Euthanasia in the pediatric age group involves a constellation of issues that are materially different from those of adult euthanasia. The difference lies in the somewhat obvious fact that infants and young children are not able to decide about their own futures and thus are not persons in the same sense that normal adults are. While adults usually decide their own fate, others decide on behalf of young children. Although one can argue that euthanasia is or should be a personal right, the sense of such an argument is obscure with respect to children. Young children do not have any personal rights, at least none that they can exercise on their own behalf with regard to the manner of their life and death. As a result, euthanasia of young children raises special questions concerning the standing of the rights of children, the status of parental rights, the obligations of adults to prevent the suffering of children, and the possible effects on society of allowing or expediting the death of seriously defective infants.

What I will refer to as the euthanasia of infants and young children might be termed by others infanticide, while some cases might be termed the withholding of extraordinary life-prolonging treatment. One needs a term that will encompass both death that results from active intervention and death that ensues when one simply ceases further therapy. In using such a term, one must recognize that death is often not directly but only obliquely intended. That is, one often intends only to treat no further, not actually to have death follow, even though one knows death will follow.

Finally, one must realize that deaths as the result of withholding treatment constitute a significant proportion of neonatal deaths. For example, as high as 14 percent of children in one hospital have been identified as dying after a decision was made not to treat further, the presumption being that the children would have lived longer had treatment been offered.

Even popular magazines have presented accounts of parental decisions not to pursue treatment. These decisions often involve a choice between expensive treatment with little chance of achieving a full, normal life for the child and "letting nature take its course," with the child dying as a result of its defects. As this suggests, many of these problems are products of medical progress. Such children in the past would have died. The quandaries are in a sense an embarrassment of riches; now that one can treat such defective children, must one treat them? And, if one need not treat such defective children, may one expedite their death?

I will here briefly examine some of these issues. First, I will review differences that contrast the euthanasia of adults to euthanasia of children. Second, I will review the issue of the rights of parents and the status of children. Third, I will suggest a new notion, the concept of the "injury of continued existence," and draw out some of its implications with respect to a duty to prevent suffering. Finally, I will outline some important questions that remain unanswered even if the foregoing issues can be settled. In all, I hope more to display the issues involved in a difficult question than to advance a particular set of answers to particular dilemmas.

For the purpose of this paper, I will presume that adult euthanasia can be justified by an appeal to freedom. In the face of imminent death, one is usually choosing between a more painful and more protracted dying and a less painful or less protracted dying, in circumstances where either choice makes little difference with regard to the discharge of social duties and responsibilities. In the case of suicide, we might argue that, in general, social duties (for example, the duty to support one's family) restrain one
from taking one's own life. But in the face of imminent death and in the
presence of the pain and deterioration of a fatal disease, such duties are
usually impossible to discharge and are thus rendered moot. One can, for
example, picture an extreme case of an adult with a widely disseminated
carcinoma, including metastases to the brain, who because of severe pain
and debilitation is no longer capable of discharging any social duties. In
these and similar circumstances, euthanasia becomes the issue of the right
to control one's own body, even to the point of seeking assistance in sui-
cide. Euthanasia is, as such, the issue of assisted suicide, the universaliza-
tion of a maxim that all persons should be free, in extremis, to decide with
regard to the circumstances of their death.

Further, the choice of positive euthanasia could be defended as the
more rational choice: the choice of a less painful death and the affirmation
of the value of a rational life. In so choosing, one would be acting to set
limits to one's life in order not to live when pain and physical and mental
deterioration make further rational life impossible. The choice to end
one's life can be understood as a noncontradictory willing of a smaller set
of states of existence for oneself, a set that would not include a painful
death. As such, it would not involve a desire to destroy oneself. That is,
adult euthanasia can be construed as an affirmation of the rationality and
autonomy of the self.7

The remarks above focus on the active or positive euthanasia of
adults. But they hold as well concerning what is often called passive or
negative euthanasia, the refusal of life-prolonging therapy. In such cases,
the patient's refusal of life-prolonging therapy is seen to be a right that de-

erives from personal freedom, or at least from a zone of privacy into which
there are no good grounds for social intervention.8

Again, none of these considerations apply directly to the euthanasia
of young children, because they cannot participate in such decisions.
Whatever else pediatric, in particular neonatal, euthanasia involves, it
surely involves issues different from those of adult euthanasia. Since
infants and small children cannot commit suicide, their right to assisted
suicide is difficult to pose. The difference between the euthanasia of young
children and that of adults resides in the difference between children and
adults. The difference, in fact, raises the troublesome question of whether
young children are persons, or at least whether they are persons in the
sense in which adults are. Answering that question will resolve in part at
least the right of others to decide whether a young child should live or die
and whether he should receive life-prolonging treatment.

