

## Editorial

### Severely handicapped infants

The problems of how to treat severely handicapped infants discussed by Harris and his three commentators in this issue are of profound importance not just in medical ethics or academic moral philosophy but for the very warp and weft of society's moral fabric.

Three schools of thought are represented in these articles. One (the conservative school) believes that severely defective infants should be treated no differently from ordinary infants and that all practicable medical efforts should be made to remedy their defects and preserve their lives. The second (middle) school believes that when the survival of such infants is at best likely to be one of severe handicap no medical treatment should be given other than to relieve the infant's pain and distress; this school rejects killing such infants but favours letting them die. The third (radical) school agrees with the second that some handicapped children would be better off dead rather than living the defective lives otherwise ahead of them but criticises the belief that letting such children die is morally preferable to killing them 'quickly and painlessly'.

No substantial attempt to resolve this exceedingly complex matter can be made here—such an attempt would have to analyse at least the following philosophical problems: the principle of respect for (or sanctity of) life; the role of quality-of-life assessments, including the relative importance of predicted future suffering versus predicted failure of human flourishing; the moral differences if any between fetuses and neonates; the concept of personhood and its moral relevance; the moral differences, if any, between killing and letting die, and associated issues such as the moral differences, if any, between acts and omissions, intending and foreseeing and the doctrine of double effect; the nature of rights and especially of the 'right to life'; and the role of parents or other kin, doctors and other carers, and society and the law in decision-making for infants. Nonetheless brief discussion of the reasoning underlying the three positions outlined above may be helpful.

The conservative position, held by some Roman Catholics and members of Pro-Life movements is based on the principle of the sanctity of life—'respect for life' in its secular variant. The great advantage

of this position, when unmodified, is that every (innocent) human being is entitled to the same care, fetus or baby, handicapped or not, dying or living. The disadvantage is that medical technology can now preserve innocent human lives to an unprecedented degree, and sometimes at an unprecedented cost both in terms of resources and in terms of the impaired quality of life that is preserved.

To temper the requirement that equal efforts must be made to preserve all (innocent) human lives regardless of their quality and regardless of the costs two principles enable Roman Catholics—and others—to use other criteria. The first is that the sanctity of human life is essentially a negative principle and forbids intentional killing. The second is the principle of ordinary and extraordinary means. This in essence permits a cost-benefit analysis of any proposed treatment, which may be regarded as morally optional if it involves excessive expense, excessive pain, excessive difficulty or other inconvenience, without reasonable or proportionate hope of benefit.

### Unanswered questions

This second principle was considered at length in the last issue of the *Journal*. Among the crucial questions it leaves to be answered are what is to count as a benefit? Is it preservation of any (innocent) human life; is it preservation of any such life provided that it has the capacity of 'mind' (as Gormally, responding to Downie's criticisms, argues in the correspondence columns of this issue); or is it the preservation of a life with 'the capacity for human flourishing' (which is what Gormally argues 'respect for human life' means, in the first (1) of the three booklets reviewed by Downie in the last issue of the *Journal*); and must the answers be exclusive or could these three alternatives represent a hierarchy of benefits?

In the light of the answers to these questions must be elaborated the criteria for determining whether a proposed treatment involves 'excessive' expense, pain, difficulty, or other inconvenience. In principle there need be no conflict between those who hold the conservative position modified by the principle of ordinary and extraordinary means and those who hold the middle position. Whether in practice there is a conflict will turn on what answers are given to the questions outlined above.

The conflict between Lorber and Harris is over the first principle, whereby there is claimed to be a moral distinction between killing and letting die. Although there is no doubt that the medical profession and the Law are overwhelmingly at one with the Roman Catholic Church over this, it is philosophically a very difficult position to sustain, as Harris' detailed arguments indicate. The debate between him and his commentators repays careful study and readers are also referred to the collection of essays *Killing and letting die* (2) which reflects a wide and interdisciplinary variety of carefully argued cases. In addition may be recommended Lorber's original paper (3), those by Campbell and Duff (4) (5), defending the middle view, and the books by Glover (6) and Harris (7) defending the radical view. For the defence of the conservative view may be especially recommended the impressive Roman Catholic philosophical work by Grisez and Boyle (8).

### Danger of inconsistencies

If upholders of the middle position side with Roman Catholics over the moral importance of the killing—letting die distinction—some are liable to be hoist by their own petard. Thus if it is morally impermissible to kill neonates why is it morally permissible to kill fetuses? Conversely if fetuses may be killed because they *might* be severely handicapped, what is morally so special about being born, or about 'viability' which disallows killing babies who *do* have severe handicaps? Roman Catholics will also attack the middle and radical views for inconsistency if either propose, as is likely, to treat severely handicapped neonates differently from adults with similar disabilities.

For instance a temporarily comatose (and so non-consultable) accident victim with handicaps similar to those qualifying a neonate with spina bifida to selective non-treatment would almost certainly be kept alive on the basis that it is not the doctors' or the relatives' right to decide for the patient that his life will not be worth living. Many severely handicapped adults assert that their lives *are* worth living. Similarly, the Pro-Lifer might argue, the spina bifida neonate should at *least* be kept alive until he can decide for himself.

One way of trying to meet these objections has been to argue that only persons have basic or intrinsic moral rights (see Lockwood's paper in this issue for a discussion of rights). Other entities, including very young children, only have rights insofar as persons confer these upon them, for instance through laws or stable customs. Tristram Engelhardt of the Kennedy Institute of Ethics

argues somewhat along these lines (9) and characterises persons as 'self-directive self-conscious beings'. There are of course major problems for this theory both in characterising the concept of person and in offering operational criteria for distinguishing persons from non-persons. One objection which is not valid however is that acceptance of this theory would yield defenceless *all* young infants and other human beings who were not 'self-directive self-conscious beings'. Lack of basic or intrinsic moral rights in no way entails lack of legal or customary rights—it does however permit society to withdraw such legal or customary rights, an option which is not available for basic or intrinsic moral rights. Neither would the liberty of persons to have and protect and love their babies be impaired.

Such a theory attempts to underpin intuitions that where there are weighty reasons why certain living human beings—fetuses, severely handicapped neonates and permanently unconscious human beings—may be killed or allowed to die even though the same weighty reasons could not justify killing or letting die human persons. There are many problems associated with this moral stance; so there are with all the others. Doctors and others who wish to have the moral option of denying the right to life certain living human beings on the basis of distinctions concerning future quality of life must consider the opposing arguments seriously. They concern fundamental moral problems for whose solution *ad hoc* or empirical decisions, common sense and kind heart are, alas, not sufficient.

### References

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- (2) Steinbock B, ed. *Killing and letting die*. Englewood Cliffs, New Jersey: Prentice-Hall, 1980.
- (3) Lorber J. Ethical problems in the management of myelomeningocele and hydrocephalus. *Journal of the Royal College of Physicians of London* 1975; 1: 47-60.
- (4) Campbell A G M, Duff R S. Deciding the care of severely malformed or dying infants. *Journal of medical ethics* 1979; 5: 65-67.
- (5) Duff R S, Campbell A G M. Moral and ethical dilemmas in the special care nursery. *The New England journal of medicine* 1973; 289: 890-894.
- (6) Glover J. *Causing death and saving life*. Harmondsworth, Penguin Books 1977.
- (7) Harris J. *Violence and responsibility*. Routledge and Kegan Paul. London. 1980.
- (8) Grisez G, Boyle J M, eds. *Life and death with liberty and justice*. University of Notre Dame Press, Notre Dame, Indiana. 1979.
- (9) Engelhardt H T. Ethical issues in aiding the death of young children, in reference (2) 81-91.