts Ramsey's concern must not be set aside, we have already seen that criteria other than medical indications might morally be applied. Thus, we must cautiously enter the domain of substituted judgment.

There are at least four possible loci of decision-making: the parents, the physician, a review committee, and the courts. Each has its benefits and drawbacks. Each does, in fact, have a role to play, but the preponderance of opinion among moralists has given priority to parents. Parents, of course, do not *own* their children. They are not free morally or legally to do whatever they wish with their children. Weber correctly observes that "it is better to speak of the obligations rather than the rights of parents." Where obligation lies, there lies also a degree of priority in decision-making. "They have the obligation to care for their children and the obligation to make decisions that seriously affect the future of their children."³³ The relationship of decision and nurturing can also be noted here. Engelhardt points out that "the decisions in these matters correctly lie in the hands of the parents, because it is primarily in terms of family that children exist and develop. . . ."³⁴ Both the general obligation of parents to children and their specific role in nurturing direct us to the parents as having primary claim on the role of decision-maker.

Although at an earlier point in the development of neonatal medicine, the press of very limited time often forced physicians into the decision-making role, modern procedures make this decreasingly true. This being so, Daniel Maguire argues that the doctor may be an inappropriate person to be given a primary role in decisions due to such factors as traditional professional roles, the trend toward mixing experimentation and care, lack of specific ethical training, and fear of legal complications.³⁵ The physician does, however, have medical information necessary to make an informed decision. Facts about the infant's current status and probabilities regarding future developments must be shared with the parents. Thus, the first role of the doctor in this process is as a source of information.³⁶

A hospital review committee, made up of institutional personnel,

possibly including community representatives, has the disadvantages of emotional abstraction and the compromise nature of decision-by-committee. Such a committee, nevertheless, might play a useful role in establishing general hospital guidelines within which parents and physicians could work. Similarly, the courts represent the wider interests of society. Not always equipped to be the first voice of decision, the courts play a role in appeal of decisions at a lower level. However, if other courts follow the recent decision of the Massachusetts Supreme Judicial Court in the case of Joseph Saikewicz,³⁷ they will play a more central role than proposed here. Some ambiguity remains about the exact implications of the Saikewicz decision, but it did intend to claim to the court's jurisdiction primary decision-making prerogative in at least certain nontreatment contexts. Although it now appears to include fewer cases than first feared by many physicians and ethicists,³⁸ this ruling will result in more decisions in the courts. The more this is restricted to conflict of judgment situations mentioned below, the less will the court involve itself in actions outside its special competence.

Thus we return to the parents as primary locus of decision. Some argue that the emotional involvement of parents makes them unfit for decision. Deliberation would be swayed by rejection of the infant, growing out of shock or disappointment,³⁹ or by need to compensate due to feelings of guilt. Studies are mixed on this matter. While some show the danger does exist, others have shown it can be less of a problem than anticipated. Raymond Duff has observed that "if families regardless of background are heard sympathetically and at length and are given information and answers to their questions in words they understand, the problems of their children as well as the expected benefits and limits of any proposed care can be understood clearly in practically all instances."⁴⁰ Duff found the parental decisions to have been thoughtful and reasonable. Rosalyn Darling also found data suggesting that parents can be responsible in their judgments. Her study showed that though many parents admitted disappointment, the typical attitude came to be "realistic acceptance." In fact, she found physicians to define the situation as a tragedy more often than parents.⁴¹ Considering this possibility for careful and thoughtful decision-making by parents and noting that parental reaction may be correlated with the nature of the defect and options of community support perceived to be available,⁴² we recall the point made earlier. If we as a society wish to establish a bias toward life, we must also make commitments to provision of support and enrichment resources.

Priority in the decision-making process and the generally responsible action of parents would not, of course, guarantee that choices will always be correct. Here is the second point at which physicians and society, through review committees or the courts, may play an

important role. We have seen their role in provision of information and guidelines. Here the issue is intervention. When the parents' decision can reasonably be construed as acceptable, no steps should be taken to counter that choice. Three points of intervention may be appropriate, however: one opposing nontreatment, two pursuing it. Engelhardt argues that "society has a right to intervene and protect children for whom parents refuse care . . . when such care does not constitute a severe burden and when it is likely that the child can be brought to good quality of life."⁴³ Engelhardt views such intervention as necessary both for the sake of the specific child and with the social impact in mind that selective nontreatment in such cases could have in undermining respect and care for children in a more general sense. The link between intervention and responsibility for nurturing should be called to mind. To overrule the parents' decision may require us to provide them with counseling and community support to help them fulfill the role we are asking of them. Or we must make available adequate institutional care for children whose parents cannot or will not raise them. To intervene without such provision is unfair both to parents and children.

