

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

R Graham & J Rankin

Introductory points

In addition to responses to the specific questions posed by the Working Party, we would like to raise two general issues that relate to the document as a whole, and which in our view require further ethical consideration.

(1) The use of the term 'congenital anomaly' requires explicit definition as a broad term. The questions posed within the consultation document rely heavily on the phrase 'congenital anomaly'. It is important to highlight (for example with a detailed footnote) that this term covers a broad spectrum of abnormalities, from those that are lethal to those that are severely disabling, to those that may be considered minor. Clearly the perceived severity of the prognosis of individual conditions will impact greatly on the longer term implications and will impact on the ethical issues raised by prolongation of life.

(2) Ethical debate about prolongation of life must include the perspective of the care givers, as well as that of the fetus/infant and woman/parent. The ethical debates surrounding prolongation of life, and conversely, bringing about the death of the fetus/sick infant tend to be dominated by the dichotomy posed between the rights of the fetus/infant and the rights of the woman. However, it is important to also consider the impact of the right of health care professionals to conscientiously object to providing all but emergency care associated with termination of pregnancy. As a result of this right, women's access to abortion services in the UK is dependent on the existence of health care professionals who are willing to carry out the tasks associated with termination of pregnancy. Therefore it is important to consider the experience of those providing these health care services within the context of debate about ethical boundaries. In particular it is important to consider, from the perspective of the health professionals involved: a) the current situation around termination of pregnancy and withdrawal of care from sick infants; and b) the implications of any future policy changes.

Responses to specific questions

Question 1:

The only grounds for overriding the wishes of a pregnant woman should be the same as for all other medical interventions (i.e. on the basis of her mental status or in certain emergency situations?). As the woman is a full legal subject and the fetus is not, it would be incongruent to favour fetal rights over those of the mother without her consent.

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There is a need to distinguish between the consideration of intervention that is provided against parental wishes, and the consideration of the woman's requests for intervention that are refused. These constitute different circumstances in which the woman's wishes may be overridden, and the ethical principles are different.

Question 2:

In all cases, prolongation of life may be appropriate, even where that prolongation is expected to lead to an early delivery room/neonatal care unit death (see Spinnato et al., 1995, who comment on aggressive intrapartum management in US). However, unlike the US there may be a lack of consensus in the UK (Gross, 1999:460). This means that guidelines must have sufficient flexibility to allow prolongation where appropriate, rather than specific rules about when not to prolongate. Where explicit guidelines have been developed to determine thresholds for treatment of extremely premature infants, the threshold is considered negotiable depending on the circumstances of the case in question (see Sheldon, 2001) rather than a definitive gestational age.

For some conditions (such as Down's Syndrome and Spina bifida) there is some available data to make more informed judgements about how an anomaly may impact on the health of the affected population. However, it is important to recognise that there is a lack of data available for most other congenital anomalies, in terms of predicting mortality and morbidity beyond 12 months.

The final decision is taken by parents, and the space for that decision is created by professional interpretation of the law and personal ethics. See also response to Q 8&9 about perceived lack of consensus in UK.

Question 3:

In addition to the questions suggested in the consultation document, it is important to determine how health professionals providing care experience both aggressive and palliative intervention strategies. Further ethical questions related to that experience could include:

1. What impact would any proposed policy changes have on those who implement policy as health care providers (for example, in terms of how distressing health care work is coped with by the professionals involved)?
2. How should the two elements of (i) prevention of pain/suffering; and (ii) preservation of individual autonomy; be balanced? These two elements should be considered for all groups involved: the fetus, the parents, and the health care providers.

Question 4:

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What influence does societal support for those who are disabled have on decision-making re: TOP/treatment withdrawal? This includes:

- Determining the responsibility of the state for developing adequate support services and ensuring meaningful accessibility
- The relative economic disadvantage suffered by those who are not able to live independently

Question 5:

Issues of whose opinion should matter most will depend on nature of discrepancy between the different parties. For example, discrepancies may arise over different interpretations about (i) the morality of ending life; (ii) perceptions of ability and desire to cope with risk of long term disability in a dependant; (iii) the prevention of suffering - immediate, and long term.

Where the issue is about long term risk, then the ultimate choice should rest with the person who would take ultimate responsibility for providing that care - i.e. the main carer. If the discrepancy of opinion centres around prevention of suffering in the immediate term, professional opinion may need to play a more significant role. In all cases there is a need for parents to have access to good information so that they can make a fully informed decision.

The law is appropriate for challenging medical opinion where medical opinion is considered to be unreasonable.

Question 6 & 7:

Question needs to provide clearer remit of what economics should be balanced against.

Also the weight given to economic considerations will be dependent on the appropriateness of the measures used. So for example, Quality of Life (QoL) measures will be based on the main carer's view of QoL where children are unable or considered incapable of communicating this themselves. Similarly, using QALYs or other measures that rely upon years of life are problematic because they have the potential to reproduce existing inequalities between those with different health status, and those of different age groups.

Question 8 & 9:

Policies may be developed but there can be no expectation of successful implementation of definitive thresholds of care. There may be a relative lack of consensus within the UK about the ethics of late term abortion and prolongation of life (Gross, 1999), and the range of conditions that are included within the remit of the discussion is broad. As a result, health professionals and parents need to retain a larger degree of discretion to encompass the necessary case-

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by-case consideration. It is difficult to envisage new legislation that could encompass the necessary discretion.

If policies (with sufficient discretion) are to be developed, then it is important to explore the feasibility of such policy development with the key stakeholder perspectives: parents, health professionals, disability groups, and patients themselves where of sufficient age.

References

Gross, M. (1999) 'After feticide: coping with late-term abortion in Israel, Western Europe, and the United States', *Cambridge Quarterly of Healthcare Ethics* 8: 449-462.

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Spinnato, J.A., Cook, V.D., Cook, C.R., Voss, D.H. (1995) 'Aggressive intrapartum management of lethal fetal anomalies: beyond fetal beneficence', *Obstetrics and Gynecology* 85 (1): 89-92.