Ethical aspects of neonatal care

It is prudent for all those concerned in neonatal care to consider whether the care that they provide matches that that is technically and ethically demanded by society. The present time has never been more appropriate, for medical ethics has caught the imagination of the media, in particular the approach to the congenitally malformed baby. It is possible that the public interest has peaked as the subject is in danger of overexposure, there being a limited number of controversial situations and a limit to the number of times they can be discussed. Nevertheless, while the spotlight is on, it is a useful exercise to rationalise decision making and examine the possibility of a wider professional input.

There are four contentious points: the justification of intensive care for the very low birthweight baby, the withdrawal of intensive care in the brain damaged baby, the non-treatment of malformed babies, and the personnel involved in decision making.

The justification of intensive care

It does not seem so long ago that the results of intensive care against conservative management of the preterm baby were being compared and some paediatricians were drawing some comfort from the results.¹ Even if such comparisons were interpreted as not being in favour of intensive care, it was only a matter of time before it became clear that enthusiastic obsessional neonatal care works and saves many lives. There are several reports from different parts of the world dealing with improved neonatal mortality and quality of survival.^{2,3} The ethical dilemma is not whether to provide such care but to justify not providing it. If there was no alternative there would be no problem, but practically all parts of the United Kingdom operate a form of regional policy enabling high risk pregnancies or babies to be transferred to facilities where intensive care is available. The regional centres are capable of offering over 50% survival for babies weighing between 750 and 1000 g and as high as 90% between 1000 and 1500 g. This puts great pressure on the paediatrician in the district general hospital who for either logistic or personal reasons opts to set up and run an intensive care unit when regional facilities are adequate. At present this is rarely the case, and most intensive care in the United Kingdom is still performed outside regional centres. It is vital for audit to

include not only acceptable perinatal survival but to take into account iatrogenic problems, bronchopulmonary dysplasia, recurrent hospital admissions, and cot deaths. Only with the complete results of intensive care can the decision to offer it be deemed logical. It is, of course, expensive but peanuts when compared with the highly emotive, more questionable, transplant programmes. The detailed costs have been published recently;⁴ the daily cost per intensive care cot of £235 is money well spent, particularly when such care can be offered in conjunction with a discontinuation option when things go wrong (see below). In these circumstances, I believe that the long term handicap associated with the perinatal period can be minimised.

The opting out facility

One is required by the Hippocratic oath to act for the benefit of one's patients but, above all, to do no harm. This principle of not doing the patient harm (non-maleficence) is particularly important as medical technology enables an aggressive approach to be offered to the less and less mature. The clinician's freedom to stop intensive treatment when the probable outcome is severe handicap is part of the package of neonatology.

Clinical assessment of the baby has been helped considerably by ultrasound confirmation of brain damage. In skilled hands there is good correlation between the ultrasound appearance and postmortem findings.⁵ Follow up studies have pointed with some certainty to an unacceptable quality of life with extension of intraventricular haemorrhage into the cerebral cortex or with bilateral periventricular leucomalacia.⁶ On the other hand, ventricular dilatation associated with haemorrhage may not necessarily be so bad. Although the area is somewhat grey, by using a combination of clinical and ultrasound information the parents can be given a fairly accurate picture of the likely long term outcome, and a meaningful discussion with the clinician can then take place.

If intensive care is withdrawn the intention is that the baby should die, and this could be interpreted as an active measure. Whether this is killing or allowing to die has no moral relevance—what is important is whether the decision is correct. The fact, however, that such decisions can be made and are morally justifiable without completely dispro-

ving any possible chance of a meaningful recovery emphasises that the newborn, and particularly the very immature babies, are special cases. We live in a society that is tolerant of what is, in effect, abortion on demand. Life clearly does not begin at the fusion of the gametes, and it is not necessarily logical to use as a basis the appearance of the head at the perineum (I accept that this discussion avoids the Catholic definition). At what stage a human being acquires 'rights' is tied in with the acquisition of personhood, which has various definitions such as the ability to relate and the capacity for self awareness or to have complex thought processes. The view of society (not pressure groups) that influences decisions that have to be made is that the fetus and the newborn are not yet endowed with the same rights as children or adults.

The malformed baby

The moral issues relevant to the preterm baby apply also to the baby with congenital malformations. Yet the fact that neonatologists find, for instance, the Down's syndrome baby with duodenal atresia a complex problem means that there are extra factors involved. These factors are the definition of the quality of life, the balancing of the baby's interest against the autonomy of the parental decision, and, finally, the withdrawal of special or even ordinary care.

It is completely avoiding the issue to refuse to define the quality of life. To suggest that a person who can achieve a physical and mental age of no more than 2, will remain totally dependent, and will be unable to communicate can have a good quality of life is wrong. It would be an evil person who would support a life of such wretched existence. Although our options may be limited by the attitudes of neurosurgeons, nearly all paediatricians consider that a spina bifida baby with a high lumbar lesion with no sphincter control and effectively paralysed below the waist should not be actively treated. In other words, the expected quality of life would be unacceptable. It is equally clear, however, that given the right background Down's syndrome children have a very reasonable quality of life. When the mongol baby has duodenal atresia an operation has to be performed that in this day and age cannot be described as an extraordinary measure. If such a baby were rejected he is not likely to be greatly disadvantaged in later life for not having known his genetic parents. Social services would inevitably be involved and a surgeon would be found to act in the best interests of the baby. The most difficult situation arises when intelligent, caring parents believe that when refusing surgery they

are acting in the best interests of the baby and the existing family.

Despite the well publicised previous cases, there is no legal precedent for this dilemma. I believe that most paediatricians would be uncomfortable acquiescing to no surgery partially because of the practical problems involved. These should not, however, override a logical moral decision.

Professional involvement in decision making

The situation described above is most complex. A second medical opinion may be helpful, but it is an extremely experienced and sensitive paediatrician who can judge parental reaction as being representative in the period immediately after birth. Seemingly rational parents may not be acting in their own best interest, let alone the interests of the baby. The involvement of the family doctor is desirable, but I can see a role here for a sympathetic psychologist. This is not to advocate the American committee approach where the composition of the committee may turn out to be as unsatisfactory to the clinician as that for choosing a unit general manager. At the moment we continue to face the difficulties as and when they arise and in the absence of a better system confront the problems as Campbell advocates.^{7 8}

In conclusion, certain generalisations must be stated. Each case should be treated on its individual merits without preconceived ideas. The decision made should be that which would reflect the overall moral view of that particular society at a given time. A baby is an unprotected individual who cannot express a view on the desirability to live, and the paediatrician must act primarily in his interest. What Lord Hailsham once said to Enoch Powell is for us a good guideline, 'Moderation in all matters'. There is no room for extreme views or practice in neonatology.

The series 'Philosophical Medical Ethics' by Dr Raanan Gillon running 1985-6 in the *British Medical Journal* is compelling reading. I have quoted perhaps inaccurately and out of context from this series and therefore have not acknowledged any particular article as a reference.

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