THE STATUS OF CHILDREN

Adults belong to themselves in the sense that they are rational and free
and therefore responsible for their actions. Adults are sui juris. Young
children, though, are neither self-possessed nor responsible. While adults
exist in and for themselves, as self-directive and self-conscious beings,
young children, especially newborn infants, exist for their families and
those who love them. They are not, nor can they in any sense be, respon-
sible for themselves. If being a person is to be a responsible agent, a bearer
of rights and duties, children are not persons in a strict sense. They are,
rather, persons in a social sense: others must act on their behalf and bear
responsibility for them. They are, as it were, entities defined by their place
in social roles (for example, mother-child, family-child) rather than beings
that define themselves as persons, that is, in and through themselves.
Young children live as persons in and through the care of those who are
responsible for them, and those responsible for them exercise the children's
rights on their behalf. In this sense children belong to families in ways that
most adults do not. They exist in and through their family and society.

Treating young children with respect has, then, a sense different from
treating adults with respect. One can respect neither a newborn infant's or
very young child's wishes nor its freedom. In fact, a newborn infant or
young child is more an entity that is valued highly because it will grow to be
a person and because it plays a social role as if it were a person.9 That
is, a small child is treated as if it were a person in social roles such as
mother-child and family-child relationships, though strictly speaking the
child is in no way capable of claiming or being responsible for the rights
imputed to it. All the rights and duties of the child are exercised and
"held in trust” by others for a future time and for a person yet to develop.

Medical decisions to treat or not to treat a neonate or small child
often turn on the probability and cost of achieving that future status—a
developed personal life. The usual practice of letting anencephalic chil-
dren (who congenitally lack all or most of the brain) die can be understood
as a decision based on the absence of the possibility of achieving a per-
sonal life. The practice of refusing treatment to at least some children
born with meningomyelocele can be justified through a similar, but more
utilitarian, calculus. In the case of anencephalic children one might argue
that care for them as persons is futile since they will never be persons. In
the case of a child with meningomyelocele, one might argue that when the
cost of cure would likely be very high and the probable lifestyle open to
attainment very truncated, there is not a positive duty to make a large investment of money and suffering. One should note that the cost here must include not only financial costs but also the anxiety and suffering that prolonged and uncertain treatment of the child would cause the parents.

This further raises the issue of the scope of positive duties not only when there is no person present in a strict sense, but when the likelihood of a full human life is also very uncertain. Clinical and parental judgment may and should be guided by the expected lifestyle and the cost (in parental and societal pain and money) of its attainment. The decision about treatment, however, belongs properly to the parents because the child belongs to them in a sense that it does not belong to anyone else, even to itself. The care and raising of the child falls to the parents, and when considerable cost and little prospect of reasonable success are present, the parents may properly decide against life-prolonging treatment.

The physician’s role is to present sufficient information in a usable form to the parents to aid them in making a decision. The accent is on the absence of a positive duty to treat in the presence of severe inconvenience (costs) to the parents; treatment that is very costly is not obligatory. What is suggested here is a general notion that there is never a duty to engage in extraordinary treatment and that “extraordinary” can be defined in terms of costs. This argument concerns children (1) whose future quality of life is likely to be seriously compromised and (2) whose present treatment would be very costly. The issue is that of the circumstances under which parents would not or would be obligated to take on severe burdens on behalf of their children or those circumstances under which society would not or would be obligated. The argument should hold as well for those cases where the expected future life would surely be of normal quality, though its attainment would be extremely costly. The fact of little likelihood of success in attaining a normal life for the child makes decisions to do without treatment more plausible because the hope of success is even more remote and therefore the burden borne by parents or society becomes in that sense more extraordinary. But very high costs themselves could be a sufficient criterion, though in actual cases judgments in that regard would be very difficult when a normal life could be expected.10

The decisions in these matters correctly lie in the hands of the parents, because it is primarily in terms of the family that children exist and develop—until children become persons strictly, they are persons in virtue of their social roles. As long as parents do not unjustifiably neglect the humans in those roles so that the value and purpose of that role (that is, child) stands to be eroded (thus endangering other children), society need not intervene. In short, parents may decide for or against the treatment of their severely deformed children.

