

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

The Policy, Ethics and Life Sciences (PEALS) Research Centre

Question 1

This of course depends on the meaning of “serious” – it is very difficult to give an adequate account of serious and attempts to describe a threshold are in danger of begging the question. Such definitions are notoriously vague and we note that under the terms of the Abortion Act there is in practice a liberal interpretation of “serious abnormality” as seen in the recent contested case of the termination for cleft lip and palate. We suggest that “serious abnormality” includes conditions that combine profound physical and likely cognitive impairment with poor or limited prognosis but note that in some instances this is a changing territory. However, even in the context of severe abnormality, if there is a high chance of successful correction, albeit with some residual disability, then intervention is probably justified.

In consideration of whether it is ever right to override the wishes of the pregnant woman, there are two aspects to acknowledge. First there is the question of whether it is ever justified *in the interests of the fetus* to override the wishes of the woman who does not wish the fetus to be treated? We note that in law the matter has been explored in a sequence of cases (*Re S* [1992] 4 All ER 67, *Re MB (Caesarean section)* (1997) 2 *Family Court Reports* 541, *St George's Healthcare NHS Trust v S* [1998] 3 All ER 474) with the issue “settled” in the latter case when the appeal court ruled (*inter alia*) that bizarre, irrational even repugnant opinions did not result in S lacking mental capacity or constitute a mental disorder with the conclusion that the right of the woman to refuse treatment ought to be respected in spite of any consideration of the welfare of the fetus. Whilst the position in law may be clear the moral and social implications are far from clear. Midwives and obstetricians have reported how difficult they have found these situations where they have been forced to witness the death or injury of a healthy fetus that would have survived but for want of a proven medical intervention. The women concerned have also been reported to express regret that their decision was not overruled in such circumstances. A senior obstetrician reported to one of the authors that he would rather risk prosecution than stand by in similar circumstances believing that the woman generally would be pleased to have a healthy child. It is clearly right to support individual autonomy with legal sanction but where regret comes soon after such a choice and with serious cost such judgements seem questionable.

The situation is of course more complicated when the matter concerns the treatment or amelioration of a serious condition, where the outcome is uncertain but at best there is unlikely to be a normal live birth. It is important that in such circumstances health professionals have as accurate knowledge as possible regarding effectiveness of treatment and long term prospects for survival and quality of life. The woman concerned should be supported to make the best possible decision; but it should be *her* decision.

Some general measures that might contribute to good practice in such circumstances include:

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- Early discussion between health professionals and patient with a view to aiding the patient to identify her own coping strategies and preferences with regard to certain hypothetical situations.
- Informed and trained midwives capable of discussing such topics in antenatal classes.
- Communication skills training for health professionals with the aim of establishing and maintaining effective communication with their patient throughout their care.
- Use of additional personnel with expertise in counselling and specific knowledge of disabilities.
- Attempts should be made to help the patient to identify their abiding wishes should such circumstances arise in which they may have to accept or reject intervention.
- Where modest interventions are judged likely to be highly beneficial then communication methods that are highly persuasive are justified.

However in circumstances where the fetus has serious abnormalities and the future prognosis and quality of life of the child is open to question then the discussion ought to be informative and supportive taking full account of the fact that the woman is likely to be the best judge of her ability to cope with caring for a seriously disabled child. However, it should be noted that the possibility of adoption for a disabled child is an option that could be sensitively explored with the prospective parents. Above all the woman must be supported in making her own decision and such support must be maintained no matter what the outcome or future frame of mind regarding the decision.

This said, we suggest that the Council consider recommending a review of the Law in this area as we believe that the right to self-determination can be wielded as a blunt instrument in circumstances where the outcome of respecting such a right is repugnant. We do not suggest a return to the days in which a pregnant woman's wishes were overridden with impunity. However we believe there is a more nuanced middle ground to explore in this area.

The second aspect of this question concerns the situation in which a pregnant woman demands that doctors intervene to treat or save her ailing fetus in the face of a contrary medical opinion. In the recent past the competent person's right to self determination has been construed solely in terms of the right to *refuse* treatment however the Burke case (undecided in the Court of Appeal at time of writing) raises the possibility that under Human Rights legislation then an individual may have a positive entitlement to treatment and this might well be extended to the pregnant woman's claim to have her fetus treated. In the Burke case the General Medical Council (GMC) guidance entitled *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* was criticised. Munby J noted that there was too much emphasis on the patient's right to refuse rather than to require treatment with a failure to acknowledge the presumption in favour of life-preserving treatment. A decision in Burke might also have implications for the situation under discussion here.

