

Critical care decisions in fetal and neonatal medicine: ethical issues

a guide to the Report

Introduction

Major improvements in medical care mean that extremely premature and very ill babies have better chances of survival and making a good recovery. However, it can be difficult to predict whether an individual baby will have a limited lifespan and the extent to which he or she will recover from any health problems or develop disabilities. This means that families and health professionals sometimes have to make complex and emotionally demanding decisions about a baby's treatment and care. These decisions may be about:

- the care of a fetus and mother before the birth;
- whether to resuscitate a newborn baby, and admit him or her to neonatal intensive care; and
- whether to continue invasive intensive care or replace active treatment with palliative care.

The Nuffield Council on Bioethics has published a Report, *Critical care decisions in fetal and neonatal medicine: ethical issues*, which

examines the ethical, social, and legal dilemmas raised by fetal and neonatal medicine. When making decisions about a newborn baby, in many instances there will not be an answer that is clearly 'right' or 'wrong'. The Report concentrates upon how a decision should be arrived at and who should make the decision.

The Report was produced by a Working Party which included neonatologists, an obstetrician, a children's nursing professor, philosophers, social scientists, lawyers, a health economist, and individuals who have worked with families of extremely premature babies and disabled children. This guide sets out some of the conclusions and recommendations that are discussed in more detail in the Report.

[Notes in square brackets throughout refer to chapters and paragraphs in the Report].

Fetal medicine: The branch of medicine that is concerned with the health and development of the unborn baby (or fetus).

Neonatal medicine: The branch of medicine that is concerned with the diagnosis and treatment of ill newborn babies. Strictly speaking, the 'newborn' or 'neonatal' period is the time within 28 days of delivery.

Background

Extremely premature babies

We use the term 'borderline of viability' to describe extremely premature babies who are born at or before 25 weeks and six days (pregnancy usually lasts for 40 weeks). In England, 1,600 out of 584,000 (0.28 percent) deliveries were at the borderline of viability in the year 2004-2005.¹ This percentage has been increasing since the beginning of the 1980s, which may be due to several factors, including the rise in fertility treatment. Most extremely premature babies die, but the age at which they can survive has dropped by about one week for every decade in the past 40 years. A 1995 UK-wide study called EPICure showed that the percentage of babies born alive in 1995 between 22 to 23 weeks who survived to leave hospital was 1%; at 23 to 24 weeks it was 11%; at 24 to 25 weeks, 26%; and 25 to 26 weeks, 44% (see Table 1). Survival before 22 weeks is very rare.² More recent data from other countries and specific areas in the UK indicate that survival rates have become higher since EPICure, and these may be more useful for providing advice to parents.

If an extremely premature baby survives to leave hospital, he or she may grow up with disabilities. Data from the EPICure study remains the best available for advising parents in the UK on likely

outcomes. Of the babies born between 23 to 24 weeks who survived, about two thirds had moderate or severe disabilities. By 25 to 26 weeks, two thirds had no or mild disabilities (see Table 1).³ When looking at these data, it is important to remember that a 'mild' disability need not affect everyday life, for example having a moderately low IQ score or needing to wear spectacles. Further, children who have disabilities due to prematurity represent an extremely small proportion of the total number of children with disabilities in the UK [paras 5.4-5.10].

Other babies needing intensive care

Decisions about treatment do not just concern premature babies. Babies born at any gestational age can have brain injury, acquired during pregnancy or the birth itself, or, rarely, an abnormality of brain structure that remained undetected until after birth. A range of serious conditions affecting other parts of the body, such as the heart, lung, bowel and kidney may be found in the newborn child [paras 6.4-6.13].

