

COMMITTEE II

The Value of Human Life

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**HARD CHOICES:
ETHICAL QUESTIONS RAISED BY THE BIRTH OF
HANDICAPPED INFANTS**

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by Helga Kuhse and Peter Singer *

I. THE ISSUE

We are now able to sustain the lives of many seriously ill or handicapped infants who, only a decade or two ago, would have died soon after birth because the means were not available to keep them alive. Not all seriously ill or handicapped infants will benefit from treatment, however. Some infants born very prematurely or with severe abnormalities cannot survive for long despite the most aggressive efforts to keep them alive; others will survive with severe handicaps either as part of their condition or as the result of efforts to sustain their lives. [1] With medicine's increased ability to delay or prevent death, an old question is raised with renewed urgency: Must every human life, regardless of its quality or kind, always be preserved, or are there times when an infant should be allowed, or helped, to die?

The following case will provide a background to these questions.

The Danville Siamese Twins

In May 1981, severely deformed Siamese twins were born in Danville/Illinois; the twins shared a lower body, intestinal tract, and had three legs between them - one normal leg each and a fused leg with too many toes. One of the twins had two holes in the heart. Both had trouble breathing and they had to be fed intravenously. The parents and their doctor decided that the twins should be allowed to die. However, against expectations, the twins did not die when medical treatment was withdrawn. When nourishment was withheld an anonymous telephone caller alerted authorities and the parents and their doctor were subsequently charged with conspiracy to commit murder. (2)

The above case raises difficult ethical questions. Here are some of these questions:

- Does all human life have the same value; and should we always attempt to sustain life, irrespective of its quality?
- If life should not always be sustained, how severe must a handicap or abnormality be before life-sustaining treatment may be foregone?

- If the decision is made to withdraw or withhold treatment, should we merely allow the infant to die, or should we take positive steps to help her die?
- Who should make the decision? The parents? The doctors? The courts?
- Whose interests should be taken into account - only those of the baby or those of the family as well?

To discuss these questions adequately would require a book, not a single article. (3) Here we can do little more than show the problems, sketch our views and state the reasons why we hold them.

II. DOES ALL HUMAN LIFE HAVE THE SAME VALUE?

The 'Sanctity-of-Life' View

People often say that human life has 'sanctity'. But what does 'sanctity' mean and does all human life possess this sanctity equally? Not everyone who speaks of the 'sanctity of life' subscribes the same doctrine; rather people hold a cluster of related ideas. Nevertheless, most supporters of the 'sanctity-of-life' view agree in rejecting claims that one human life is more valuable than another. For Dr. Moshe Tendler, a professor of Talmudic law, all life is of infinite value:

"...human life is of infinite value. This in turn means that a piece of infinity is also infinity, and a person who has but a few minutes to live is no less of value than a person who has but 60 years to live....a handicapped individual is a perfect specimen when viewed in an ethical context. The value is an absolute value. It is not relative to life expectancy, to state of health, or to usefulness to society." (4)

The Protestant theologian Paul Ramsey, Professor of Religion at Princetown University, takes a similar view.

"....there is no reason for saying that (six months in the life of a baby born with the invariably fatal Tay Sachs disease) are a life span of lesser worth to God than living seventy years before the onset of irreversible degeneration. A genuine humanism would say the same thing in other language. It is only a reductive naturalism or social utilitarianism that would regard those months of infant life as worthless because they lead to nothing on a time line of earthly achievement. All our days and years are of equal worth whatever the consequence; death is no more a tragedy at one time than at another time." (5)

Not everybody believes that life has infinite value, that a day, hour, or even second of life is as valuable as a life-time. Most of us would, we take it, be indifferent to our life being shortened by one second, but we are very far from indifferent to the thought that our life might be cut short by 10 or 20 years.

But there is another way of understanding the notion of the 'sanctity-of-life'. 'Sanctity-of-life' is frequently understood to mean that all human life, irrespective of its quality or kind, is equally valuable. On this view, the life of a severely deformed Siamese twin or of a severely mentally handicapped infant is no less valuable than that of a normal baby, or of any other patient.

The view that all human life has equal worth is deeply rooted in many people's pre-reflective thinking and is enshrined in the law. The central idea is well expressed by Sanford Kadish when he describes the view of human life taken by Anglo-American law:

"all human lives must be regarded as having an equal claim to preservation simply because life is an irreducible value. Therefore, the value of a particular life, over and above the value of life itself may not be taken into account."(6)

This view of the equal value of all human lives was at the basis of the criminal charges instigated against the doctor and parents of the Danville Siamese twins. While the Illinois State Attorney acknowledged that everyone may have acted from the best of motives when deciding that the infants should be allowed to die, he held:

'Motive has nothing to do with it. Quality of life has nothing to do with it. Under no circumstances do you take life because you disagree with the quality of it. These kids have lived and are human beings. They are entitled to life as long as nature gives it to them.'[2]

And, when awarding custody of the twins to the Family Service bureau, the Judge agreed that he felt compassion for all involved, but also stated that it was not up to the juvenile court to make philosophical judgments:

'(The Court) must follow a constitution of Illinois and of the United States, each of which contains a bill of rights. These bills of rights give every newborn Siamese twins with severe abnormalities an inalienable right to live.'[2]

In this case, the court rejected quality-of-life considerations and upheld the equal value of all human life. As a consequence, two severely handicapped infants were kept alive against the wishes of the parents and irrespective of the infants' prospects to ever lead independent and minimally satisfying lives.

