

South Manchester Clinical Ethics Committee

Prolonging Life in Fetuses and the Newborn

Public Consultation

Minute of CEC meeting 25-05-05

LB and AB outlined the terms of reference and broad purpose of this consultation, which has been sent to LB by the Nuffield Council on Bioethics. It was agreed that it would be appropriate for CEC to respond on behalf of the Paediatricians at SMUHT.

A number of broad areas of enquiry were outlined:

1. What appropriate measures should be taken where a fetus may suffer from serious abnormalities likely to be disabling in the long term? Are there ever circumstances where the mother's wishes may be overridden?
2. In which circumstances would it not be appropriate to use medicine and surgery to prolong the life of the newborn?
3. What are the principle ethical questions that should be considered (moral status of the foetus, acts and omissions, quality of life)?
4. What do we mean by 'quality of life' for a child, do religious and spiritual influences affect decisions, how do mass media affect decisions?
5. Who is best placed to judge quality of life for a child?
6. How much weight should be given to economic considerations in determining whether to prolong life of foetuses or newborn?
7. Should QALYs for a newborn be given the same weight as for a middle aged or elderly person?
8. Would drawing up more directive professional guidance be helpful?
9. Would drawing up new legislation be helpful?

There followed a wide-ranging debate on some of these issues. Considerable concern was given to the context in which this debate is occurring. On one level the debate is constrained by the present legal rules governing treatment of fetuses and the newborn. On another there was concern by some members of CEC that the context of the debate did not reflect true moral and cultural diversity in society. The phrasing of some questions suggests that there is an 'absolute' answer to the issue raised, whereas it was felt that answers could only be given on the basis that they reflected a particular moral or cultural perspective. At worst this might lead to purely medical or legal approaches to decision making. It was acknowledged by some members of CEC that this might lead to disagreement in practice. For example where a parent has one perspective and the medical or legal professionals have another, with neither side conceding the other's position it is likely that no resolution will be found. Failure to acknowledge this difficulty in the consultation may simply lead to a perpetuation of the present difficulties.

It was agreed that present legal rules were probably inadequate, given in particular the technological advances made in the last 10 years. However it was also agreed that such moral difficulties are presently dealt with informally on a daily basis in neonatal units throughout the country. In most cases parents and professionals settle the most appropriate way to treat the foetus or newborn in an amicable and pragmatic fashion. Trying to introduce tighter legislation, particularly in response to a few high profile cases in the media, risks developing new legal constraints to this informal process of decision making. This may then lead to loss of quality and validity in decision making and at worse could provoke more conflict between professionals and patients, rather than less.

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

CEC in general therefore had misgivings about new legislation or over regulation of what is becoming an ever more complex and sensitive area of clinical decision making.

It was agreed that improved professional guidance would however be more useful to parents and professionals. Such guidance should allow consistency of approach and the development of standards of decision making while still permitting professionals and parents to negotiate freely. The importance of individualised decision making was felt to be of paramount importance: what works for one situation may not work or be appropriate for another superficially similar one.

CEC had concerns about the use of quality of life measure in making decisions for individuals. The use of QALYs may be appropriate for population based decisions (such as the commissioning of services) but does not seem appropriate or to have any real utility for individual cases. Partly this relates to the way in which QALYs are calculated, particularly the choice of outcome measures and the robustness of research underlying such calculations.

Finally it was agreed that the issues surrounding foetuses and newborn were significantly different morally. Meaningful debate encompassing both was felt to be impossible and it was recommended that the debate should be separated into those issues relevant to fetuses and those relating to newborn.

Broad areas of agreement:

- 1) the debate should be separated into those issues concerning fetuses and those concerning newborn
- 2) supportive professional guidance would be helpful
- 3) new legislation is unlikely to be helpful
- 4) this debate must take into account moral and cultural diversity in society and should not be constrained by medical and legal models of decision making.

Postscript

Following this debate one CEC member offered the view that the rights of the mother are not absolute in decision making and that the rights of the father must also be considered.