However it should be understood that the principles of practice outlined above will still apply in this situation. It is to be hoped that a woman who is well informed, supported, and has a good rapport with her carers is likely to take a realistic view of the situation. It

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goes without saying that what is “realistic” will depend on one’s perspective. It is in this circumstance that attempts to define, as explicitly as possible the appropriateness of care along with judgements of the proportionality of intervention must be made. Such justifications are unlikely to be persuasive to a woman fixed in her belief that her fetus/neonate must be treated at all costs. There can rarely be a happy resolution of such stand offs but judgement to withhold or withdraw treatment must nevertheless be robust, and able to withstand external scrutiny as to their reasonableness.

Question 2.

The bulleted points in this question are rather too general to generate specific detailed responses however the following broad principles apply:

- The extremely premature – the borderline of viability is currently 23 – 26 weeks gestation however it is probable that this will be improved upon in the near future. It seems reasonable in the light of the poor outlook that comfort measures are most appropriate at this stage, but any guidance in this area must be open to regular review.
- Congenital abnormality per se is not a reason to withhold treatment. Congenital abnormalities can be mild or severe and vary in prognosis. Even severe congenital abnormalities can be treated and are compatible with a good quality of life. We suggest therefore that nothing is ruled out without a thorough assessment of the risks and benefits in individual cases. However prognosis should not depend upon a post-code lottery of resources.
- Where the baby has poor prospects of survival (and it is always useful to quantify such statements) then it seems reasonable to apply comfort measures rather than invasive treatment.
- Brain damage with severe disability again suggests comfort measures rather than invasive treatment, although, as our discussion below will disclose even severe disability does not preclude a good life.

Question 3.

Principal Ethical Questions:

1) The moral status of the fetus is a profound and important issue; this said we are not convinced that it is of central concern to the question in hand. There have been volumes written on this question and no doubt there are volumes still to be written. However despite the lack of a consensus on the moral status of the fetus there is wide international agreement of a pragmatic kind on how to proceed in research, treatment etc. we do not believe that any findings of this enquiry with regard to the moral status of the fetus will profoundly change matters and therefore we suggest that the Council make a statement regarding their presumption on this matter. We suggest that the presumption ought to be that the fetus, as considered in the matters in question, does have moral status of a kind at least equivalent to that of the newborn child. This position does not require a definitive statement as to whether such status is *intrinsic* or *proxy* for example in the way that John

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Harris describes this. Harris, who argues against the intrinsic moral status of the fetus, allows the caveat that neonates may aspire to proxy moral status, that is, if by harming the neonate its parents are wronged because killing their child violates the strong preference they have that their child (foetus or embryo) should not be killed.¹

We believe that the fetus is in the process of entering the moral community by going through the process by which all human individuals gain their moral status. We believe that this is achieved initially and principally, by parental love and regard for their developing child. We accept that not all of the dilemmas under consideration in this enquiry will be in circumstances where there is unequivocal parental love for the fetus but most will be. The most important question is that of what it is right to do to or refrain from doing to an individual that has moral status, and on this point we do not draw a firm line of distinction between the fetus, the neonate or the terminally ill adult.

2. Acting and omitting to act: this is another of those *big* ethical questions discussed in both ethics and law. We believe that much of this discussion is a distraction, perhaps even an academic means of avoidance of the real issues. We believe that acts and omissions can be morally equivalent and sometimes omissions may be morally *worse* than acts. However the fact that most omissions can be re-described as acts and vice versa suggests that the distinction is rather arbitrary. We would rather see a discussion of the meaning of certain acts (and omissions) in the particular context at hand. We believe that the important issues here are about death and the nature of the good death. Removing a terminally ill child from an incubator and allowing her to slip peacefully into death cradled in her mother's arms is but one example of a possible good death, and a good outcome, in what are otherwise tragic circumstances. We believe strongly that the Council should focus on these matters rather than become distracted with technical philosophical arguments.

3. Questions about quality of life are also important and also raise some hotly contested issues. There is clearly scope for further empirical research into developing instruments useful in measuring aspects of quality of life. However there are also broader questions for example about who makes such judgements and in what context. To single out one area of concern, upon which we will comment further below, we suggest that the Council attempt to distinguish the different contexts in which quality of life judgements are made. In particular it would be useful to see the distinction made between quality of life measures that inform the care of an individual from the use of such measures as justifications in the use and distribution of resources.