The view that all human life has equal worth may well be the simplest answer to the difficult issues raised about the treatment of infants born seriously ill or with major handicaps; but there are two questions that need to be asked about this simple answer. First, does anybody really believe that all human life has sanctity or equal worth and that the quality of the life in question does not count? Secondly, does this view have a sound ethical basis? For the moment, we shall focus on the first question, leaving the theoretical issues for Section III.

Implicit quality-of-life judgments

The question of whether anybody really believes that all human life has equal worth was raised by the so-called "Baby-Doe Regulations", introduced by the Federal Government of the United States of America in 1982 to prevent discriminatatory medical treatment of handicapped infants. The government was propelled into action by the death of "Baby Doe".

Baby Doe

Baby Doe was born on April 9, 1982, in Bloomington, Indiana, with Down's syndrome and an oesophageal atresia [the passage from the mouth to the stomach was not properly formed]. Without surgery to repair the defect such a baby will die. The prospects for successful surgery were fairly good but, even if surgery were performed, the baby's mental retardation would of course be unaffected. For this reason, the parents - supported by one of the doctors - decided against surgery. Baby Doe died on April 14, five days after his birth.[7]

Following Baby Doe's death, the Reagan administration took steps to ensure that handicapped infants would not, in future, be denied life-sustaining treatment.

In a 'Notice to Health Care Providers' and the subsequent so-called "Baby-Doe Regulations" hospital administrators were reminded that it was unlawful under Section 504 of the Rehabilitation Act of 1973:

"for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if

1. the withholding is based on the fact that the
infant is handicapped; and

2. the handicap does not render treatment or nutritional sustenance contra-indicated."[8]

In other words, the Reagan administration suggested that no matter how severe an infant's handicap, the efforts made to preserve her life must be no less than those made to preserve a non-handicapped infant's life in an otherwise similar condition. As Dr. C.Everett Koop, Surgeon General of the United States, put it when commenting on the government initiatives:

"This is a fight for a principle of this country - that every life is individually and uniquely sacred." [9]

But, American paediatricians were beginning to ask, did the guidelines require doctors to try and keep every infant alive - no matter what her prospects? To clarify this and other questions, the American Academy of Pediatrics took the Regan administration to court. When raising the question of the guideline's scope, the Academy referred to a number of conditions, including anencephaly when an infant is born with most or all of the brain missing. Many of these babies die at birth or soon after, but some have lived for a week or two. With modern life-sustaining means, it would be possible to keep them alive for indefinite periods. But the absence, or

virtual absence, of a brain means that even if such infants were to be kept alive, they would never be able to have conscious experiences, or respond in any way to other human beings.

Another condition mentioned by the Academy was one in which the infant lacks a substantial part of the digestive tract, for instance its intestine or bowels. The infant cannot be fed by mouth, for it will not obtain anything of nutritional value. It is not possible to correct the condition by surgery. Feeding such infants by means of an intravenous infusion directly into the bloodstream will ^ekeep them alive, but nutritional deficiencies are likely and the long-term prospects are poor.

At the Court hearing, the Department of Health and Human Services denied that doctors would be compelled to provide life-sustaining treatment in these extreme cases. The chief spokesperson for the Department's position was Dr. C. Everett Koop, himself an experienced paediatric surgeon and a supporter of the "Right to Life" movement. Referring to the case of a child having "essentially no intestine", Dr. Koop said:

"these regulations never intended that such a child should be put on hyper-alimentation [i.e., be artificially nourished] and carried for a year and a half.

Incidentally, I was the first physician that ever did that, so I know whereof I speak. And we would consider customary care in that child the provision of a bed, of food by mouth, knowing that it was not going to be nutritious, but not just shutting off the care of that child....nor do we intend to say that this child should be carried on intravenous fluids for the rest of its life."