Table 1. Summary of outcomes up to six years of age among children born alive at different gestational ages*

Outcome	22-23 weeks	23-24 weeks	24-25 weeks	25-26 weeks
Showed signs of life at birth	138 (100%)	241 (100%)	382 (100%)	424 (100%)
Survived to discharge from hospital	2 (1%)	26 (11%)	100 (26%)	186 (44%)
Died by the age of 6 years	136 (99%)	216 (90%)	284 (74%)	241 (57%)
Survived at 6 years with severe disability	1 (0.7%)	5 (2%)	21 (5%)	26 (6%)
Survived at 6 years with moderate disability	0	9 (4%)	16 (4%)	32 (8%)
Survived at 6 years with mild disability	1 (0.7%)	5 (2%)	26 (7%)	51 (12%)
Survived at 6 years with no impairment	0	3 (1%)	10 (3%)	35 (8%)

*Data are from the 1185 babies in the 1995 EPICure study who showed signs of life at birth, from an original group of 4000 births recorded (see www.epicurestudy.com). A severe disability was defined as one that was likely to make the child highly dependent on caregivers, a moderate disability as one that would probably allow a reasonable degree of independence to be reached, and a mild disability would include mild learning problems or other impairments such as squints.

¹National Statistics (2006) *NHS Maternity Statistics, England: 2004-2005*, Table 21.

2 Costeloe K, Hennessy E, Gibson AT, Marlow N, Wilkinson AR and the EPICure study group (2000) The EPICure study: Outcomes to discharge from hospital for babies born at the threshold of viability *Pediatrics* **106**: 659-71.

³Marlow N, Wolke D, Bracewell MA and Samara M for the EPICure Study Group (2005) Neurologic and developmental disability at six years of age after extremely preterm birth *New England Journal of Medicine* **352**: 9-19.

Ethical issues

Fetal and neonatal medicine raises a number of ethical issues including: the value of human life, the role of best interests, deliberately ending life and decision making.

The value of human life

The moral status of the fetus

Under English law, fetuses have no independent legal status. Once born, babies have the same rights to life as other people. This legal distinction is at odds with the teachings of many faiths and, for some, their moral intuitions. For example, there are people who think that the human embryo, from the moment of conception, has the same moral status as a born living human person. For others, the threshold relates to various stages of development of the central nervous system, even continuing after birth. Yet others consider the point of birth to be highly significant, as a new and independent being has been brought into existence [paras 2.17-2.18].

The Working Party regards the moment of birth as the significant moral and legal point of transition for judgements about preserving life. In this respect, children of six days, months or years are each worthy of equal consideration [para 2.19].

The sanctity of life

An absolute interpretation of the doctrine of the 'sanctity of life' is that taking human life is categorically wrong and it is never permissible not to strive to preserve the life of a baby. However, the Working Party believes that under some circumstances preserving the life of a baby can only lead to an 'intolerable' existence [paras 2.9-2.11].

The Working Party struggled, as have others, to define when the degree of suffering caused by continuing active treatment outweighs the benefits of the treatment to the baby. By 'intolerable' we mean an extreme level of suffering or impairment which is either present in an individual baby or may develop in the future. Our use of 'intolerability' embraces all three situations recognised by the Royal College of Paediatrics and Child Health: 'no chance', 'no purpose' and 'unbearable' [paras 2.12-2.16].

For some babies, whose quality of life is what we would describe as 'intolerable', an insistence that their lives must always be preserved,

regardless of suffering, is inhumane and of no possible benefit to them [paras 2.11-2.16].

Quality of life

Quality of life usually refers to a person's emotional, social and physical wellbeing, their intellectual capability, and their ability to perform the ordinary tasks of living within a community. However, quality of life is hard to define and people have different opinions on what comprises a 'good' quality of life. Some people would view life with severe mental or physical disabilities as not worth living, yet severely disabled people usually report that they are content with their lives and do not regard them as having less value than the lives of others [para 2.10].

We find no morally relevant differences between disabled and able-bodied children and adults. Each must be given equal consideration. It is important that all those involved in critical care decisions, including especially parents, doctors, and nurses, do not feel pressured to allow babies to die because of the risk of disability [para 2.39].

Best interests

The principle of 'best interests' is central to medical practice and UK law.⁴ It states that in all matters affecting any child his or her best interests should be the paramount consideration.

Our view is that any decision made in respect of the child must carefully consider the interests of all potentially affected persons, most usually other family members, old or young, who will live with the child or are dependent upon the immediate family in other ways. However the best interests of the baby should be the central consideration and carry the greatest weight [para 9.29].

