

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

Mrs Nicola O'Connor

QUESTIONS ANSWERED:

Question 1

ANSWER:

I don't believe there are ever circumstances when the wishes of a pregnant women can be overridden.

Question 2

ANSWER:

These need to be assessed on a case by case basis, in discussion with parents. There is no way absolute directives can be given.

Question 3

ANSWER:

I agree that these are the principle questions that need to be addressed and that underpin the debate on this topic. I believe that the moral status of the fetus is important but that few would argue that upon birth, the baby as it is then should be granted full moral status. I believe the questions of acting and omitting to act and the quality of life are more important in the context of this paper.

Question 4

ANSWER:

These are questions that should be considered by the working group. In my opinion, quality of life issues are the most important social question. Long term support of babies who have been born very premature or have had peri-natal difficulties such that they have suffered long-term damage, is a vital challenge for society. Parents need to be supported in the care of babies with special needs for years beyond the experience of NICU. Parents are often in the dark in terms of what to expect on a longer term basis and the information provision to plan for possible outcomes is certainly lacking. In some cases there is a clear cut likely outcome but often this is more difficult and will only become apparent with the passing of the years, problems relating to premature birth may often only be diagnosed once the child starts school. There should be a joined up, multi-disciplinary approach to management and follow-up of such babies until school age. Failure to offer proper long-term support will undoubtedly affect the QOL of these babies. I think it is very important that there is proper dialogue between the neonatal medicine community and the mass media - intelligent and responsible reporting of such emotive issues is crucial. The mass media does play an important role although I'm not sure to what extent it can influence decision making.

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Question 5

ANSWER:

QOL judgments must be made in consultation with parents and doctors. Parents will be best placed to know whether they can ensure adequate QOL in the future and they must ultimately make the decision on behalf of their child. Doctors must be able to provide honest assessment of likely outcomes. They must help parents understand risks and help them weigh up different risks and benefits. We benefited from a counselling service when we were on NICU - I think it is important that trained communicators are involved in such discussions. Doctors are often not the best people to break bad news!

Question 6

ANSWER:

My head says that this is clearly an important issue as the NHS is not a bottomless pit of money! However, I do not believe that economics should govern decision-making about whether to prolong life of fetuses or the newborn. It is our social responsibility to provide for these babies who endure this rocky path through no fault of their own. In terms of burden on the NHS, I believe there are other groups where the discussion of economic considerations in terms of treatment decisions are more warranted (smokers, drinkers, overweight, diet-related problems. Neonates should not be considered in this context other than to ensure that long-term provisions for support are made.

Question 7

ANSWER:

I'm not sure I sufficiently understand QALY to comment.

Question 8

ANSWER:

The UK should not set a minimum age below which resuscitation would not be permitted. It is imperative that this is assessed on a case by case basis obviously depending on availability of resources and expertise etc. On a personal note, our son Lucas was born at 27 weeks, weighing just 560 grams after a month of severe growth restriction. He went into multi-organ failure and needed massive life-support. I don't believe he would have been given the same chance had we been somewhere like Holland. Today he is completely fine and we are an incredibly happy and lucky family. I know of many babies who were born pre 26 weeks who are doing very well and obviously enjoying life and giving great enjoyment and pride to all who know them. The idea that there would be legislation preventing their chance at life is pretty abhorrent. I think a key area that would benefit from additional guidance for both professionals and parents is the area of communication and explanation and understanding of risks. From my own experience, consultants were reluctant to make any predictions of the future however hypothetical. I think it's important for parents to know and understand the range of outcomes that could be possible. It cannot be a case of 'we'll cross that bridge when

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