

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.

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QUESTION 1

A) Provided that any measures taken do not endanger the health (or future health) of the woman and in full consultation with the woman and her partner, it is reasonable to take whatever steps the parents feel are appropriate for them and their baby. The difficulty with this is that the long term prognosis in these circumstances is very likely to be very uncertain and also very difficult to convey to parents. There are very few circumstances where the long term outcome is completely certain.

B) The parents are key in deciding this, but their decision-making has to be supported by clear intelligible information. In particular in this area it is likely that some interventions offered will be of unproven benefit. Where such measures are to be offered it should be made clear to the parents what the evidence is for the intervention and a balanced view given of possible risks and benefits. So, the measures that it may be appropriate to take are those which the parents decide upon with health professionals, in this wider context.

C) a key issue is the nature of the information upon which parents base their decision. This information won't necessarily be exclusively obtained from health care professionals dealing with their case – parents access 'information' from a variety of sources – for example: the media, internet, friends etc. etc. & it can be difficult sometimes for parents to identify valid / evidence based information.

D) this should be the parents' decision, but they should be given full evidence-based information including all possible risks and benefits.

F) In cases where to do so does not endanger the mother's life and where any negative effects on the mother are short term. She (and her partner) need to be able to choose this option if that is what they wish and the intervention/procedure is available.

A) Only in circumstances where there would be clear benefit to the fetus of taking one course and clear disadvantage/danger of taking the alternative course.

B) Maternal wishes may be overridden when the pregnant woman wants a fetal treatment which clinicians are clear offers no benefit to the fetus. Clinicians may not impose fetal treatment, even if there is clear benefit to the fetus, on a mother who refuses that treatment.

C) Maternal wishes may be overridden when clinicians have clear evidence that the requested treatment has no benefit to the fetus. However – this may cause the mother to seek treatment elsewhere.

D) Only, very rarely, where there is definite evidence that damage is caused to the fetus by following the mother's wishes about administering a particular treatment. However, treatment should not be imposed on a fetus where the mother wishes to withhold that treatment.

F) No, unless fetal medicine has reached such a stage when the positive benefits and success of the procedure for the fetus are very clear and there is a minimal risk for the mother

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QUESTION 2

A) It would not be appropriate to use medicine or surgery to prolong the life of a newborn provided the outlook is very grim (and this would not apply to the vast majority of congenital abnormalities) and the parents do not wish active treatment to be given. However, a point may be reached when repeated efforts to treat or resuscitate a neonate (up to 28 days of age) or infant (2 months to 12 months of age inclusive) are resulting in extreme distress to the neonate/infant with the prospect of severe disability in later life. It would be perfectly reasonable to withhold active resuscitation measures preferably with the parents' agreement. The difficulty arises when, as with the recent baby Charlotte case, the parents and professionals disagree.

B) None of these are absolute contraindications to use of medicine/surgery to prolong life. There are subsets of various types within all these groups where the clinicians and family may agree that further use of medicine/surgery is futile.

C) babies born extremely prematurely / with congenital abnormalities should not be automatically denied medicine / surgery. Each individual case (this applies to all 4 categories listed above) should be assessed based on likely short & long-term outcomes. It would be inappropriate to initiate interventions when a baby's long-term prognosis is certain to be poor.

D) all these would depend on the wishes of the parents. It is important to provide them with all available information about probable longer term outcomes.

F) First two points – would be appropriate to intervene, second two points it would be less appropriate, unless parents explicitly wish.

QUESTION 3

A) The principal and additional questions the working party should consider are:
The rights of the parents to have control over their own future life. That is the quality of their life as well as the quality of life of the child needs to be considered.
Acting and omitting to act.

B) The points listed are all important. I wonder if the "moral status of the fetus" should be re-stated as "balancing fetal and parental rights", as this includes discussion of the possibility for fetal "rights" while also acknowledging that fetal and maternal rights cannot be treated separately. A further issue might be in defining futility in continuing treatment.

C) Agree all of the above. Acting & omitting to act is something (in my experience) that neonatal nurses can sometimes have difficulty with - not doing something can sometimes be seen as being a 'positive' action.

F) No to 1), yes to 2) and 3)

QUESTION 4

A) The most important question relates to the quality of life of the child, the quality of life of the adult that child will become and the quality of life of the parents.

B) Agree with the comment above about the broader context of quality of life.

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While religion and the media (mass or otherwise) undoubtedly do exert an influence, what is of greater interest is how parents contextualise these influences into their particular experience. I would restate the last two points as: What are the significant influences on the decisions made by parents and others involved, including clinicians, and how can we understand how these affect decision-making? This broader question allows for discussion of other powerful influences, such as the family and past experience, rather than just religion & the media.

C) agree all of the above, parents often come under a great deal of pressure from their wider family, sometimes this is in turn determined by religious / spiritual issues – but not always. The mass media (& the internet in particular) is playing an ever increasing role in influencing decision-making.

