

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 Jayne McCoy

QUESTIONS ANSWERED:

Question 1

To enable me to answer your questions consistently and reasonably I found that I first had to formulate my views and standpoint. Whilst reading the consultation paper my views formed and expanded based on the background information therein. I have added my "Statement of Views" to my response here to help clarify my answers. PROLONGING LIFE IN FETUSES AND NEWBORNS. Personal statement of views Moral and ethical standpoint A decision of whether to promote life or not, based on whether, or how badly disabled that life may be in the future, is effectively discrimination against disability. Those experiencing reduced quality of life can only truly make judgements about quality of life. It is for them to decide whether the pain and restrictions of their condition are worth suffering in exchange for the experience of life. Similarly treatment should not be withheld on the basis of economic factors. That is putting a value on human life and weighing it against the return of a profitable life or one that uses public funds to maintain it. Again it is discriminatory against disability. There are also other, immeasurable, returns that a life can bring to others such as love, example, friendship, which do not generate income, but who is to say these things are less important. To consider economic factors when treating fetuses is similar to considering whether to give expensive treatment to an adult depending on how valuable they are to society. Do we withhold treatment from a middle-aged man because he has never been in employment and has engaged in criminal activities? If medical science has the ability to give life, then it should do so in a non-judgemental fashion. Responsibility for decisions about fetuses and newborns. Whilst in the womb a fetus is inseparable from the mother. The mother therefore has all rights over the fetus as she has over her own body. I believe that these rights should continue after delivery until the newborn is able to sustain life unassisted. The same rights should be given to the father once the newborn has left the mother's womb. All decisions about whether to promote life, or withhold treatment, should be left with the parents. The issues involved are too complex to be legislated for. The parents should be given full and unbiased details about the likelihood of disabilities, the chances of survival and length of that survival, the potential suffering to the infant that treatment can cause and also the truth about the unpredictability or uncertainty of the effects of treatment. The parents should then be left to consult with their family and whosoever else they wish, to make decisions about treatment of the newborn. Parents will make the decision that is right for them and will automatically take into account religious and social factors. Some people will be prepared to take on the burden of

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

caring for a severely disabled child just to give the gift of life. Others may not have the physical or emotional resources to deal with a disabled child or an infant who may die very young. As it is the parents who will have the burden of care it is unfair for the courts to make the decision. It may be seen as reducing the quality of life of the parent. Where there is conflict between parents all efforts should be made for mediation with counselling and other resources made available to facilitate a joint decision. If this fails then the final decision should rest with the mother, as the burden of physical and emotional care usually falls to the mother. If the father is prepared to take on the full burden of care where there is still disagreement, and the issue is of being able to cope, then the father can take the final decision. The acceptance of responsibility by the father will probably need to be made in writing and legally binding. The parents should be able to make their decisions privately and free from any judgemental views being expressed by medical staff. As an infant is unable to determine its own care, the parents should be trusted to make a decision based on their views about quality of life and taking into account moral and ethical considerations. Right to life From the age at which abortion becomes illegal, the fetus has a right to life, which should be taken as the right not to have life terminated. However the withholding of treatment to prolong life should not to be considered termination and the decision of whether to proceed with intervention to prolong life expectancy should be that of the parents. The issue of people bringing wrongful life lawsuits in the USA is unacceptable. Without the gift of life those people would not be in a position to make a case about their situation. Are they able to say that experiencing nothing, being given no opportunity to experience, is better than experiencing thought, comprehension, albeit marred by pain? They should be given the opportunity legally to end there suffering if they so wish but no one should be able to sue for being given life. Note: I make this statement from the position of an atheist and able-bodied individual with no attachment to any particular moral or ethical groups.

Question 1 It is appropriate to take any action available to sustain life or correct abnormalities if it is in accordance with the mother's wishes and she has full and frank information about the possible outcomes or effects of treatment both on herself and the fetus. It would be appropriate to override the wishes of the pregnant women where she is certified mentally incapable of making rational decisions (e.g. she is mentally handicapped), or where she may have previously expressed her wishes but a change in her circumstances (death; coma with no possibility of recovery, for example) mean that the burden of care of the infant would no longer be her responsibility.