Parents, doctors and others involved in the decision making process may have different ideas about what is in the best interests of the baby.

We propose that clarifying how best interests are judged would be helpful. We suggest that when a decision must be made about whether or not to institute, withhold or withdraw treatment from a baby after birth, a number of questions should be considered, including:

- *What degree of pain, suffering and mental distress will the treatment inflict on the child?*

⁴ Within the UK there are three legal systems: in (1) England and Wales; (2) Scotland; and (3) Northern Ireland.

Ethical issues

- *What benefits will the future child get from the treatment, for example, will the child be able to survive independently of life support, be capable of establishing relationships with other people, and be able to experience pleasure of any kind?*
- *What kind of support is likely to be available to provide the optimum care for the child?*
- *What are the views and feelings of the parents as to the interests of the baby?*
- *For how much longer is it likely that the baby will survive if life-sustaining treatment is continued?* [paras 9.30-9.34].

Deliberately ending life

Taking intentional measures to end the life of a newborn baby is commonly regarded as a violation of the duty to protect the life of the patient. This applies even when that baby's condition is intolerable, with no prospect of survival or improvement. The professional obligation of doctors is to preserve life where they can. To permit doctors actively to end the lives of seriously ill newborn babies would compromise in a negative way the relationship between parents and doctors. In particular, parents may lose trust in the impartiality of the advice from doctors, which is central to the decision-making process.

It would also be very difficult to identify an upper age limit beyond which actively ending life would not be allowed. If the law were to permit the killing of a newborn baby on the grounds that this was in the baby's best interests, we have to ask why it would not be permissible to kill an incompetent adult on the same grounds [paras 2.36-2.37].

The Working Party concluded that the active ending of life of newborn babies should not be allowed, no matter how serious their condition [para 2.37].

Relieving pain and causing death

Medicines such as sedatives and pain relievers can have the effect of hastening death, particularly if given at higher doses. Death may therefore occur in cases where doctors provide such treatments to reduce pain and suffering. This would not be unlawful as long as the doctor does not intend to cause death and is guided by the best interests of the patient. Doctors may fear that their motives in providing pain relief could be misinterpreted, but the British Medical Association advises that "if the

intention is clearly to relieve pain and distress and the dosage provided is commensurate with that aim, the action will not be unlawful".

The Working Party takes the view that, provided the treatment is guided by the best interests of the baby, and has been agreed as a joint decision, potentially life-shortening but pain-relieving treatments are morally acceptable [para 2.38].

Decision making

Parents are generally considered to have the moral authority to make decisions in their child's best interests in all the circumstances of life, though not as if they owned them. They are often best placed to know what is in the interests of their child because they share a special bond that begins during pregnancy and develops over time. Legally, doctors must normally have the consent of parents before giving any treatment to a child. Doctors can only override parental wishes with a court order, except in an emergency [paras 2.37, 8.12].

Doctors have a responsibility to promote the best interests of the newborn baby and will be able to give a prediction of the outcome for the baby based on their knowledge and experience. Other people, such as family members, religious advisers or healthcare specialists may contribute advice. Nurses spend a great deal of time with the parents and their baby and are therefore well placed to provide additional insights into the best interests of both the child and his or her family.

The Working Party considers that all participants in decision making should strive to reach agreement about what is best, and every effort should be made to secure consensus within the 'partnership of care'⁵ between the parents and the healthcare team.

This is more likely to be achieved if all the appropriate parties are fully involved in any discussion, properly understand the facts, appreciate their significance, and are given the opportunity to participate in the process of deciding. In some cases, agreement about what is best may not be reached, however hard and conscientiously it is sought. We discuss this in more detail on page 6 [paras 2.48-2.53].

Recommendations

Decisions about whether to start intensive care in extremely premature babies

Current practice in most neonatal units in the UK is usually to resuscitate a baby if the outcome is uncertain and provide intensive care until the outlook is clearer. However, as life-saving treatments can be invasive and may cause suffering, it is difficult to know whether this is the right course of action if the baby is unlikely to benefit.