However, society has a right to intervene and protect children for whom parents refuse care (including treatment) when such care does not constitute a severe burden and when it is likely that the child could be brought to a good quality of life. Obviously, “severe burden” and “good quality of life” will be difficult to define and their meanings will vary, just as it is always difficult to say when grains of sand dropped on a table constitute a heap. At most, though, society need only intervene when the grains clearly do not constitute a heap, that is, when it is clear that the burden is light and the chance of a good quality of life for the child is high. A small child’s dependence on his parents is so essential that society need intervene only when the absence of intervention would lead to the role “child” being undermined. Society must value mother-child and family-child relationships and should intervene only in cases where (1) neglect is unreasonable and therefore would undermine respect and care for children, or (2) where societal intervention would prevent children from suffering unnecessary pain.11

THE INJURY OF CONTINUED EXISTENCE

But there is another viewpoint that must be considered: that of the child or even the person that the child might become. It might be argued that the child has a right not to have its life prolonged. The idea that forcing existence on a child could be wrong is a difficult notion, which, if true, would serve to amplify the foregoing argument. Such an argument would allow the construal of the issue in terms of the perspective of the child, that is, in terms of a duty not to treat in circumstances where treatment would only prolong suffering. In particular, it would at least give a framework for a decision to stop treatment in cases where, though the costs of treatment are not high, the child’s existence would be characterized by severe pain and deprivation.

A basis for speaking of continuing existence as an injury to the child is suggested by the proposed legal concept of "wrongful life." A number of suits have been initiated in the United States and in other countries on the grounds that life or existence itself is, under certain circumstances, a tort or injury to the living person.12 Although thus far all such suits have ulti-
mately failed, some have succeeded in their initial stages. Two examples may be instructive. In each case the ability to receive recompense for the injury (the tort) presupposed the existence of the individual, whose existence was itself the injury. In one case a suit was initiated on behalf of a child against his father alleging that his father’s siring him out of wedlock was an injury to the child. In another case a suit on behalf of a child born of an inmate of a state mental hospital impregnated by rape in that institution was brought against the state of New York. The suit was brought on the grounds that being born with such historical antecedents was itself an injury for which recovery was due. Both cases presupposed that non-existence would have been preferable to the conditions under which the person born was forced to live.

The suits for tort for wrongful life raise the issue not only of when it would be preferable not to have been born but also of when it would be wrong to cause a person to be born. This implies that someone should have judged that it would have been preferable for the child never to have had existence, never to have been in the position to judge that the particular circumstances of life were intolerable. Further, it implies that the person’s existence under those circumstances should have been prevented and that, not having been prevented, life was not a gift but an injury. The concept of tort for wrongful life raises an issue concerning the responsibility for giving another person existence, namely, the notion that giving life is not always necessarily a good and justifiable action. Instead, in certain circumstances, so it has been argued, one may have a duty not to give existence to another person. This concept involves the claim that certain qualities of life have a negative value, making life an injury, not a gift; it involves, in short, a concept of human accountability and responsibility for human life. It contrasts with the notion that life is a gift of God and thus similar to other “acts of God,” (that is, events for which no man is accountable). The concept thus signals the fact that humans can now control reproduction and that where rational control is possible humans are accountable. That is, the expansion of human capabilities has resulted in an expansion of human responsibilities such that one must now decide when and under what circumstances persons will come into existence.

The concept of tort for wrongful life is transferable in part to the painfully compromised existence of children who can only have their life prolonged for a short, painful, and marginal existence. The concept suggests that allowing life to be prolonged under such circumstances would itself be an injury of the person whose painful and severely compromised existence would be made to continue. In fact, it suggests that there is a duty not to prolong life if it can be determined to have a substantial negative value for the person involved. Such issues are moot in the case of adults, who can and should decide for themselves. But small children cannot make such a choice. For them it is an issue of justifying prolonging life under circumstances of painful and compromised existence. Or, put differently, such cases indicate the need to develop social canons to allow a decent death for children for whom the only possibility is protracted, painful suffering.

I do not mean to imply that one should develop a new basis for civil damages. In the field of medicine, the need is to recognize an ethical category, a concept of wrongful continuance of existence, not a new legal right. The concept of injury for continuance of existence, the proposed analogue of the concept of tort for wrongful life, presupposes that life can be of a negative value such that the medical maxim primum non nocere (“first do no harm”) would require not sustaining life.