To intervene in favor of nontreatment may be more difficult to justify, given the recognition of parental obligation to protect and care for their children and covenantal moral and legal obligations to continue care once it is begun. Two possibilities for such intervention have been suggested and should at least be mentioned. Engelhardt proposes that a challenge to the decision to continue treatment might be appropriate where extended life for the infant would lead to enduring pain, etc., which has been lightly considered by the parents.⁴⁴ This circumstance would seem rare. Also possible is the situation brought about by the problem of allocation of scarce resources. One of the propositions put forward by the Sonoma Conference states:

In cases of limited availability of neonatal intensive care, it is ethical to terminate therapy for an infant with poor prognosis in order to provide care for an infant with a much better prognosis.⁴⁵

Such a stance is not above moral challenge.⁴⁶ We have noted above the general acceptance of the principles of parental obligation to care and the covenantal obligation of care which has begun. Applied to the situation under consideration, this would seem to mean that intervention in favor of nontreatment in such cases will probably also be infrequent. While intervention in favor of nontreatment cannot be excluded out of hand, challenge against nontreatment is more easily justified and would no doubt be the more common.

A thorough and clear legal review of selective nontreatment of defective newborns has been provided by John Robertson⁴⁷ and will not be treated extensively here. A few remarks will suffice. Direct, active taking of the life of the newborn (*not* under consideration in this essay) is clearly defined legally as murder. But participants in

selective nontreatment, family or medical personnel, could also be held criminally liable, for charges ranging from homicide to neglect to violation of child abuse laws. Although prosecution has been rare and conviction even more so, there is no assurance that it will always be so. The spotlight thrown by more public discussion of this issue may encourage legal action. With increased legal action or without it, the threat of prosecution may inhibit parents and medical personnel in their decision-making. These deliberations are difficult to carry out apart from legal considerations which affect them. If we accept as moral the decision for selective nontreatment, we must allow those who make the decisions to do so without excessive fear of the law.

Carte blanche in decision-making is neither legally nor morally acceptable. Drafting of clear and useful legislation has not moved far with regard to other contexts of decisions to allow death. There is no reason to believe it will prove easier with regard to newborns. Some argue that any legislation would prove restrictive to decisions currently made quietly in the absence of specific law. This overlooks the possible persecution under existing law and the effect on decision-making of fear of this possible legal action, but it does caution us to proceed carefully in this matter. Two suggestions are in order. First, laws which *permit* rather than *mandate* decisions are preferable. This would maintain respect for a bias toward life, avoid the spectre of assigning certain infants to death, and still allow for decisions that should be made. Second, legislation and the courts can look after the processes by which decisions are made to assure that full deliberation has taken place.⁴⁸ To involve the courts in all initial deliberations would be cumbersome, time-consuming, and counterproductive to the process being pursued. Development of fair yet cautious laws will not be necessary. But as Duff and Campbell urged in their 1973 article, "If working out these dilemmas . . . is a violation of the law, we believe the law should be changed."⁴⁹

Conclusion

Each year parents, physicians, and courts are facing questions of treatment or nontreatment of defective newborns. Developing ethical reflection, changing medical possibilities, and increasing court rulings render the decision-making process, already painful and difficult for those involved, even more complicated. Against the background of personal anguish and perplexing deliberation for those who must come to the point of decision, continued effort must go into ethical analysis and policy formulation.

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9. See, for example, Stanley Hauerwas's overextension of this analogy in his chapter "Having and Learning to Care for Retarded Children" in his *Truthfulness and Tragedy* (Notre Dame: University of Notre Dame Press, 1977), pp. 147-156. Hauerwas moderates his position somewhat in later chapters.
10. Ramsey, Paul, *The Patient as Person* (New Haven: Yale University Press, 1970), pp. 118-124; Daniel Maguire, *Death by Choice* (New York: Schocken, 1970), pp. 122-125.
11. Examples of the breadth of application of such criteria by traditional moralists are found in Charles J. McFadden, *Medical Ethics*, 6th ed. (Philadelphia: F. A. Davis Co., 1967), pp. 239-261.
12. Ramsey, *Edges*, pp. 153-160.
13. *Ibid.*, p. 155; emphasis mine. Application to non-conscious persons will be discussed below.
14. Hauerwas, *Truthfulness and Tragedy*, p. 178; Weber, *Who Shall Live?* pp. 90-91.
15. *Ibid.*, pp. 90-98.
16. Jonsen, Albert R. and Lester, George, "Newborn Intensive Care: The Ethical Problems," *Hastings Center Report*, VIII (Feb., 1978), p. 16.
17. Smith, David H., "On Letting Some Babies Die," *Hastings Center Studies*, II (May, 1974), pp. 37-46.
18. Ramsey, *Edges*, p. 194.
19. *Ibid.*, pp. 214-217; Ramsey, *Patient as Person*, pp. 161-162.
20. McCormick, "To Save or Let Die," pp. 172-176.
21. *Ibid.*, p. 175. McCormick's interpretation and application of Pope Pius XII's teaching in this regard (see above under "Assumptions") has not gone unchallenged. See, for example, Ramsey, *Edges*, pp. 172-173, footnote 33.
22. Fletcher, "Indicators of Humanhood"; "Four Indicators."
23. Nelson, *Human Medicine*, pp. 19-24.
24. Tooley, Michael, "Abortion and Infanticide," *Moral Problems in Medicine*, ed. by Samuel Gorovitz et al. (Englewood Cliffs: Prentice-Hall, 1976), pp. 297-317.
25. McCormick, "To Save or Let Die," p. 175.
26. Gustafson, James, "Mongolism, Parental Desires, and the Right to Life," *Perspectives in Biology and Medicine*, XVI (Summer, 1973), p. 550.