For this reason, the Working Party gave careful consideration to whether or when intensive care should be withheld from babies born extremely prematurely. We concluded that the considerable

variability in outcome for such babies meant that a complete ban on intensive care would be an unjustifiable infringement of the interests both of the child and their parents. However, clearer guidance on whether to give intensive care to extremely premature babies would help parents and doctors make more informed decisions about treatment in individual situations.

We propose below a set of guidelines to provide a basis of discussion for professional bodies and parents. The guidelines should be reviewed regularly and revised to reflect any changes in outcomes for extremely premature babies [9.13-9.19].

Guidelines on giving intensive care to extremely premature babies

■ At 25 weeks and above

Intensive care should be initiated and the baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.

■ Between 24 weeks, 0 days and 24 weeks, 6 days

Normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, unless the parents and the clinicians are agreed that in the light of the baby's condition it is not in his or her best interests to start intensive care.

■ Between 23 weeks, 0 days and 23 weeks, 6 days

It is very difficult to predict the future outcome for an individual baby. Precedence should be given to the wishes of the parents. However, where the condition of the baby indicates that he or she will not survive for long, clinicians should not be obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile.

■ Between 22 weeks, 0 days and 22 weeks, 6 days

Standard practice should be not to resuscitate the baby. Resuscitation should only be attempted and intensive care offered if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, and if the clinicians agree that it is in the baby's best interests.

■ Before 22 weeks

Any intervention at this stage is experimental. Attempts to resuscitate should only take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent.

Further recommendations

Withdrawing treatment and palliative care

After an initial decision has been taken to start intensive care, there may come a time when parents and doctors begin discussing whether withdrawing active treatment would be in the best interests of the baby.

The reasons are generally:

- when intensive care is proving futile, in that death appears inevitable;
- when a baby has suffered a severe brain injury and for whom there appears to be a very high risk of severe disability as he or she grows up;
- when a baby is discovered to have a serious malformation, dysplasia (abnormal development of tissues or organs) or a genetic condition with a serious outcome for which there is no treatment [para 6.3].

Once a decision has been made to withhold or withdraw treatment for a baby, or where there are no appropriate treatments, palliative care should be provided. The main focus of palliative care is the relief of pain and other distressing symptoms. However, healthcare professionals working in neonatal intensive care do not receive mandatory training in palliative care and access to teams who specialise in this area of medicine is extremely limited. Currently, the use of techniques in palliative care for management of pain and symptoms in babies, and the availability of support for parents, varies greatly across the UK.

The Working Party recommends that the NHS should train all professionals working in neonatal medicine in the basic principles of palliative care. Specialist advice in palliative care should be made available to help with complex cases in the same way that specialists would be consulted in other difficult medical cases [paras 6.18-6.21].

Decisions during pregnancy

Major improvements in technology and medicine mean that nowadays pregnant women are offered a range of tests, scans and screening procedures, and the results provide great reassurance for many. However gaining more information about the developing fetus can mean the woman has to make some difficult decisions. If a fetal abnormality is confirmed, options for surgery are very limited, so her choice is often

between continuing the pregnancy knowing that the fetus or baby may die or develop disabilities, delivering the baby early, or terminating the pregnancy [paras 4.2-4.12].

We consider that a pregnant woman who has chosen to continue her pregnancy has strong ethical obligations to protect the health of the future child. We are not persuaded, however, that the law should require pregnant women to submit to medical or surgical interventions to benefit a fetus against their will [para 9.6].

The Abortion Act 1967 only permits termination of pregnancy after 24 weeks if a fetus is at "substantial risk of serious handicap or there is a risk of grave permanent injury to the woman". For terminations at 22 weeks or later, feticide (ending the life of the fetus, usually by lethal injection into the heart) is usually carried out to ensure that a baby is not born alive. When a woman does not want feticide, some doctors may have concerns because they believe that they are legally obliged to try to save a baby who shows signs of life when born. However, there is no legal obligation to prolong the life of a baby when they have no hope of survival or they will suffer more than benefit from the treatment. What is done should be appropriate to the baby's condition [paras 4.13-4.18].