The idea of responsibility for acts that sustain or prolong life is cardinal to the notion that one should not under certain circumstances further prolong the life of a child. Unlike adults, children cannot decide with regard to euthanasia (positive or negative), and if more than a utilitarian justification is sought, it must be sought in a duty not to inflict life on another person in circumstances where that life would be painful and futile. This position must rest on the facts that (1) medicine now can cause the prolongation of the life of seriously deformed children who in the past would have died young and that (2) it is not clear that life so prolonged is a good for the child. Further, the choice is made not on the basis of costs to the parents or to society but on the basis of the child’s suffering and compromised existence.

The difficulty lies in determining what makes life not worth living for a child. Answers could never be clear. It seems reasonable, however, that the life of children with diseases that involve pain and no hope of survival should not be prolonged. In the case of Tay-Sachs disease (a disease marked by a progressive increase in spasticity and dementia usually leading to death at age three or four), one can hardly imagine that the terminal stages of spastic reaction to stimuli and great difficulty in swallowing are at all pleasant to the child (even insofar as it can only minimally perceive its circumstances). If such a child develops aspiration pneumonia and is treated, it can reasonably be said that to prolong its life is to inflict suffering. Other diseases give fairly clear portraits of lives not worth living:
for example, Lesch-Nyhan disease, which is marked by mental retardation and compulsive self-mutilation.

The issue is more difficult in the case of children with diseases for whom the prospects for normal intelligence and a fair lifestyle do exist, but where these chances are remote and their realization expensive. Children born with meningoencephalocele present this dilemma. Imagine, for example, a child that falls within Lorber’s fifth category (an IQ of sixty or less, sometimes blind, subject to fits, and always incontinent). Such a child has little prospect of anything approaching a normal life, and there is a good chance of its dying even with treatment. But such judgments are statistical. And if one does not treat such children, some will still survive and, as John Freeman indicates, be worse off if not treated. In such cases one is in a dilemma. If one always treats, one must justify extending the life of those who will ultimately die anyway and in the process subjecting them to the morbidity of multiple surgical procedures. How remote does the prospect of a good life have to be in order not to be worth great pain and expense? It is probably best to decide, in the absence of a positive duty to treat, on the basis of the cost and suffering to parents and society. But, as Freeman argues, the prospect of prolonged or even increased suffering raises the issue of active euthanasia.

If the child is not a person strictly, and if death is inevitable and expediting it would diminish the child’s pain prior to death, then it would seem to follow that, all else being equal, a decision for active euthanasia would be permissible, even obligatory. The difficulty lies with “all else being equal,” for it is doubtful that active euthanasia could be established as a practice without eroding and endangering children generally, since, as John Lorber has pointed out, children cannot speak in their own behalf. Thus, although there is no argument in principle against the active euthanasia of small children, there could be an argument against such practices based on questions of prudence. To put it another way, even though one might have a duty to hasten the death of a particular child, one’s duty to protect children in general could override that first duty. The issue of active euthanasia turns in the end on whether it would have social consequences that refraining would not, on whether (1) it is possible to establish procedural safeguards for limited active euthanasia and (2) whether such practices would have a significant adverse effect on the treatment of small children in general. But since these are procedural issues dependent on sociological facts, they are not open to an answer within the confines of this article. In any event, the concept of the injury of continued existence provides a basis for the justification of the passive euthanasia of small children—a practice already widespread and somewhat established in our society—beyond the mere absence of a positive duty to treat.

CONCLUSION

Though the lack of certainty concerning questions such as the prognosis of particular patients and the social consequence of active euthanasia of children prevents a clear answer to all the issues raised by the euthanasia of infants, it would seem that this much can be maintained: (1) Since children are not persons strictly but exist in and through their families, parents are the appropriate ones to decide whether or not to treat a deformed child when (a) there is not only little likelihood of full human life but also great likelihood of suffering if the life is prolonged, or (b) when the cost of prolonging life is very great. Such decisions must be made in consort with a physician who can accurately give estimates of cost and prognosis and who will be able to help the parents with the consequences of their decision. (2) It is reasonable to speak of a duty not to treat a small child when such treatment will only prolong a painful life or would in any event lead to a painful death. Though this does not by any means answer all the questions, it does point out an important fact—that medicine’s duty is not always to prolong life doggedly but sometimes is quite the contrary.

NOTES

1. I am grateful to Laurence B. McCullough and James P. Morris for their critical discussion of this paper. They may be responsible for its virtues, but not for its shortcomings.