27. Jonsen and Lester, "Newborn Intensive Care," p. 17; Jane V. Hunt, "Mental Development and the Survivors of Neonatal Intensive Care," *Ethics of Newborn Intensive Care*, ed. by Albert R. Jonsen and Michael J. Garland (Berkeley: Institute of Government Studies, 1976), pp. 47-52.; Robert Veatch, "The Technical Criteria Fallacy," *Hastings Center Report*, VII (Aug., 1977), pp. 15-16.

28. Engelhardt, H. Tristram, Jr., "Ethical Issues in Aiding the Death of Young Children," *Beneficent Euthanasia*, Marvin Kohl, ed. (Buffalo: Prometheus Books, 1975), pp. 180-192.

29. Johnsen, A. R., et al., "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal," *Pediatrics*, LV (June, 1975), p. 760. See also Albert R. Jonsen and Michael J. Garland, "A Moral Policy for Life/Death Decisions in the Intensive Care Nursery," *Ethics of Newborn Intensive Care*, op. cit., pp. 147-149. This application of the "do no harm" principle is recent and has not met universal acceptance. See Ramsey, *Edges*, pp. 239-241.

30. Robertson, John A., "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," *Stanford Law Review*, XXVII (Jan., 1975), pp. 252-255.

31. This implication is not to be interpreted as the general demand for social justice, the case for which can be made on other grounds. It is not being argued that every child has as its birthright a fulfilled life in a just society. It is, rather, a call to provide access to a decent minimal level of personal human life for those who without aid would have little opportunity to achieve even that.

32. Ramsey, *Edges*, p. 161; see his full discussion, pp. 160-171. See also his "The Saikewicz Precedent: What's Good for an Incompetent Patient?" *Hastings Center Report*, VIII (Dec., 1978), pp. 36-42.

33. For example, Weber, *Who Shall Live?*, pp. 115-116. See also F. Raymond Marks, "The Defective Newborn: An Analytic Framework for a Policy Dialog," *Ethics of Newborn Intensive Care*, op. cit., pp. 122-123.

34. Engelhardt, "Ethical Issues," p. 184.

35. Maguire, *Death by Choice*, pp. 177-184.

36. Weber, *Who Shall Live?*, pp. 106-110.

37. Annas, George J., "The Incompetent's Right to Die: The Case of Joseph Saikewicz," *Hastings Center Report*, VIII (Feb., 1978), pp. 21-23.

38. Annas, George J., "After Saikewicz: No-Fault Death," *ibid.*, June, 1978, pp. 16-18; Ramsey, *The Saikewicz Precedent*.

39. Fletcher, John, "Attitudes Toward Defective Newborns," *Hastings Center Studies*, II (Jan., 1974), pp. 24-28; Marrianna A. Cohen, "Ethical Issues in Neonatal Care: Familial Concerns," *Ethics of Newborn Intensive Care*, op. cit., pp. 55-62.

40. Duff and Campbell, "Moral and Ethical Dilemmas," p. 893. See also Beverly Kelsey, "Which Infants Shall Live? Who Should Decide? An Interview with Dr. Raymond S. Duff," *Hastings Center Report*, V (April, 1975), pp. 5-8.

41. Darling, Rosalyn Benjamin, "Parents, Physicians and Spina Bifida," *ibid.*, VII (Aug., 1977), pp. 10-14.

42. Cohen, "Ethical Issues in Neonatal Care," pp. 57-63.

43. Engelhardt, "Ethical Issues," p. 185.

44. *Ibid.*

45. Jonsen, et al., "Critical Issues," p. 761.

46. Childress, James, "Who Shall Live When Not All Can Live?" *Soundings*, LIII (Winter, 1970), pp. 347-354; Ramsey, *Edges*, pp. 232-234.

47. Robertson, "Involuntary Euthanasia," pp. 213-269. A summary can be found in John A. Robertson and Norman Fost, "Passive Euthanasia of Defective Newborn Infants: Legal Considerations," *Journal of Pediatrics*, LXXXVIII (May, 1976), pp. 883-889.

48. *Ibid.*, pp. 888-889.

49. Duff and Campbell, "Moral and Ethical Dilemmas," p. 894.