Dr. Koop made a similar remark about the other case mentioned by the Academy, that of an infant born with most or all of her brain missing:

"We would not attempt to interfere with anyone dealing with that child. We think it should be given loving attention and would expect it to expire in a short time."[10]

But Dr. Koop's view that these infants should not be kept alive is at odds with the belief that all human lives are of equal worth. For example, in the passage quoted above, Dr. Koop referred to the possibility of "carrying" an infant without an intestine for "a year-and-a-half"; yet Dr. Koop did not say that doctors should sustain such an infant's life. But why not? Would he not think an

18-months extension of life worthwhile for a normal child, or for a normal adult? If he would, the obvious explanation for his different view in the first case is that he does not regard the life of an artificially nourished infant as valuable as that of a normal infant or normal adult.

'Medical Decisions'

It is sometimes thought that the decision to refrain from employing life-sustaining procedures in the case of, say, infants born without intestines or brains is but a medical decision, which does not involve quality-of-life judgments. In its defence of the "Baby Doe Regulations", the Reagan administration resorted to this type of argument.

When the Court found [on procedural grounds] in favour of the American Academy of Pediatrics, the Department of Health and Human Services issued a new "Proposed Rule" in July 1983. The new rule gave considerably more information on the circumstances in which it was to apply. In particular, it stated that 'futile therapies which merely temporarily prolong the process of dying' in an infant born with anencephaly or intra-cranial bleeding need not be employed.

"Such medical decisions, by medical personnel and parents, concerning whether to treat, and if so what form the treatment should take, are outside the scope of Section 504." [11]

In other words, the Department suggested that in these cases treatment is futile because it will only temporarily avert death; and what is 'futile' is, according to the Department, a 'medical decision'.

But this will not do. Sophisticated modern techniques could indefinitely prolong the lives of children with anencephaly or intra-cranial bleeding. The judgment that someone whose life could indefinitely be prolonged by available medical means is 'terminally ill' and therefore should not have his or her life prolonged is not a medical judgment; it is an ethical judgment about the desirability of prolonging that particular life.

Could the Department defend its view by saying that whether a patient is terminally ill is a medical judgment, based on the fact that the patient can survive only with the help of medical treatment? We think not. For if one were to take that view, then also a patient suffering from diabetes, would be 'terminally ill' and doctors would not be required to provide 'futile' therapy. The fact that no-one in their right mind would regard insulin therapy as 'futile' should make us realize that judgments about the futility of treatment are not

purely medical judgments based on the prospects of extending the patient's life, but are rather judgments concerning the desirability of extending a life that is of a certain quality or kind.

Also the "Proposed Rule" has since been struck down by a federal court. The Department of Health and Human Services' appeal of this decision is at the time of writing still pending before the Supreme Court.

In the meanwhile, the Department has introduced a final rule under an amendment to the Child Abuse and Prevention Act. This rule, which is now in effect, recognizes a number of exceptions in the provision of life-sustaining treatment. It says, for example, that treatment is not required when "the infant is chronically and irreversibly comatose"[12]. But this is, of course, again a quality-of-life judgment: a comatose infant's life need not be prolonged because comatose life is judged to be different and less valuable than conscious or self-conscious life.

Ordinary and Extraordinary Means

There is yet another way in which supporters of the view that all

human lives are equally valuable make implicit quality-of-life judgments. This is the traditional Catholic distinction between ordinary and extraordinary means of treatment. Here it is claimed that there is no moral obligation to use "extraordinary means" of treatment; our obligations extend only to the provision of "ordinary means". Since it would require "extraordinary means" to keep alive an infant with virtually no brain or without an intestine, it is ethically acceptable to provide only ordinary care, and allow the infants to die.

The Catholic theologian Leonard Weber has discussed the ethical issues raised by the birth of seriously handicapped infants in his book Who Shall Live? [13] Weber explicitly rejects the view that decision making ought to be based on quality-of-life considerations. A quality-of-life approach, he says, offends against the equality of all human lives; the "extraordinary-means-approach", on the other hand, will offer some protection against an

"arbitrary decision being made on the basis of a judgment about the worth of a particular type of life. The decision will still be difficult and may still involve judgments about what constitutes successful treatment, but the focus on means is a constant reminder that we should not decide who should live or die on the basis of the worth of someone's life." [14]

What, then, is according to Weber extraordinary treatment? For handicapped infants, Weber holds, treatment is extraordinary or non-obligatory when it does not offer a reasonable hope of success, when it imposes an excessive burden in terms of, for example, repeated surgical interventions, or if such treatment leaves the child seriously handicapped:

"If, for example, the oxygen supply to the brain has been stopped and the opportunity to resuscitate such a person only comes when it is probable that extensive damage has already been done to the brain, it should be considered an extraordinary means to attempt to restore normal blood circulation, no matter how common the procedure." [15]

While Weber recognizes that others might want to say that non-resuscitation in this case involves a quality-of-life judgment, he nonetheless thinks it is the treatment which imposes an extraordinary burden. As he puts it, the child "would not have this burden if it were not for this treatment now." [16]

But the "burden" Weber speaks of is, of course, the infant's medical condition - the kind of life the infant will have after

resuscitation. The future quality of the infant's life leads Weber to call the treatment "extraordinary" and hence non-obligatory. But if that is so, then he is - regardless of the terminology used - making a quality-of-life judgment.