Question 2

It would be appropriate in all cases to prolong life if it is in accordance with the wishes of the parents.

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

Question 3

The moral status of the fetus is important as it brings with it the right to life and therefore medical treatment. The question of who makes decisions on behalf of a being with rights and status also follows from this issue. Acting and omitting to act should be considered, with not acting being viewed as distinct from termination of life. Quality of life is not an issue that should be taken into account by medical or legal persons, as it is a discriminatory judgement. This can only be considered by the affected person themselves or their legal guardian (here usually the parents).

Question 4

Whilst I accept that all these factors have an effect on the decisions made about prolonging life in fetuses and newborns, they are not issues, which the council should give opinions or statements upon. The giving or not of medical treatment should not be based upon "quality of life" judgements, not should they be influenced by the whims of the media. The religious and spiritual factors are too varied and complex to allow a cohesive statement of policy. By handing the responsibility of decision making to the parents and families of the infant in question then all these factors will be taken into account by the people best placed to assess the benefits and limitations of treatment. What should be considered is whether medical staff should be in the position of making moral, social or economic judgements about their work. Surely they should remain impartial and prolong or maintain life in accordance with the wishes of their patients.

Question 5

A decision of whether to promote life or not, based on whether, or how badly disabled that life may be in the future, is effectively discrimination against disability. Judgements about quality of life can only truly be made by those experiencing reduced quality of life. It is for them to decide whether the pain and restrictions of their condition are worth suffering in exchange for the experience of life. As an infant is unable to determine its own care, the parents should be trusted to make a decision based on their views about quality of life and taking into account moral and ethical considerations. Whilst in the womb a fetus is inseparable from the mother. The mother therefore has all rights over the fetus as she has over her own body. I believe that these rights should continue after delivery until the newborn is able to sustain life unassisted. The same rights should be given to the father once the newborn has left the mother's womb. All decisions about whether to promote life, or withhold

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

treatment, should be left with the parents. The issues involved are too complex to be legislated for. The parents should be given full and unbiased details about the likelihood of disabilities, the chances of survival and length of that survival, the potential suffering to the infant that treatment can cause and also the truth about the unpredictability or uncertainty of the effects of treatment. The parents should then be left to consult with their family and whosoever else they wish, to make decisions about treatment of the newborn. Parents will make the decision that is right for them and will automatically take into account religious and social factors. Some people will be prepared to take on the burden of caring for a severely disabled child just to give the gift of life. Others may not have the physical or emotional resources to deal with a disabled child or an infant who may die very young. As it is the parents who will have the burden of care it is unfair for the courts to make the decision. It may be seen as reducing the quality of life of the parent. Where there is conflict between parents all efforts should be made for mediation with counselling and other resources made available to facilitate a joint decision. If this fails then the final decision should rest with the mother, as the burden of physical and emotional care usually falls to the mother. If the father is prepared to take on the full burden of care where there is still disagreement, and the issue is of being able to cope, then the father can take the final decision. The acceptance of responsibility by the father will probably need to be made in writing and legally binding. The parents should be able to make their decisions privately and free from any judgemental views being expressed by medical staff. Medical advice is just that – advice. There should be no need to challenge it in law as the ultimate decision is made by the parents, who can choose to follow advice or not. Advice is not prescriptive.

Question 6

None. Treatment should not be withheld on the basis of economic factors. That is putting a value on human life and weighing it against the return of a profitable life or one that uses public funds to maintain it. It is discriminatory against disability.

Question 7

It would be unethical and immoral to make medical decisions using a quality of life measure. Who is to say what the condition of life is worth in any form.

Question 8

No, professional directives are incapable of keeping up with clinical developments or of meeting every possible situation. The parents decided

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 to create life; it should be their decision whether to prolong that life if it is possible to do so. Doctors will not intervene or suggest treatment if there is no possible chance of improvement in the condition of the life under consideration. Therefore if there is an opportunity to improve life it is up to the parents to make the moral, social and ethical decision about whether intervention is worth the risks.

Question 9

Only legislation regarding the moral status of the fetus and newborn, and who is to take responsibility for decisions made over the life of that infant is relevant.