Journal of medical ethics, 1984, 2, 71–72

Approaches to medical ethics

Ethics and the severely malformed infant: report on a multidisciplinary workshop

Graham Clayden *St Thomas's Hospital, London*
Najla Mattar *Nightingale School, St Thomas's Hospital, London*

Editor's note

This paper is a report of a multi-disciplinary half-day workshop convened by the authors to discuss medico-moral issues. It was held at St Thomas's hospital and participants included a variety of staff members from within the hospital and from the community health services.

Design of the workshop

The afternoon consisted of three parts. The questionnaire overleaf was given out and after a preliminary explanation of the terms, members of the workshop were invited to make their individual responses. They were then divided to provide a mixture in each group of the various disciplines represented. (The 35 members included medical students, midwives, community nurses, paediatric nurses, tutors and liaison officers). Each group was then asked to discuss the same questionnaire, to try to reach a consensus and then mark their results on an overhead projection sheet. After this period (and tea) a plenary session gathered these overhead projection sheets and from the superimposed sheets areas of general agreement or discord could be easily seen.

The first question on the questionnaire caused a number of problems. The main arguments hinged on parental rights or autonomy. This was set against a discussion of the balance of quality versus quantity of life for the infant. A discussion of the differences between utilitarian theories and deontological theories (1) came up via consideration of the resource implications of some of these decisions.

The difficult question of the relative value of life at the different periods of the developing fetus arose, as did the glaring contrast between the legality of abortion of a normal but socially unwanted fetus with the charge of murder for the mercy killing of a severely deformed, perhaps suffering, newborn baby.

When question five was discussed the moral debate about acts of omission and commission and about the Roman Catholic doctrine of ordinary and extraordinary means became fairly heated. Question four demonstrated mixed feelings and opinions about the deliberate withholding of potentially damaging information. Discussion included the issues of truth-telling and trust and we even stumbled upon the Hippocratic oath. This was seen to express the duty of non-maleficence alongside the duty of beneficence. The former is associated with the maxim 'above all, do no harm' and the latter with, 'help, according to my ability'.

Conclusion

By the end of the afternoon a constructively questioning atmosphere had been engendered and some of our firmly held convictions (or were they prejudices?) were becoming shaky. The value of multidisciplinary discussion of these issues was widely accepted and there was definitely a demand for more information about philosophy or theology, depending, it seemed, upon people's religious learning and leanings. We were convinced that more workshops should be organised: there are a number of suitable fields, ranging from resource allocation priorities and justice to mental health and freedom. We hope to be able to organise future workshops with the departments most closely involved, inviting a broad range of participants as previously mentioned and, we hope, attracting some moral philosophers too.

Key words

Medical ethics; multidisciplinary workshop; congenital abnormality.

References

(1) Based on the discussion in Beauchamp T L, Childress J F. *Principles of biomedical ethics*. Oxford: Oxford University Press, 1983, 2nd edition.

Questionnaire on ethics and the severely malformed infant

1. Which of the following infants do you think should be treated intensively, even against the parents' wishes?
   a) Spina bifida with hydrocephalus and large spinal defect
   b) Down's syndrome with duodenal atresia
   c) Severely premature baby with lung disease, mother wanted abortion but too late
   d) Rhesus baby of Jehovah's Witness needing exchange blood transfusion
   e) Baby of a narcotic addict with withdrawal syndrome

1.i On what grounds did you come to your decision?

2. Who should be present routinely when a paediatrician first discusses the defects of a severely malformed baby with mother?
   a) Father of baby
   b) Mother's mother/father
   c) Nurse/midwife
   d) GP
   e) Health visitor
   f) Priest
   g) Social worker
   h) Lawyer

2.i Who should make the decision?

3. Should a parent be able to sue a health authority following the birth of an abnormal baby if screening tests were not offered? Y/N

4. If another defect (possibly harmless) is discovered at amniocentesis, should the parents be told? Y/N

5. If a severely affected baby is not being treated intensively, which of the following regimes are justified?
   a) Increasing doses of sedative/analgesic Y/N
   b) Water feeds only Y/N
   c) Milk feeds on demand Y/N
   d) Regular milk, including tube feeds Y/N
   e) Antibiotics Y/N
   f) Ventilator support Y/N

(Continued from page 60)

respect for autonomy this may be linked to the fact that actions require time and energy and thus are a greater intrusion upon the autonomy of the agent than are omissions which in general require less time and energy. Once again such a distinction, even if supportable, does not support the bare acts-omissions doctrine – but it does indicate a similar and potentially morally relevant distinction.

The practice of treating killing and letting die as being of intrinsic moral difference can thus not be based on the bare difference between acts and omissions. However, a variety of other moral considerations – utilitarian welfare maximisation, Roman Catholic absolutism, and the principles of non-maleficence and respect for autonomy – can be adduced to justify social practices not unlike those that result from the 'bare' doctrine of acts and omissions.

References and notes

(1) See for example British Medical Association. *The handbook of medical ethics*. London: BMA, 1981: 34–35.
(2) Clough A H. The latest decalogue. Quoted in Glover J. *Causing death and saving lives*. Harmondsworth: Penguin, 1977: 92.
(3) Mason J K, McCall-Smith A. *Law and medical ethics*. London: Butterworths, 1983: 178–189.
(4) Rachels J. Active and passive euthanasia. *New England medical journal* 1975; 292: 78–80. Reprinted: See reference (5).
(5) Steinbock B, ed. *Killing and letting die*. Englewood Cliffs: Prentice Hall, 1980. An excellent collection.
(6) An argument referred to neutrally in the BMA handbook. See reference (1): 35.
(7) Slack A. Killing and allowing to die in medical practice. *Journal of medical ethics* 1984; 10: 82–87.
(8) The Linacre Centre. Is there a morally significant difference between killing and letting die? In: *Prolongation of life*. London: The Linacre Centre, 1978: 7–10.