

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

Where *in utero* intervention can correct an abnormality, it should be weighed only against the likely outcome of postnatal correction or doing nothing. Consideration should be given to the relative distress caused to the parents in the event of a failed intervention *in utero* or postnatally: it seems probable that less distress would result from a failure leading to a stillbirth or termination (“we tried but failed”) than a failed postnatal correction (“he underwent several operations after he was born, and was fatally damaged as a result”).

An intervention that will sustain the life of an otherwise nonviable fetus, with no chance of correcting an abnormality either *in utero* or postnatally, is not justified.

The wishes of a pregnant woman should be overridden

- (a) if she is mentally incapable
- (b) if her wishes would harm a fetus that she wants to deliver
- (c) if they would endanger her

but there is no reason why a mother should not choose to terminate a fetus she does not want to carry, or to sacrifice herself to preserve a viable baby.

Question 2

It would be inappropriate to undertake a life-extending intervention in the following order of priority

- (a) where the baby has a poor prospect for survival because of an overt disorder or complication of pregnancy, i.e. where the case is clear and objective
- (b) in the case of brain damage and likely severe disability the case is to be judged on its probabilities
- (c) in the case of congenital abnormalities, the case must be judged on the basis of the present and practical tolerability or treatability of those abnormalities
- (d) in the case of extreme prematurity with no other complications, treatment should be administered for as long as it is likely that the baby will survive reasonably unscathed and develop normally.

Question 3

(1) The “moral status” of a fetus, or indeed an adult, is undefined, unresolvable, and likely to be eternally contentious. It is a weak basis for legislation or action, and should be dismissed from the Working Party’s agenda as having no practical value.

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(2) There is a strong objective basis of experience for setting out the ethical arguments around action and inaction.

(3) The concept of quality of life can be refined and developed towards objective measures.

Item (2) is likely to lead to the setting of arbitrary limits that can be reviewed in the light of experience, and is therefore a prime candidate for discussion that will lead to legislation or its reform.

Item (3) should develop into consensus guidelines (but not statutes) for decision makers.

Q4 The quality of life for a child must be separated into the immediate and short term (SQL), prospective (PQL) and quasi-subjective (QQL) components of quality.

SQL relates to immediate distress and the ability of parents and clinicians to relieve it. The judgement is primarily clinical.

PQL considers, *inter alia*, the fact that a family is not a stable entity. The youngest child, if a net acceptor, will become the responsibility of the taxpayer: to what extent can the State replace his parents' and siblings' care? The oldest child, if an acceptor, will become a burden on his siblings, whose own PQL must be considered independently of the parents' wishes.

QQL can be quantified. We can judge a person's ability both to integrate in society and to lead an independent life. Integration involves communicating and transacting with others: thus a "normal healthy intelligent adult" may be considered to have 100% integration; and a profoundly deaf person who can work and shop for necessities but can only communicate freely with trained signers would have a lower integration factor. Independence within society includes self defence (including the ability to deal with official paperwork and the like) and self nutrition.

A common presumption throughout society is that someone who sees himself as a net donor, or an acceptor of justly earned care and benefits, will have a subjectively good quality of life. Again, it is possible to quantify this. QQL is an attempt to evaluate a person's *self*perception as a donor or worthy acceptor, in view of these objective measures.

Religious and spiritual influences are idiosyncratic, contentious, and not open to challenge or scrutiny. They must not be allowed to affect any decisions taken on behalf of others, or that might affect other people. They should be expunged from the Working Party's agenda.

The function of the mass media is to entertain, to disseminate the political or religious views of their owners, and to sell consumer products. They may usefully broadcast the findings of the working party, but they have no locus in influencing clinical or

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legislative decisions. The recently observed phenomenon of mass media prompting and fostering public displays of false emotion (“dianafication”) is sinister, and the general standard of reporting scientific and medical issues (“frankenstein foods”) is embarrassing.