Quality-of-life criteria are also implicit in the now classical definition, by the Jesuit theologian Gerald Kelly, of 'extraordinary treatment' as:

"all medicines, treatments and operations, which cannot be obtained without excessive expense, pain or inconvenience, or which, if used, would not offer a reasonable hope of benefit." [17]

Take the terms "excessive" or "benefit". How do we determine whether a life-sustaining treatment is excessively expensive or burdensome, or whether it will benefit a particular patient? Initially, we might want to say that a treatment benefits a patient if it sustains her life. But is a longer life always of benefit to a patient? We think not - and neither do those who rely the distinction between ordinary and extraordinary means. Whether a treatment is of benefit depends on the patient's medical condition

and on whether it can provide the patient with an acceptable quality of life. Even the Catholic Church acknowledges this when, in the Vatican's Declaration on Euthanasia, it is stated that it might be better to speak not of "extraordinary" but of "disproportionate means" of treatment. [18] But when is a treatment disproportionately expensive or burdensome - or, in the language of Gerald Kelly - "excessively" so? Quite clearly, the answer to this question will vary in accordance with the patient's medical condition, with the quality and quantity of life available to the patient with or after treatment. An unpleasant operation, for example, might be disproportionately burdensome for a terminally ill patient because it will extend an already burdensome life by only a short period. On the other hand, if a patient were by the same operation to gain another 20 or 30 years of normal life, then the operation would not be disproportionately burdensome.

The upshot is that the distinction between ordinary and extraordinary means [or between proportionate and disproportionate means] has little to do with "means" - considered simply as means - but much with the prospects of particular patients, including the patient's prospective quality of life.

We conclude that even those who claim that all human life is of equal worth do not, in practice, take this rhetoric seriously.

Can the claim be defended that all human life is of equal worth? We do not think so. In the following we state our reasons for that view.

III. WHY WE SHOULD REJECT THE SANCTITY-OF-LIFE VIEW

What's special about human life?

We have already noted that even those who speak of the 'sanctity-of-life' do not take their rhetoric seriously. In various ways, quality-of-life considerations enter into their life and death decisions. We should, however, also notice something else. Those who speak of the 'sanctity-of-life' do not really mean to say that all life is sacred or has the same value. It is human life which they see as sacred; they are not generally saying that the life of a sheep, chicken, earthworm or lettuce has the same value as the life of a human being. While this may seem quite obvious, we should keep this fact in mind because it

will remind us that even those who want to rank all human life equally are making different judgments about the value of different lives. The fact that they are making such judgments entitles us to ask what the distinctions are based on; or, to put the question differently, what is it that gives value to human life, but not - or not to the same degree - to the lives of other living things?

Two answers are possible. The first answer is that human life has sanctity simply because it is human life, that is, because it is the life of a member of the species homo sapiens. The second answer is that human life has special value because humans are rational, autonomous, purposeful, moral beings, with hopes, ambitions, life-purposes, ideals, and so on. Any of these qualities, or a combination of them, could serve as the basis for a moral distinction between human beings and lettuces or chickens. That such distinguishing qualities are needed is clear: for if the value of life were based on mere 'life', rather than on one or more of the above characteristics, every life - including the earthworm's or the lettuce's - would be equally valuable.

It is not difficult to see that the second answer does point to a morally relevant difference between some lives and others. For

example, it is quite plausible to hold that the life of a self-aware, rational, purposeful being that sees itself as existing over time is more valuable than the life of an entity or being who lacks these characteristics. But here we must note the following: if one takes this approach, then one is not saying that human life has sanctity, but rather that rationality, the capacity to be moral or purposeful, the capacity for the holding of ideals, and so on has "sanctity". Of course, one may still hold that human life has sanctity or special value, but only insofar as bodily life is a precondition for rationality, purposiveness, or whatever else one takes the valuable characteristic to be. One would not, on this view, be able to argue that the lives of all members of the human species have special value - for example the lives of the irreversibly comatose, or the lives of those who are not and never will be rational and purposive beings.

In the context of a discussion concerning the treatment of handicapped infants, it is also important to note that no newly born infant - whether handicapped or not - is a rational, purposive or moral being. Most infants do possess the potential to develop these characteristics. But this raises the separate question of whether we should treat a being on the basis of its actual characteristics, or its potential. Leaving this issue aside for the moment, we must also

note that unfortunately some newborn infants do not even possess the potential to develop these characteristics. Anencephalic infants and some severely brain damaged or retarded infants fall into this category.

The second approach, then, does not give us a reason for preserving the lives of all human infants and cannot serve as the basis for the view that all human lives, irrespective of their quality or kind, are equally valuable.

