

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.

**Question 1a:**

This is a risk:benefit equation. Is the abnormality going to be only mildly disabling and compatible with a quality of life considered acceptable/desirable by parent(s)? If the correction of abnormalities will enhance chances of quality survival without undue risk, then clearly this is ethical. Where the measures carry significant risk of premature end to the life of the foetus who would have only minor abnormalities, this would make a decision to intervene more debatable. Where a correction of abnormality is a one-off opportunity and would not be available after birth, then this needs to balance in favour of treatment. Decision must clearly be made by parent(s) who are as fully informed as possible about both risks and outcomes.

**Question 1b:**

In my view, the wishes of a pregnant woman can only be over-ridden when her view is at such an extreme from a consensus opinion that the extremity itself implies faulty decision making or unethical beliefs. We should remember that we give parents enormous freedoms to put their unborn foetus or child at risk e.g. participating in various activities in pregnancy, allowing children to participate in dangerous activities, etc, and only intervene when these decisions by parents are at such an extreme that they are not considered to be normal behaviour. We should be extremely circumspect about overriding informed parent(s) decisions. The stance of English law is correct in it's practical application, by placing the (live) pregnant woman's rights over those of the (potential) foetus in utero. The US model is out of balance by allowing the foetus to sue it's parents.

**Question 2:**

Again, all of these questions depend on degree and cannot be simplistically answered. In the case of extreme prematurity, an informed parent(s) would have to decide whether a 50% risk of severe disability would be sufficient grounds for them to take the view that nature should take its course. Exactly similar decisions need to be taken in relation to the other three bullet points.

**Question 3:**

- i) It would be a brave committee that is able to make a pronouncement on the moral status of the foetus. This will be part of the decision making process for the parent(s).
- ii) I do not think there is any ethical difference between acting and omitting to act. It would be helpful if the working party were able to consider this, coming to a conclusion which would be applicable to most ethical systems, though not to some religious beliefs which clearly need to be identified.
- iii) As 3i.

**Question 4:**

In can't see the benefit of answering these questions. Bereaved parents in our local confidential enquiry interviews say that, part of coming to terms with their excruciating decision, is accepting that they made the best choice within the knowledge and options available at that time for their baby's particular situation. Controversies in the media and tabloid description of 'miracle' babies only serve to cloud the issue. They feel that it is a very individualised and personal matter.

**Question 5:**

In general, I believe that parent(s) views should take precedence. This is strongly supported by our bereaved parent interviews. They emphasise the importance of a non-judgemental atmosphere and good communication skills of the professionals involved so that the parents are as well informed as possible.

I have recently co-written an article about how these decisions might be made, and can forward this in due course with permission from the Archives of Disease in Childhood.

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.

**Question 6:**

Some weight must be given to this, if there are economic costs to the family, but even less to economic cost to the nation. However, national and regional resources and support are limited and must be allocated with equity.

**Question 7:**

I am not qualified to answer this, but I would think it is possible that QALY in a newborn could be discounted, in comparison to an adult who has an established independent existence whereas an infant has only a potential independent existence and social relationships.

**Question 8:**

Yes to both questions. In part b, exchange the word "permitted" to "expected".

**Question 9:**

No, I see no need for new legislation.

Ethical and professional guidelines help to inform, but provision for local professional training in bereavement and communication skills must go hand in hand, for a compassionate and collaborative response.