

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

Royal College of General Practitioners

Question 1:

The answer to the first question within question 1 is that each case must be judged individually and on the basis of existing guidelines, such as those listed on pages 36 to 37 in the consultation paper, which we believe, are as specific as they can be.

The answer to the second question is clearer: the pregnant woman has autonomy over her person and any action intended to benefit the foetus can only be undertaken if it either has no consequence at all to the pregnant woman, or it is done with her consent. An exception, where the wishes of the pregnant woman are overridden, could be if she suffered from serious mental health psychotic illness.

Question 2

All the circumstances listed in the question could affect a decision to use, or not to use, medical or surgical techniques to prolong life. To obtain further help than the current guidelines provide, a quality-adjusted life (QALY) score should be devised. As a general rule, treatment should be commenced if there is any degree of uncertainty as time may be an issue. In the last three scenarios, the parents' wishes are extremely important. It is also essential that foetal pain and suffering is limited.

Question 3:

1 The moral status of the fetus

2 Acting and omitting to act

3 Questions about the quality of life

The questions listed are the principal ethical questions that the Working Party should consider but we would rank their importance in the reverse order to that printed (making 'questions about the quality of life' first), on the grounds that once a more objective assessment of the effect of medical intervention is clearer, the moral issues, which are in themselves much harder to deal with, may become easier to solve. The rights of parents should also be taken into consideration.

Question 4:

Quality of life could be judged in a similar way to that for older people, but some of the areas will of course be different and there will be different priorities, such as the ability to engage in family life; socialising with other children in play and education; achieve independence in life. The consideration of social issues raises, in itself, ethical and moral issues of their own.

If the assessment is to be widely applicable, it cannot be specific to religious groups yet where there are religious and spiritual influences on decisions they can be expected to be unique in each case and will affect both healthcare professionals and parents. There also needs to be a debate around the quality of life issues trying to separate cultural influences.

The mass media itself should not influence the decision and it is questionable whether consideration by the Working Party on this matter will make any difference. This question has far lower importance than the first two listed in the question.

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Question 5:

The quality of life needs to be judged as objectively as possible, by the main professional carer for the child, but the assessment itself will of course involve the parents very closely. The family may be in the best position to judge the quality of life. Consideration could be given to the availability of some type of trained objective mediator, rather than a legally qualified person acting in a legal capacity, to help to reconcile in cases of disagreement.

If both parents are involved, equal weight should be given to the opinions of both parents (whether legally married or co-habiting) but if they disagree, the healthcare team may need to arbitrate.

The Court should be reserved for when agreement cannot be reached about a decision. Then the role of the Court is indeed needed and there should be no question as to whether or not this should ever happen, as raised in the last part of Q5. Yet in issues with such emotional content, the final legal judgment can never be expected to change the opinion of the losing party.

The family may wish to involve a religious or spiritual leader.

Question 6:

How much weight is difficult to quantify, but not nil. Moralists could well argue the case from a utilitarian philosophy that the state should only be expected to put in a certain level of funding which equates to the overall good the state can expect for the newborn, family and the wider community as a whole. The practical issue is in fact implicit in funding limits for the NHS, whereby the state gains from the sense of confidence in health amongst the population as a result of the NHS being able to provide care well in excess of the earning ability of individuals who become seriously ill.

Question 7:

Yes, if the criteria can be made appropriate to the age of the person being assessed, then ideally the measurement would be in the same unit. However, the limitations of QALY, or any other measure where applicable, need to be taken into consideration, such as different perspectives from person to person as to the meaning of 'quality of life'. These limitations would disqualify the use of a QALY measure in the opinion of some people.

Question 8:

It is important for any further professional guidance, or information to parents, to note the increasing evidence about the long term disabilities of children born very prematurely.

On the question whether there should be a minimum age below which resuscitation normally should not be permitted, our members differ in their opinion. Some suggest a minimum age could assist health professionals and reduce the need to involve the Court, although they concede that it is likely to seem irrelevant to emotionally involved parents. Others disagree. If an age limit were put forward, however, some of our members would not wish it to be left to the individual to take a case by case approach, rather it should be based on existing evidence and QALY and then if a baby is born below that age it should be allowed to die.

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Question 9:

Prescriptive legislation is impossible in decisions whether to treat or not, while clear professional guidelines are preferable. Guidelines are preferable as they leave room for manoeuvre where expectations arise and also allow decisions to be made on a case by case basis.