The first answer does cover all human infants - by definition. But can the fact that a being belongs to the species homo sapiens, rather than to another species, tell us anything about the value of that being's life? In our view it cannot. The difference to which it points is simply a difference in species. Nothing is said as to why species should matter. While it may initially seem obvious that human life is more valuable than non-human life, it is also "obvious" to the racist or sexist that a person's race or sex should determine how that person ought to be treated. But just as race or sex are not morally relevant in themselves, neither is species. If we say that the lives of beings of our own species are valuable, but the lives of beings of other species are ^{not} ~~do~~, merely because these beings do

not belong to our species, then on what basis can we criticize the racist who says that beings of his or her race have special value, but beings of other races do not? We believe that neither race nor species are morally relevant in themselves. What matters are a being's capacities - the kind of life a being has.

This conclusion should, in our view, also be applied to severely handicapped infants. We should not argue that they must have their lives sustained because they are human. We must ask what kind of beings they are and what kind of life they have.

It is not life which has value, but only life of a certain quality

Consistently applied, the "sanctity-of-life" view does not allow any quality-of-life judgments. In other words, on this view life would have to be prolonged even if the patient would not benefit from such efforts. One example would be the extension of an infant's life in a situation where that infant - either because it is born without a brain or has suffered severe brain damage after birth - will never be able to have conscious experiences. Whilst such an infant will not experience pain or suffering, neither will it experience pleasure or

joy - or any of the things that make life valuable. Its life would be like a dreamless sleep. Would it be of value to the infant to have its life prolonged? We think not - for the infant cannot be benefited by anything we do.

In this case, life would be of no value to the infant. Are there also situations where life can be a disvalue? This question is raised by the following case which is in some ways similar to that of Baby Doe:

Brian West

Brian West was born in October 1980 to Susan and John West. Brian was born with Down's syndrome and a severe form of oesophageal atresia, that is, there was no connection between the back of his mouth and his stomach. Doctors recommended surgery to construct a new oesophagus. Brian's parents refused consent for the operation, and the court took custody of Brian and ordered sufficient medical treatment to keep him alive.

During the next 26 months, Brian's treatment involved, at different times, the attachment of a permanent abdominal feeding tube, the insertion of a breathing tube in his mouth, and the attachment of an intravenous needle to his neck. When, in

November 1982, the reconstructive surgery was finally performed, Brian weighed only 15 lbs. He responded to the surgery with respiratory shock, a massive blood infection, and temporary kidney failure. John West gave the following account:

'Whenever we visited him during this time, he was screaming in pain. He was tied spread-eagle in his hospital crib for six weeks to keep him from pulling at his surgical wounds. I don't think he ever recovered from this. When the wounds healed, he never showed the same level of alertness or interest in toys as he did before the surgery. He had recurring episodes of pain as gastric juices backed up into his esophagus (it lacked the valve which is normally present to prevent this). He continued to have numerous bouts with pneumonia.' [19]

In November 1982 Brian went into hospital because of breathing problems. He became unconscious and was placed on a respirator. When taken off the respirator, Brian was found to have suffered brain damage and to be blind. He spent five weeks in intensive care.

'Whenever he was awake, he was agitated and writhing in his bed.....The doctors told us they had no idea whether he was in pain or not, but one look at him made your whole body cringe...On December 21, 1982, thank God, he died. We loved Brian and we always wanted the best for for him.' (20)

If all human life were of infinite or equal value, there would be no point in considering whether everything possible should always be done to keep an infant alive. But the above case raises just this issue.

Considering Brian's life from his point of view - disregarding entirely what his parents went through, and the cost of his medical care - it would have been better if he had died shortly after birth. Extended periods of his life were wrought with pain and suffering, so whatever better moments he may have had in his short existence cannot have compensated for them. Those who obtained the court order to save Brian's life did Brian no good: on the contrary, they did him great harm.

Looking back over Brian's life now that it is over, this judgment seems undeniable; but could one argue that at the time when the court order was granted, it was in Brian's interests to have the surgery

carried out? After all it was not then apparent how bad the outcome would be. It might have succeeded. Was the risk worthwhile?

In taking any risk, we weigh the possible benefits against the possible costs, and try to assess the probability of each. Here the fact that we are dealing with infants, rather than with older children or adults, is relevant.

IV. INFANTS AND PERSONS

Unlike an older child or adult, an infant cannot choose whether or not to undergo prolonged, invasive and sometimes painful life-sustaining treatment - whether she would want to undergo the pain and suffering to gain a few more months of life, a year, or a life-time. Does this mean that we must always attempt to sustain the infant's life, or should we allow infants like Brian West, Baby Doe and the Siamese twins to die?

This question cannot be answered, we believe, until we have reflected on the issue of what it is that distinguishes the lives of newly born infants from the lives of older children and adults.