2. The concept of extraordinary treatment as it has been developed in Catholic moral theology is useful: treatment is extraordinary and therefore not obligatory if it involves great costs, pain, or inconvenience, and is a grave burden to oneself or others without a reasonable expectation that such treatment would be successful. See Gerald Kelly, S. J., Medico-Moral Problems (St. Louis: The Catholic Hospital Association Press, 1958), pp. 128-141. Difficulties are hidden in terms such as “great costs” and “reasonable expectation,” as well as in terms such as “successful.” Such ambiguity reflects the fact that precise operational definitions are not available. That is, the precise meaning of “great,” “reasonable,” and “successful” are inextricably bound to particular circumstances, especially particular societies.

3. I will use the term euthanasia in a broad sense to indicate a deliberately chosen course of action or inaction that is known at the time of decision to be such
as will expedite death. This use of euthanasia will encompass not only positive or active euthanasia (acting in order to expedite death) and negative or passive euthanasia (refraining from action in order to expedite death), but acting and refraining in the absence of a direct intention that death occur more quickly (that is, those cases that fall under the concept of double effect). See note 4.

4. But, both active and passive euthanasia can be appreciated in terms of the Catholic moral notion of double effect. When the doctrine of double effect is invoked, one is strictly not intending euthanasia, but rather one intends something else. That concept allows actions or omissions that lead to death (1) because it is licit not to prolong life in extremis (allowing death is not an intrinsic evil), (2) if death is not actually willed or actively sought (that is, the evil is not directly willed), (3) if that which is willed is a major good (for example, avoiding useless major expenditure of resources or serious pain), and (4) if the good is not achieved by means of the evil (for example, one does not will to save resources or diminish pain by the death). With regard to euthanasia the doctrine of double effect means that one need not expend major resources in an endeavor that will not bring health but only prolong dying and that one may use drugs that decrease pain but hasten death. See Richard McCormick, Ambiguity in Moral Choice (Milwaukee: Marquette University Press, 1973). I exclude the issue of double effect from my discussion because I am interested in those cases in which the good may follow directly from the evil—the death of the child. In part, though, the second section of this paper is concerned with the concept of proportionate good.


7. This somewhat Kantian argument is obviously made in opposition to Kant’s position that suicide involves a default of one’s duty to oneself “… to preserve his life simply because he is a person and must therefore recognize a duty to himself (and a strict one at that),” as well as a contradictory vocation: “that man ought to have the authorization to withdraw himself from all obligation, that is, to be free to act as if no authorization at all were required for this withdrawal, involves a contradiction. To destroy the subject of morality in his own person is tantamount to obliterating from the world…” Immanuel Kant, The Metaphysical Principles of Virtue: Part II of the Metaphysics of Morals, trans. James Ellington (Indianapolis: Bobbs-Merrill, 1964), p. 83; Academie Edition, VI, 422-423.


9. By “young child” I mean either an infant or child so young as not yet to be able to participate, in any sense, in a decision. A precise operational definition of “young child” would clearly be difficult to develop. It is also not clear how one would bring older children into such decisions. See, for example, Milton Vieder- man, “Saying ‘No’ to Hemodialysis: Exploring Adaptation,” and Daniel Burke, "Aiding the Death of Young Children"


24. Positive duties involve a greater constraint than negative duties. Hence it is often easier to establish a duty not to do something (not to treat further) than a duty to do something (to actively hasten death). Even allowing a new practice to be permitted (for example, active euthanasia) requires a greater attention to consequences than does establishing the absence of a positive duty. For example, at common law there is no basis for action against a person who watches another drown without giving aid; this reflects the difficulty of establishing a positive duty.

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Joe P. Tupin

Some Psychiatric Issues of Euthanasia

It is generally agreed that each of us has a right to life. It is somewhat new to consider that we also have a right to death. The second of these two rights constitutes perhaps the most unique and important aspect of freedom, a freedom to say yes to death. Little argument is raised about a person’s right to exercise this freedom when it involves volunteering for dangerous duty during a war or civil disaster. Much more controversial is the person’s right to exercise that freedom when desperately ill or in pain. In fact, preservation of life is pursued, often even over the protests of the patient, with a dedication, even vengeance, that ignores those qualities of life desired by many. Since these issues are dealt with elsewhere in this book, I propose to start with the assumption that a person does have a right to consent to his own death, and will proceed to discuss some practicalities related to the exercise of that freedom. In most situations the decision is not a clearcut choice between cure and death or even significant remission.