Question 4:

We believe that these are important areas of enquiry. Here we focus on the quality of life question. One useful way of unpicking the concept of quality of life is via axiological theories, theories of the good life. Some have argued that having a disability is incompatible with having a good life we believe this is untrue, a problem here is the common confusion between objective and subjective notions of quality of life. We would draw the Council's attention to a recent book by Professor Steven Edwards (2005) *Disability: Definitions, value and identity* Radcliffe Publishing, in which he argues that living a good life (a quality life) is not incompatible with disability. In making his case

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Professor Edwards draws extensively upon axiological theory. Edwards's arguments are mainly conceptual in nature but there is also extensive empirical evidence regarding the quality of life of individuals living with disability; and this should also be taken into account.

Question 5:

This matter is most easily and conveniently resolved when all parties agree. However, as is often the case, there are differences of opinion between professionals and parents and between parents and parents and other family members. There are many issues which deserve separate consideration for example factors that affect breakdown in communication, power differences between the involved parties, and the established infrastructure through which these disagreements are mediated, to name but a few.

One of the central factors in the dynamics of these contested situations is the nature of the judgement that needs to be made. The individual, whose quality of life is in question, is unable to speak for him or herself and future predictions are by their very nature imprecise. Health professionals are required and empowered in certain circumstances to plan their approach on judgements of *best interests* but this concept is itself not sufficiently clear so as to distinguish best *medical* interests from the range of interests a motivated and loving family may consider paramount. The problem is that there is no single uncontested account of what constitutes an individual's best interests and it would be futile to attempt to give such an account. A possible approach might be to attempt to give an account of the sort of considerations that go into medical judgements of best interest together with some account of the process by which parents may contribute to such judgements. There is no room in this process for facets of medical paternalism but a process that is transparent, equitable and respectful may foster trust and co-operation even when there are fundamental disagreements.

Doctors are notorious for underestimating the quality of life of individuals living with disability. Therefore doctors and prospective parents would benefit from being properly informed perhaps by being exposed to the views of adults from the disability community, or families living with disability. This has been the aim of one of the authors through the "Answer Project" a Wellcome Trust funded project to create a resource for parents facing antenatal screening. This resource can be located at www.antenataltesting.info

Recourse to the law should be the last resort, although inevitably the law will have informed earlier aspects of the dispute. However where it is necessary to go to Court then the procedures ought to be person friendly, sensitive and swift.

Question 6.

Clearly there are economic constraints and opportunity costs involved in every health decision and it would be helpful to have more open and general discussion of this fact. In deciding what role economic considerations ought to play in fetal/neonatal medicine then this should be framed with due consideration of a concept of justice, what is fair, and how are we to treat people as equals? Some people will have conditions that are expensive to

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treat, others will be inexpensive to treat, but to treat people as equals does not require that we treat people the same with respect to the resources put at their disposal.

We do not believe that the point at which a decision in an individual case is the time or place to discuss economic factors. Rather the economic considerations should inform public policies generally and national approaches to standards in fetal/neonatal care in particular. It is possible, but clearly not always, to distinguish between clinical and financial factors in a decision for example by asking whether this is an intervention that would be used in circumstances where cost was no object.

In addition we believe that concepts such as cost, benefit and efficiency all of which are morally and politically laden terms should be thoroughly unpicked and disclosed.

Question 7:

QALYs and other such measures are problematic both with regard to the methods through which they were developed and the uses to which they are put. QALYs, it is argued, are robust because of the methods used to develop them. QALYs get their validity from intra – person comparisons in other words by asking individuals to rate different life states (conditions) symptom clusters, making trade-off judgements but in respect of their own life (intra-person comparison). However QALYs are often used (this is true of the NICE applications) in a way which makes *inter-person* comparisons – comparisons between different people.

It may be obvious that where an individual faces a choice between two different treatment options that they and the system should prefer the option which maximises their QALY gain. However it does not follow that where this involves different people that the one who stands to gain most QALYs should automatically benefit at the expense of the other. This is quite a different matter and constitutes a moral and political judgement far removed from the intra-person comparison that formed the basis of the QALY measure. Choices I make for myself with regard to my own life are different in kind from the judgement that the establishment should make between me and another citizen. Comparing the old against the young in a crude way is potentially divisive and unfair.

Question 8.

Directive professional guidance can be helpful although there are subtle differences between guidance, regulation and legislation which can often serve to confuse in a particular context. Any guidance should also permit as much scope as possible for allowing good clinical judgement that also involves the parents in the process. Any guidance must include a date for regular and thorough review given that this is a rapidly changing arena.

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Question 9.

New legislation is time consuming, inflexible and often out of time with the pace of change. We believe that much could be done to clarify the existing legal position and would prefer this to new primary legislation. However we have indicated above the areas we believe would benefit from further review.

¹ Harris J (1999) The Concept of the Person and The Value of Life. *Kennedy Institute of Ethics Journal*. 9,4,293-308