Adults and children - but not infants - are self-aware and purposeful beings with a sense of the past and the future: they can see their lives as a continuing process; they can identify with what has happened to them in the past, and they have hopes and plans for the future. For this reason we can say that - in normal circumstances - continued life is what they want, and is in their interests. Newborn infants are not capable of seeing their lives in this way. They can have no desire to continue to live, because they have no concept of their own future life. There are no links, either of memory or of anticipation, between the separate moments of their existence. This means that, strictly speaking, we cannot even say that continued life is in their interests; for while it may be true that a newborn infant will, if all goes well, grow into a happy child and lead a worthwhile life, that later life is not linked, at the mental level, with the life of the infant. The infant and the child or adult are physically the same organism, but the child is a person, in the full sense of the term, and a newborn infant is not.

We shall use the term 'person' to refer to those who understand that they exist over time with a past and a possible future. The lives of persons can be seen as journeys on which they have embarked. Although we know that the final destination must be death, there are

goals along the way which we are hoping to achieve before the trip is over. Extending a person's life through medical technology will normally extend the journey and increases the possibilities of reaching some of these goals. The value of life-saving procedures is especially apparent in a case where accident or illness threatens to cut off the journey when it has still some way to go, and so thwarts the fulfillment of hopes and desires which might otherwise have been realized.

It might be objected that our journey begins with birth, or even conception; that death in utero or shortly after birth is the worst possible fate, for it ensures that none of the goals which might have been achieved will ever be reached. But this is a mistake. The journey is not underway in any purposeful sense, for the foetus or the newborn infant is not aware of itself as a being with a past and a future. The foetus or infant has no goals, no hopes, no expectations. This means that the journey we have talked about gets under way only some time after birth when there is a being capable of seeing itself as a traveller, and capable of wanting to reach some goal, however simple that goal might be. If this is correct, then it must also be correct that the loss of life for a newly born infant is, other things being equal, much less significant than the loss of life for an older child or adult.

This conclusion has far-reaching consequences for the difficult questions we raised at the beginning; but before we come to these, we shall consider an objection to what we have just said - for the objection helps to clarify our position. This objection relates to the infant's potential.

The argument from potential and the infant's best interests

We have claimed that the death of a foetus or infant does not have the same moral significance as the death of an older child or adult because there are no hopes which will go unrealized, and no goals which will not be reached. But, someone might object, a foetus or infant - and this includes many handicapped infants - have the potential to have, and realize many of the goals that we have been speaking about. It is the loss of that potential - the fact that, to invoke our metaphor, the whole journey will never be made - which constitutes the tragedy in the death of a foetus or infant. Compared with such a loss, it scarcely matters whether the hopes and desires have ever been consciously felt.

This argument from potential is sometimes invoked to justify aggressive treatment of seriously ill or handicapped infants. If the treatment succeeds, so the argument goes, the future child or adult will be grateful that her life was saved and that many of her plans and goals can now be realized. Hence, a supporter of this view might say, it was in the infant's interest to undergo the treatment.

Based on this view, many people believe that the guiding principle should be 'the best interests of the infant'.

Life-sustaining treatment should be given to an infant if her future life, with or after treatment, would contain more benefits than burdens. This view is, for example, taken by the United States President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its report Deciding to Forego Life-Sustaining Treatment. [21] Whilst this view has an obvious appeal, there are a number of reasons as to why we think we should not accept it. The most important reasons have to do with the special status of infants.

Let us begin by asking: "What are the interests of an infant? Obviously a newborn infant can feel pain, be cold and hungry; it can therefore be said to have an interest in not experiencing pain, to be warm and well-fed. But those who suggest that decisionmaking

should be based on the 'best interests of the infant' are looking much further ahead than this. They are thinking of the whole future of the infant, and whether the future life will - in its totality - contain more benefits than harms for the child or adult into which the child will develop.

There is, however, a problem in seeing life five years hence, no matter how good a life it may be, as in the interests of this infant lying here in front of us. Suppose that if we continue treatment there is a good chance that this infant will in five years be a normal child playing in the sandpit with her friends. Suppose that we do continue treatment, everything works out as we had hoped, and the child is brought back to see us, clearly enjoying life as much as any five-year-old. Can we then think back to the day we stood before the newborn infant, wondering whether to operate, and say to ourselves: "In that case, at least, treatment was in the best interests of the infant"? Before we say this, we ought to ask: in what sense is the child I see before me now the same person as the infant who was then in the neonatal intensive care unit?

There is, of course, a physical continuity between the child and the infant. The latter developed into the former. Because of this, they may be said to be the same physical organism, despite the great

changes that have taken place. But there is no mental continuity. The child cannot look back and recall the time she was an infant in the neonatal intensive care unit. Nor could the infant look forward to the time when she would be an older child.

