

CLINICAL ETHICS

Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby

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In the United Kingdom women have access to termination of pregnancy for maternal reasons until 24 weeks' completed gestation, but it is accepted practice for children born at or beyond 25 weeks' gestation to be treated according to the child's perceived best interests even if this is not in accordance with parental wishes. The authors present a case drawn from clinical practice which highlights the discomfort that parents may feel about such an abrupt change in their rights over their child, and argue that parents should have greater autonomy over treatment decisions regarding their prematurely born children.

based on recent UK data shown in table 1. She was advised that although figures for 26 weeks' gestation births are less complete, the disability rate at this gestation is likely to be considerably less than 50%.^{7,8} The medical team explained that although a child born in very poor condition or at 23–24 weeks' gestation might not be resuscitated (depending in part on parental wishes), they would feel obliged to resuscitate and support a child born at 25 weeks' gestation or later in reasonable condition. The woman and her husband were concerned at the prospect of having a disabled child—she had some experience of caring for disabled children in her work as a teacher, and through having a disabled niece. They were disturbed that at 25 weeks' gestation they might not have the opportunity to withhold resuscitation despite a 50% risk that the child would die before leaving hospital, and a 50% risk of disability in the child if they did survive. For this reason they elected to terminate the pregnancy.

Since the Abortion Act in 1967 women in the UK and increasingly in other countries have had widespread access to legal abortions.^{1,2} In the UK 98% of abortions take place to safeguard the woman's physical or mental health, and such abortions are permitted up to 24 weeks completed gestation.³ This contrasts with practice regarding children born at this stage—guided in the UK by the Children Act—which emphasises that the welfare of the child should be the primary concern when making decisions surrounding their care.⁴ Practice among paediatricians, supported since 1989 by the Children Act, has been to put the child's perceived best interests above their parents' wishes in cases of conflict. For example if parents wish to withdraw treatment from their baby and the medical team disagree then most practitioners in the UK will overrule the parents.⁵ This abrupt change in attitude toward the fetus in utero and the child ex utero at similar gestations may lead to conflict. We present a case from our practice which brings into focus this potential for conflict, and highlights some of the ethical issues surrounding the treatment of children born very prematurely.

THE OUTCOME OF PREGNANCIES WITH SECOND TRIMESTER RUPTURE OF MEMBRANES

The outcome of pregnancies with rupture of membranes before 26 weeks' gestation has been the subject of a number of reviews.^{9–13} These estimate the mean latency before delivery as 10–21 days, with delivery occurring within seven days of rupture of membranes in up to 50% of cases. In some cases delivery may not occur for 10 weeks or more. Although the overall risk of premature delivery, death, and disability is high with rupture of membranes at 23 weeks' gestation, those who do deliver at or beyond 26 weeks' gestation have a reduced risk of poor outcome.^{7,8} If the couple in the case described were assured they would have the option of not resuscitating a child born at 25 weeks' then they might have continued this pregnancy, in the hope of going beyond 25 weeks' gestation and delivering a child with a higher chance of survival and a lower risk of disability. In the light of this case we shall review law and practice in relation to refusing parental requests to withhold treatment from their 25 week gestation baby, and discuss whether such a denial of parental wishes is justified.

CASE HISTORY

A 31 year old woman in her second pregnancy presented at 23⁺² weeks' gestation with spontaneous rupture of membranes. She was counselled that the timing of labour and delivery were uncertain, but the risk of delivery before 26 weeks' gestation was high. She was advised that the child had a 10% chance of survival to discharge from hospital if born at 23 weeks' gestation, and a 50% risk of disability if they did survive.⁶ Increased survival rates were given for the child if born at 24 or 25 weeks' gestation, but similar rates of disability. This information was

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Table 1 Outcome of extreme prematurity in the United Kingdom and Ireland, March to December 1995⁶