Q5 SQL is best evaluated by parents and immediate family, whose natural role is to maximise that quantity in the short term

PQL must be evaluated by the professionals whose (successors’) task will be to maintain QL when the family disperses or cannot cope

The weight to be attached to a given opinion depends on the prognosis of QQL and the influence that person or body will have on QQL. The job of healthcare managers is to advise professionals on resource availability, and to plan future resource allocations in response to professional forecasts of demand - management has no competence or locus in determining service policy or specific clinical cases. The courts should be the last resort in determining a particular case.

Unless it is clear that the mother will not be primarily responsible for nurturing the child, her opinion must take precedence, followed by the joint opinion of the parents.

Competent siblings or other close relatives may be involved in QL issues. However no individual can give an undertaking that lasts the lifetime of a newborn, so such input should be biased towards SQL matters.

The outcome of any useful decision process is that A will do X by an agreed date. Therefore the view of A must predominate in the first instance. If A refuses to carry out an action agreed by the other parties as reasonable, and will not relinquish his authority in the matter, the courts may be asked to enforce the decision and/or transfer A’s authority.

We must distinguish between medical advice, and actions taken in the light of that advice. Advice can be challenged at any time without recourse to the law. The purpose of the law is to constrain (or, rarely, demand) action. Where people seek to influence clinical action through the courts, it is important that the process be quick and cheap (so that justice is not denied or delayed) and expert - i.e. argued on the specific case rather than precedent. The business of instructing barristers to argue points of law before a judge in a public court should be avoided: scientific and professional witnesses should be personally examined by a tribunal of experts in medical ethics, in a closed session that bears the authority of a magistrate’s court. The tribunal’s judgement may of course be challenged by appeal to a regular court, where the tribunal should appear as expert witnesses.

Question 6

We could spend the entire gross domestic product to prolong the life of one individual to the best of our scientific capability, but this would not be equitable or ethical.

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Referring to para 2.2 above, we expect finite resources to be distributed fairly according to need and probable effectiveness. It is objectively better for society to spend money spent on returning a donor to the field of play than prolonging the life of an acceptor on the sidelines, but we are driven by personal compassion to support the needy but hopeless case, whether a damaged neonate or a terminally sick adult. The solution may be to apply the economic and social considerations that apply to the more familiar adult case, to the rarer instance of a sickly child. If prolonging life merely means prolonging pain, we should not do it. If it means progressing towards a cure or improved QL, we should do it for as long as we are not disadvantaging a stronger claim on resources.

Question 7

Optimisation of QALYs can determine the course of intervention for an individual, but the QALY parameter is too imprecise for comparison between cases. In allocating finite resources, both the PQL and the QQL must be considered for each patient. The middle-aged donor has a high PQL and the elderly “worthy acceptor” has a high QQL, compared with an unhealthy newborn.

Question 8

“Directive professional guidance” is undesirable. It is seen as either unwarranted interference or an abrogation of legislative responsibility. The current Ionising Radiation (Medical Exposure) Regulations, for instance, are positively harmful and practically unenforceable, but cannot be challenged or set aside by professionals as they are statutory. Professional guidance should be an aide-memoire or ready-reckoner. Directives must be phrased as statutory limits and offences.

Setting an arbitrary level and qualifying it with “normally” is undesirable, particularly where every case is abnormal. Weak legislation creates work for lawyers and mischief-makers. There are three “strong” approaches:

- (a) Leave the decision to resuscitate entirely to the judgement of those present. This may generate civil litigation, which tends to be expensive, inconclusive, and favouring the wealthy.
- (b) Fix an arbitrary limit and set down valid defences for breaching that limit, or
- (c) Make it an offence to withhold treatment, subject to listed exceptions.

Question 9

Legislation based on rights is always undesirable. One man’s right is another man’s duty, so conferring rights on an acceptor group may reduce the willingness of donors to give, or challenge society’s capacity to provide. But a clear definition of wrongs and acceptable mitigations would probably be welcomed. Such statutes must

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acknowledge that the final responsibility for prolonging life or withholding treatment, is thereby traceable to Parliament.

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