

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

Jan Deckers

QUESTIONS ANSWERED:

Question 1

ANSWER:

The chances of making a significant improvement in the fetus's condition must be weighed against the risks associated with the procedure. A relatively non-invasive procedure that can make a major improvement in the fetus's condition is easier to justify than an invasive procedure that may only make a minor difference. In most situations, this implies that chorionic villus sampling and amniocentesis are immoral because of the high risks associated with these diagnostic tools. For these procedures to be justifiable there must be a relatively high chance that the fetus is affected with a treatable condition. Like with children, fetuses can also suffer from neglectful parents. It would be appropriate to override the wishes of parents when health care professional or courts have good reason to believe that a particular lifestyle choice, for example one's diet, may negatively affect the development of the fetus. As non-disabled people do not have the right to discriminate against disabled people, pregnant women do not have the right to discriminate against disabled fetuses, and therefore should not be allowed to have an abortion on disability grounds. A pregnant woman's wish to have an abortion, therefore, can be overridden. However, there are situations when it would be unethical not to comply with a pregnant woman's wish to have an abortion. These situations should be limited to situations when there is a serious risk that continuing with the pregnancy will result in the death of the woman (e.g. ectopic pregnancy), or when conception has occurred after a coercive act (e.g. rape), and when the fetus is not viable outside the womb.

Question 2

ANSWER:

In all these situations, it is appropriate to weigh up the costs involved per unit of health gained against what could be achieved with the same financial resources elsewhere. It would be unethical to provide expensive treatment to a baby when that baby is unlikely to ever live free from invasive procedures when that money could be used for the development and provision of drugs for conditions such as malaria and HIV. What needs to be borne in mind, however, is that it is not possible to gauge accurately what the long-term prospects are for the quality of life of babies with these conditions, and that it is notoriously difficult to estimate what some babies will be able to achieve in the long-term (given the great variety in responses to treatment). It is good practice to err on the side of caution. For those who have a reasonable chance of achieving a state of living life relatively autonomously (i.e.: without the aid of expensive machines that may, to a large extent, take over autonomous body functions), it is advisable to think that their quality of life is good, in spite of their abnormalities.

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Question 3

ANSWER:

All questions are important. I refer for the moral status of the fetus to my 'Why Current UK Legislation on Embryo Research Is Immoral' (in *Bioethics* 19 (2005,3) 251-271), where I develop egalitarian speciesism or the view that all humans are equal and deserve more moral significance than members of nonhuman species. There are no justifiable grounds for discrimination within the human species. This does not imply that all humans should be treated the same, as circumstances are morally relevant. It also does not imply that the right to life is absolute. With regard to the distinction between 'acting and omitting to act', in some situations, omissions are easier to justify than actions. The reason why many people are opposed to euthanasia relates to a deep sense that there is something good about allowing natural processes to take their course. When medicine can no longer restore the autonomous functioning of the body, it is appropriate to withhold or withdraw treatment, rather than to prolong a life that has no hope of being able to be restored in its autonomous functioning. However, especially in situations when the person is too young to give informed consent, it would not be appropriate to give a lethal injection to someone who is dying. It would contravene the goal of 'primum non nocere'. We need to learn to live with the fact that people die. Controlling death is more problematic than allowing death to take control. With regard to the notion of 'quality of life', three issues must be borne in mind. Firstly, we must think about the quality of life of all humans equally. This implies an imperative to allocate health care resources more fairly. Secondly, judging the quality of life others experience is difficult. Judgments of the quality of life of disabled people may be influenced by a lack of personal contact with disabled people (in our disabling society) and many people with severe disabilities value their lives more highly than the value that is bestowed on them by others. Thirdly, we are all prepared to suffer relatively great temporary discomfort for our long-term benefit.

Question 5

ANSWER:

The courts should ultimately make the decisions, informed by the best medical opinion. In situations when the courts cannot be consulted, healthcare professionals should decide in a team as they are the best placed to assess whether there is a reasonable chance that treatment will benefit the fetus or the newborn baby. The views of both parents should carry equal weight.

Question 8

ANSWER:

No minimum age should be specified, because of the following three reasons. Firstly, determining the time when someone becomes pregnant may not be accurate. Secondly, neonatal care may advance and the age when premature babies can be kept alive may decrease. Thirdly, specifying a minimum age presupposes that all fetuses develop at the same rate, which is countered by evidence.

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Question 9

ANSWER:

There is a moral imperative to draw up new legislation as disability should not be a legitimate ground for abortion.