This is not a simple matter of a limit to the length of recall of the child, or the range of anticipation of the infant. It is not as if the child can now remember being a two-year-old, and the two-year-old could remember her first birthday, and the child who had just turned one could remember the first weeks of her life. If there were this kind of overlapping continuity, it would be possible to say that the infant and the five-year old are the same person, just as a rope made up of overlapping strands would still be one rope, even though no single strand reached from one end to the other. But we have no conscious links with our infancy, because as an infant we were not beings with the kind of awareness encessary for spanning time. [22]

This makes it very dubious to claim that the happy child shows that a decision to continue treatment was in "the best interests of the infant". It may show that the decision was justified because,

among other things, it made possible the enjoyable and worthwhile life now being lived by the child; but this is a different matter. The infant has no interest in becoming that child; its interests are much more limited than that: not to suffer, to be warm and comfortable, and so on. If the infant has good prospects of intact survival, but the form of treatment required will cause prolonged pain and discomfort, we may have to recognize that we are doing it, not in accordance with, but despite 'the best interests of the infant'.

This issue is raised starkly in the context of infants born prematurely, at the margin of viability. In many cases, doctors will not give anaesthetics for invasive treatments - including major surgery - because this would put an additional strain on the infant's immature system, thereby threatening the infant's chances of survival. But this practice - one doctor calls it a "barbarism"[23] - is surely not in the infant's best interests. If this is correct, this means that in some extreme cases the suffering of the infant - unavoidable if it is to be kept alive - may in itself be sufficient reason to forego the treatment. The situation of Brian West may have been one such case.

Moreover, if the argument is that treatment, including very painful treatment, can be justified because it is likely to result in the existence of a person who, 5 or 20 years from now, will be glad to be alive, then we must also consider the issues from yet another perspective: that of abortion and even non-conception, both of them widely accepted. In other words, if the argument is that it would be wrong to let an infant die because this would result in there not being - in 5 or 20 years' time - a person leading a worthwhile life, then the same argument would lead to the condemnation of not only abortion but also non-conception. In both cases, there is the loss of a possible life - a journey which will never be made, a life which will never be lived.

Here we should note that our concern is not to deny that, other things being equal, it is a good thing to bring additional human beings into existence - at least if they can be expected to have lives above a certain minimal quality; but this conclusion gives us no reason to see the death of a foetus or newborn infant - from the future person's perspective - as more tragic than anything else which prevents the existence of such a person

This answers the objection. What we must now do is ask:
"Whose interests should be taken into account when we make life
and death decisions for a seriously ill or handicapped infant?"

VI. IN WHOSE INTERESTS?

In the last Section we sketched the philosophical difficulties that lurk behind the idea that decision-making should be based on "the best interests of the infant". These difficulties are one reason as to why we think this approach is misguided. There is, however, also another - more straightforward - reason: many other factors should, in our view, be taken into account - including the interests of the parents, and of any children they may already have. It is, for example, often pointed out that the survival of a handicapped child is also the creation of a handicapped family. While that judgment may be too severe in some cases, in others it is the simple truth. [24]

There is no reason to assume that the interests of the child or person who the handicapped infant might become should

automatically outweigh all these other interests. The birth of a severely handicapped infant can dramatically change the lives of the parents and siblings. To disregard their interests altogether is incompatible with the principle of equal consideration of the interests of all those affected by our decision - and such a principle is fundamental to ethics.

If we speak about equal consideration of interests, there is also one other interest which we have not, so far, raised: the "interests" of the next child in the queue.

One of the more firmly established findings about families with a disabled child is that they are less likely than other families to have further children. Shouldn't we take the interests of those children into account - the interests of the children who will not exist if the handicapped infant survives?

Peggy Stinson is an American woman who has published a book called The Long Dying of Baby Andrew. The book is based on a journal she kept during the period when doctors were, against her wishes, trying to save Andrew's life - despite the fact that he was highly

unlikely to survive without severe brain damage. Peggy Stinson's journal shows that, like most mothers in her situation, she was concerned about what Andrew's long-term survival in a damaged state might do to her plans to have another child. On February 17, when Andrew was two months old, she wrote:

'I keep thinking about the other baby - the one that won't be born. The IICU [Infant Intensive Care Unit] is choosing between lives. It may already be too late for the next baby. If Andrew's life is strung out much longer, will we have the money, the emotional resources, the nerve to try again?'

[26]

The journal entry for April 30, 1977 is particularly interesting because it poses the philosophical question that is at the hub of this issue:

'Thirty-fifth birthday coming up next week; haven't got forever to try for another child. If we wait much longer, until our insurance runs out or we're billed for Andrew's custodial care, we'll know we can't afford another child. Or we won't have the nerve to try again.'

We want another child. I'm not going to let Pediatric Hospital [where Andrew was kept alive against his parents' wishes] destroy our chance to have one. At this rate we'll have neither Andrew nor the next child, who, because of Andrew's extended course, will have lost the chance to exist at all.

