

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

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1. In the presence of serious fetal abnormalities which are likely to be disabling, the pregnant woman should have the option of terminating the pregnancy. If she chooses to continue with the pregnancy, the interests of the fetus/neonate should be the primary concern. These interests would revolve around issues of quality of life, and pain and suffering. After delivery, supportive care should be given. This would include warmth, fluids and nutrition. In specific instances, e.g. spina bifida, infection of the open sac may occur and antibiotics would then be warranted to prevent the pain involved. Treatment might also involve surgery aimed at improving quality of life, but should stop short of ventilation and major resuscitation.  
The parents' wishes should be taken into consideration. If the parents wish for more active intervention than discussed above, the situation should be managed with extensive counselling regarding prognosis and feasibility of prolonging meaningful life. In a resource poor setting, the parents' wish for more active management can be overridden in favour of using the resources for candidates with a better prognosis.
2. In the following circumstances, it would not be appropriate to use medicine or surgery to prolong the life of the newborn:
  - a. When the baby has severe congenital anomalies which would compromise quality of life.
  - b. When the baby has poor prospects of survival because of a genetic or other disorder
  - c. When the baby has acquired brain damage and is considered likely to have severe disabilities in later life
3. Of the three ethical questions for the working party to consider, I would consider the most important to be issues about quality of life.
4. Of the three social questions, all are important, but probably the most important is the effect of spiritual/ religious influences on decision making.

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5. In assessing the quality of life, a number of variables apply. The first is the actual abnormality: whether there is physical or mental handicap, whether surgery is involved to improve the prognosis, whether pain and suffering are present. Secondly, the family situation is important : whether there is a single parent, whether there is an extended family support system, the effect on other family members, the economic resources of the family, e.g. if a wheelchair is required, whether they can afford to pay for it if not provided by the state.

A multidisciplinary team is therefore needed to decide on quality of life. This should include medical staff, social services, family members and extended family and community support systems. If there is dissent about management, an Ethics Committee may be consulted.

If the couple are married, the opinion of both parents should be taken into account. If unmarried, the mother's opinion should take preference.

If there is a deadlock between the opinions of the parents and medical personnel, with respect to parents wanting more active management than is offered, the law may be involved. If the parents wish for supportive care only in the face of a serious abnormality, their wishes should be respected.

6. If resources in terms of ventilators or NICU beds are limited, The competing needs of extremely preterm neonates with a poor prognosis and babies with a better prognosis should be taken into account. If the neonate survives with handicap, it has been stated that the cost of caring for a disabled child is exorbitant. However, older children or adults, who are disabled due to trauma or illness carry the same burden to healthcare costs and social resources, yet they are accommodated. It does not seem a reasonable argument therefore to deny neonates care for this reason.

7. The issue of weighting QALYs differently for neonates and adults is a difficult one. While an elderly person may have had a good quality of life for 60 years and then had a deterioration in this quality of life due to illness or disability, this change might influence how that person perceived their quality of life, making them less prepared to endure pain and suffering that was not present before. A neonate born into the situation, might be more interested in preserving life as this was the only one he/she had.

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This would be very dependent on the prevailing social milieu and attitudes to disability, as well as personal and religious beliefs.

8&9. It would be useful to parents and professionals if professional guidelines are drawn up by bodies such as the College of Medicine. As the intact survival rate < 24 weeks is so low, guidelines on not to resuscitate below this level would be advisable. Professional guidelines, rather than legislation, would be more helpful.