

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.

Centre for Family Research

Question 1

When you talk of 'sustaining' the life of the fetus, I assume you mean in utero. It is appropriate to offer women whose baby has an abnormality all the necessary information, physical care and emotional support that she needs to make the best decision for her about the outcome of the pregnancy and throughout whatever decision she makes. The decision *not* to continue with a pregnancy can only be made by the mother, hopefully in consultation and agreement with the baby's father. The decision to terminate is one also for the mother, or parents if they are in agreement, but at later gestations this decision can only follow the offer of a termination, which will be dependent on the judgement of doctors that the risk of handicap is sufficient to lie within the law. Decisions about correcting abnormalities before birth can, again, only be made after full discussions between the parents and a range of health professionals about the safety, risks and benefits of a particular procedure in particular circumstances. It is important that good data are collected and evaluated about the outcomes from procedures that are in any way experimental and that units offering fetal surgery undertake regular audits of their procedures such that parents can make properly informed decisions. It is necessary to examine outcomes through a child's development and not just in the short term.

During a pregnancy, there are no circumstances when it is appropriate to override the wishes of a pregnant woman when her wishes are within the law. Abortion cannot be forced on any woman regardless of the state of the fetus, but similarly no procedure should be forced on any woman that she does not feel is in her best interests. This has been addressed in court in the context of caesarean section – the autonomy of the woman is paramount. It is essential that we bear in mind that all available evidence shows that women are deeply committed to their fetuses as the pregnancy progresses and do not make decisions lightly or flippantly or irresponsibly (Statham, 2003; Statham et al 2004).

Once a baby is born, different considerations apply and these are outside of my research experience so I will not comment on questions 2, 6 and 7.

Question 3:

These are important ethical questions although for the reasons stated above I would query whether the moral status of the fetus is relevant to debates about newborns. I look forward to reading the working party's deliberations on 'quality of life' and particularly how it is possible to apply ethical principles to the emotionally fraught situation in which individual parents, doctors and nurses find

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themselves. An interesting concept that we explored in some as-yet unpublished work on health professionals' experiences of feticide concerned the value of ambivalence. We wrote:

This is not to say that all doctors make the same decisions [about whether or not to offer late termination]; some are clear that they have views about some abnormalities for which they personally would not wish to be involved in a termination, which accepting that it may be acceptable within the law. Within the study, professionals were willing to express their ambivalence about these difficult areas. They were immensely thoughtful about what they do and the possible implications. We have suggested that it is their very awareness, their ability to recognise risks and to allow themselves to face up to their feelings, including ambivalence about what they are doing that ultimately enables these individuals to feel comfortable with this difficult aspect of their work. Kero and Lalos (2000) have explored ambivalence in women and men after termination for non-medical reasons. They have suggested that such ambivalence might not be problematic, as often presumed. It may indicate openness to the complexity of the issues when incompatible values around social responsibilities and ethical perspectives come into conflict. We would suggest that the ambivalence that was expressed by the health professionals within this study serves a similar purpose: these are individuals who have to combine their own sense of personal and social responsibility, their ethical perspectives and the duties of their chosen profession to women and unborn babies, within a legal framework that is not precise. (Statham et al 2002)

The value of ambivalence in this difficult area should be considered.

Question 4:

Issues around quality of life are important for parents making decisions, and have wider societal impact. From the parents' point of view, religious and spiritual influences are personal and individual and should not be considered relevant by the working party. It may be important to consider the religious and spiritual dimensions on health professionals' practices and what this means for patients. It is essential that the mass media is appropriately informed and challenged when it misleads but I do not know of research evidence that could be brought to address the question of media influence on decisions. A recent case that has had high media profile, the attempt by Joanna Jepson to obtain a judicial review of abortion law may have influenced doctors in their decisions but I would suggest that it was the threat of prosecution rather than the media that was influential. Our own research suggested that attitudes to post-24 week termination were changing even before this case.

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Question 5:

The parents, or in the case of disagreement the mother, must make the ultimate decision in the case of a fetus. Parental judgements of quality of life will be derived from the information they are given at the time of a diagnosis and also by prior experiences. Their personal beliefs and attitudes, often but not always underpinned by a particular faith, may however demand that they do not consider quality of life as long as there is life. In the antenatal period, this must be respected. I cannot answer these questions in relation to newborns.

Question 8:

In the antenatal period, the professional guidance around abortion provided by the RCOG and regularly reviewed would seem appropriate. Ensuring that best practice in antenatal screening is followed in all regions will benefit health professionals and parents. Training and support for health professionals should be extended as these are difficult areas which place heavy demands on staff.

Question 9:

Abortion legislation works well in cases of fetal abnormality, providing the flexibility that is needed to deal with complex issues.