We recommend that a code of practice be developed for the healthcare team to achieve clarity about what the law does and does not require doctors to do. Such a code would also help ensure that pregnant women are given sufficient information about possible outcomes if a baby is born alive following termination on grounds of fetal abnormality [para 9.10].

Avoiding the courts

No matter how clear the guidelines for making critical care decisions, doctors and parents will sometimes disagree. The number of court cases relating to neonatal medicine seems to be increasing. However, involving the courts can be a very stressful experience for the child's family and the professionals, and it is costly in financial terms.

The Working Party took the view that going to court should be avoided where possible. The Report considers a range of options to strengthen communication and understanding between professionals and parents. Nurses can play a vital role. A member of the neonatal unit or hospital

staff can facilitate discussion. Clinical ethics committees could be involved or professional mediators could be appointed to help the parties who disagree find a resolution. If resolution is not possible, mediation could reduce bad feeling, or narrow down the issues that need to be addressed by the courts.

We recommend that NHS Trusts should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee.

There are potential advantages to using mediation much more regularly in disputes about critical care decisions in neonatal medicine. We recommend that the Government should examine the benefits that mediation may offer [paras 9.35-9.40].

Lifelong support for children who survive

For children who leave the neonatal unit with serious disabilities, a practical concern for parents is how they will manage their child's needs and gain financial and other help if required. However, the availability in the UK of support services for disabled children and adults, and their families, is uneven at best.

There is an inconsistency in trying very hard to save the lives of very ill babies without providing enough care and support for the children who survive.

We urge the Government to accept further responsibility for supporting families who care for disabled children and adults by providing more resources to ensure that adequate and effective services are provided uniformly across the UK [paras 9.45-9.46].

Resource considerations

The current level of provision of neonatal intensive care in the UK does not always meet demand. Some have questioned whether funds are being spent appropriately on treating babies whose outlook may be very poor.

At the local level, doctors should continue to do the best possible for the baby in front of them. They should be aware of, but not driven by, the resource implications of their decisions, which should be based on the best interests of the babies concerned.

At the national level, there is a need for a much broader independent analysis of the use of NHS resources, with a view to providing national guidance on allocating resources for healthcare in an efficient and equitable manner [paras 9.41-9.44].

Data collection and information

Decisions about the treatment of extremely premature babies are particularly difficult because of the lack of information on which to base predictions of future health. Parents must be provided with accessible information about the nature of any future disability and the long-term consequences of decisions [para 9.51].

It is crucial that more data are collected about the health of premature and seriously ill babies as they grow up, and that this information is linked to subsequent medical and educational records [para 9.49].

It is also necessary to identify variations in practice, experience and views that might lead to improved processes of communication and support for decision-making.

Research should be carried out on how the different parties interact with each other when making decisions about the treatment of extremely premature babies and how this is affected by prior experience [para 9.48].

Training

Healthcare professionals are sometimes not well informed about the legal framework within which they work. Misunderstandings about the role of the criminal law in relation to withholding and withdrawing treatment are not uncommon.

We recommend that professional bodies should encourage medical and nursing schools to develop educational programmes in the law and ethics relating to fetal and neonatal medicine [para 9.54].

Summary

- *It is often difficult to predict whether an extremely premature or very ill baby is likely to survive, for how long and if he or she will have any health problems or disabilities. Making decisions about treatment can be very difficult for parents and doctors.*
- *The Council has proposed guidelines, on a week-by-week basis, on whether to give intensive care to premature babies born before 22 weeks up to those born after 25 weeks.*
- *Conclusions and recommendations are made in a number of other areas, including: the role of best interests, deliberately ending life, withdrawing treatment, decisions during pregnancy, avoiding the courts, long-term support for children who grow up with disabilities or health problems, information for parents and training for healthcare professionals.*

Copies of the Report are available to download from the Council's website:
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To order a printed copy or CD, please email bioethics@nuffieldbioethics.org

Published by
Nuffield Council on Bioethics
28 Bedford Square
WC1B 3JS

Telephone: +44 (0)20 7681 9619
Fax: +44 (0)20 7637 1712
Internet: www.nuffieldbioethics.org