D) I agree that these questions are important, also the influence of wider family and community.

F) 1) The quality of life for parents and the rest of the family is important, as well as that of the child and developing individual 2) I would prefer to ask about cultural differences, not simply religious/spiritual differences 3) The role of the media is relevant, but not something that the WP can actually address.

QUESTION 5

A) The parents

B) The child, at some point, then the parents.

C) the parents, if 'child' means newborn baby / infant.

D) Initially the parents, and as the child grows older the child herself/himself.

F) Parents and health professionals together

A) Unless there is some over-riding principle the parents should always have primacy over decision making. Difficulties arise when there is extreme disagreement between professionals and parents as in the recent baby Charlotte case. Professionals also have a duty to their patients including a duty not to cause undue pain and distress.

B) The parents' decision should nearly always carry the most weight.

C) The parents in the first instance, where there is disagreement between parents & health care professionals – the latter must always act in accordance with their duty of care / codes of conduct.

D) I agree that it should be the parents in the first instance. But difficulties might arise where there is disagreement between the mother and the father; in this case each situation needs individual resolution, there should be no general rule.

F) The parents together

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A) Ideally parents would agree. In the case of disagreement between parents it would always be easiest to take the more conservative route. However, in the long term it is highly likely that if the child is severely disabled in the future that the mother will be the primary carer and therefore it could be argued that in the face of disagreement between parents the mother's views should have primacy. On the other hand no professional should be required to be party to actions with which they do not agree.

B) Parents together. Where there is disagreement between parents every effort should be made to explore and understand the reasons for that and to support the family in achieving consensus.

C) Ideally parents together – but when there is disagreement between unmarried parents, fathers are often shocked to discover the extent of their legal status.

F) Parents together

B) Whoever is needed by the key parties. Both the parents and the health professionals involved may seek advice and support from diverse sources according to their circumstances and needs.

D) This would vary according to each 'family' and its social context.

F) Health professionals, possibly other family members

A) Decisions of these types need to be taken after all the necessary medical investigations have been completed so that as much information is available as possible and extensive discussion between the professionals involved and the parents. No professional should be required to be party to actions with which they do not agree.

B) Decisions need to be made in the light of as much relevant information as possible. Where there is disagreement between parties to the decision every effort should be made to explore and understand the reasons for that and to achieve consensus. In general it appears highly undesirable for these decisions to end-up in court. Professionals with skills in mediation or conflict resolution may be helpful, especially where these people are part of the team and already known to the family.

C) Agree with most of the above, except that when professionals with skills in mediation are brought in, it may be better if this person is someone from 'outside' of the team – so that all of the parties involved can feel confident that the 'mediator' is acting in a completely unbiased way.

F) It is important to allow time, probably in the course of several meetings for everyone to express their views and to discuss the issues and to revisit these as many times as possible. It is really important for parents not to feel rushed.

A) The law should always be the last recourse when disagreements between the parents and between the parents and professionals cannot be resolved.

B) Last resort.

C) Only if it has not been possible to reach a decision any other way.

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D) I agree that it should be the last resort.

E) While the law should be the last resort, it is important that this option continues to exist for parents who genuinely feel the need to challenge medical advice

F) Would expect this to happen when people feel their views and wishes have not been heard and when such views are very well established

A) A similar weight to the weight given in relation to prolonging the life of any person.

E) Economic considerations are probably more important when considering these issues in the majority rather than in individual situations. It is important that parents understand their personal potential economic impact if choosing to prolong the life of their fetus / newborn.

F) Some weight should be given, but in the context of considering the emotional as well as the financial cost

QUESTION 7

A) No

B) Yes

C) no

E) although QALYs rely on giving more value to an older person (I think!), it appears inconsistent to value the life of a newborn as lower than that of an older person. Indeed, the lives of children are often viewed by society as more important – when children are killed, the reaction of the public is stronger. However, the life of a fetus and its value is a more complicated question, relying on a view around when a fetus becomes a person.

F) Probably

QUESTION 8

A) Yes, but it is not clear on what basis more directive guidance could be formulated except in the example given below.

B) No

C) rather than 'directive professional guidance' constantly updated information pooled together in an easily accessible format re: current issues / research findings would be useful – so that informed decisions can be made

D) I agree that updated, easily accessible information should be made available, rather than directive professional guidance.

E) I suspect that more directive guidance would be of more use to professionals than to parents

F) No

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A) Yes. Information on gestation-specific long term outcome is provided by the results of the EPICURE study.

B) No. Resuscitation should not be offered based on an arbitrary cut-off around gestational age. Although the EPICURE study provided long-term outcome data, it still remains impossible to say that (for example) all babies born before 26 weeks will not survive, or will be severely disabled. Resuscitation should be based on a multi-factorial approach incorporating gestational age, weight, condition of the infant, infection and so on.

F) Probably not

QUESTION 9

A) This rather depends upon what the purpose and extent of the legislation would be.

B) No

C) No

F) Probably not