Jeff [a junior doctor at the hospital more sympathetic to the Stinson's view than the other senior medical staff] once said our 'next child' was theoretical, abstract - its interests couldn't be considered. Strictly speaking that may be so, but that next baby seems real enough to me. To Bob too. Decision this week to change that abstraction into a real person before it's too late." [27]

Is the 'next child' an abstraction whose interests cannot be considered before it is born, or even conceived?

The argument that we should take the 'next child' into account has been well put by R.M. Hare, in a discussion of abortion of a foetus known to have a handicap. [28] Hare points out that in such

discussions one interest is frequently overlooked: the interest of 'the next child in the queue'. Suppose, he says, that a couple have planned to have two children. The second child is discovered, during pregnancy, to have a serious handicap. If the foetus lives, the couple will not have any more children. If the foetus is aborted, the couple will seek to have a second child. There is a high probability that this second child will be normal. In this situation, Hare argues, we should consider not only the interests of the child now in the womb, but also the interests of the possible child who is likely to live if, and only if, this child does not live.

This account can be applied to the situation of the severely handicapped newborn infant. Here too couples are often likely to have a further child only if the newborn infant does not live.[25] Should we exclude this fact from our deliberations of whether to treat a handicapped infant? We think we should not - at least not if we believe that treatment is justified in terms of the interests of the future child or person. There is, of course, another reason as well: the pain and suffering that will sometimes have to be inflicted if we want to ensure the survival of a seriously ill or handicapped infant.

VII. WHO SHOULD DECIDE?

There is now general agreement that adult, competent patients - not the doctor - should decide whether they want to undergo certain treatment, including life-sustaining treatment. But who should make the decision whether or not a severely handicapped infant lives? There have been proposals, especially in the United States, for ethics committees - or even Courts - to decide difficult cases.

But committees or courts are hardly well-suited to the type of urgent decisionmaking which can be required, at any hour of the day or night, in a neonatal intensive care unit. Moreover, there is a fundamental objection to this way of making decisions put by Robert and Peggy Stinson in their book about the treatment of Baby Andrew:

"We believe there is a moral and ethical problem of the most fundamental sort involved in a system which allows complicated decisions of this nature to be made unilaterally by people who do not have to live with the consequences of their decisions." [29]

We agree: it cannot be right for others to override the desire of parents that their extremely handicapped baby should not live, and then to return that infant to the unwilling parents, with all the consequences that bringing up such a child may have for them and their other children. It would be different if there were other couples willing to adopt the child, or if the community were prepared to pay for the kind of institutional care that would be needed for the child to have a good life; unfortunately, very few couples are willing to adopt severely handicapped children, and institutional care is almost everywhere far below the standard required. In virtually every case, the infant's best, and usually only, chance of a decent life is with the parents. In these circumstances the parents' views about treatment should be decisive.

We recognize that the birth of a handicapped infant can be a great shock to the parents, and it will sometimes be difficult for them to make such important decisions immediately after birth. However, in a well-known article, two paediatricians have reported their experience that parents, regardless of background, can make informed, understanding decisions if they are carefully and sympathetically told the facts in words they can understand. [30] We

see no reason to doubt this. We also think that the situation could be ameliorated if, as another paediatrician - William Silverman - has suggested, obstetricians were to discuss with expectant parents the possibility of the baby being born handicapped, seriously ill or extremely prematurely, and the need to make decisions about treatment in such circumstances. [31] Such discussions would arouse less anxiety if they were perfectly routine, taking place perhaps at prenatal classes.

VIII. CONCLUSION

We have argued that parents should, other things being equal, decide whether their severely handicapped infant lives or dies. One issue we have not raised is how the infant should die.

Many people draw a moral distinction between doing something that results in death, and merely 'doing nothing' that also results in death - or between killing and letting die. Thus it is often thought that letting die is sometimes permissible, but killing never. Based on this distinction, doctors will frequently decide not to act to preserve the life of handicapped infants - such as the Danville Twins and Baby Doe - but not take active steps to end the infants' lives.

We deny that there is a moral distinction between killing and letting die. If all other factors, such as motivation and outcome, are the same, killing and letting die are morally equivalent. Does this mean it does not matter whether an infant is killed or allowed to die? We do not think so. To the extent that letting die can often be a drawn out and distressing process for all concerned - including of course the infant - we think that there are circumstances where severely ill or handicapped infants should not only be allowed to die, but should be helped to die.

* Parts of this article are drawn from a book: Should the Baby Live?, Oxford University Press, 1985; sections of the article are also drawn from an article "Ethical Issues Raised by the Birth of Extremely Premature Infants". in [eds.] V. Yu and C.Wood: Prematurity, to be published by Churchill Livingstone in 1987.

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