	Gestation (weeks)			
	22	23	24	25
Number of live births	138	241	382	424
Survival to discharge from hospital (%)	1	11	26	44
Survival without disability at 30 months age (%)	0.7	5	12	23

underpinned by the Children Act, which makes the best interests of the child the overriding consideration, and the Human Rights Act which emphasises the universal right to life.^{4 14} These Acts of Parliament support the maintenance of life in children unless it is clearly against their interests to do so, but the regularity with which treatment withdrawal cases reach the Courts attests to the difficulty of determining what is in the child's best interests. Moreover the issue of whether the best interests of a very premature neonate are viewed with the same weight in these decisions as those of an older child is not clear. Perhaps the best known Court case in which parents wished to withhold treatment from their child against medical advice was that of Baby Alexandra, a child with Down's syndrome in need of life saving surgery.¹⁵ The Court of Appeal upheld the physicians' request for surgery against parental wishes, concluding that the infant's life was not "demonstrably so awful" that she should be allowed to die. Many would agree with this stance that children should be given the opportunity to live unless their life is clearly not worth living.

A contrasting case is that of Child T, who had failed liver surgery for biliary atresia at age 3 weeks and was offered a liver transplant. Parental refusal of this life saving treatment was upheld by the Court of Appeal as in the "child's best interests".¹⁶ At the time of this decision, liver transplant surgery in children had a 10 year survival rate of 76%, with just 29% of these survivors needing a further liver transplant during those 10 years.¹⁷ These outcome figures might be viewed as comparable with those of a child born at 25 weeks' gestation, and it is conceivable that the same court would allow parents to withhold treatment from a 25 week neonate against medical advice.

United States law

In the US parental autonomy over the upbringing and nurturing of their child has been interpreted as constitutionally safeguarded.¹⁸⁻²⁰ However this principle may be overridden if the health and safety of the child are in jeopardy.^{21 22} As in the UK, the legal position is unclear when the best interests of the child are not evident, and where treatment is only marginally beneficial parental autonomy to withdraw treatment may be upheld.^{23 24}

PRACTITIONERS' VIEWS ON PARENTAL INVOLVEMENT IN DECIDING TO WITHHOLD OR WITHDRAW TREATMENT FROM A CHILD

Professional guidelines

UK practice guidelines do not easily apply to the resuscitation of a child born at 25 weeks' gestation, but they do suggest that in cases of dispute between physician and parent treatment should generally be continued until the issue is resolved, if necessary by the Courts.^{25 26} Canadian and US guidelines suggest that whereas non-resuscitation of children at 23 or 24 weeks' gestation might be appropriate depending on parental wishes and prognostic factors, children of

25 weeks' gestation or greater should be resuscitated in all cases in the absence of fatal anomalies.²⁷⁻²⁹

Surveys of practice

In UK hospitals many nurses and doctors feel that the ultimate responsibility of deciding to withdraw treatment from a premature baby is too great a burden for parents to bear.^{5 30} In practice, treatment withdrawal decisions are usually made by the medical team, not only in the UK but in the majority of European countries.^{31 32} More specifically, most European practitioners (with the exception of those in the Netherlands) would resuscitate a baby born at 24 weeks' gestation even in the face of parental opposition.³³

SHOULD PAEDIATRICIANS RESUSCITATE 25 WEEK GESTATION BABIES AGAINST THE PARENTS' WISHES?

The law in the US and UK does not provide specific guidance as to when paediatricians should accede to parents' wishes regarding their child's treatment, but surveys suggest that neonatal practice in the UK and Europe is patriarchal. Although parents may be involved, it is often clinicians who ultimately decide when treatment might be withdrawn, and this is also common practice when deciding whether to resuscitate children born very prematurely. In many centres those born at 25 and even 24 weeks' gestation in good condition are routinely resuscitated whether their parents wish it or not. Below we discuss three important ethical questions which arise from this practice.

1. SHOULD THE BEST INTERESTS OF VERY PREMATURE CHILDREN SUPERSEDE THOSE OF THEIR PARENTS?

If the best interests of the child are to be given greater weight than parental wishes then this relies on the child being a person and having the rights of a person. The acquisition of this "personhood" or moral status by a developing human being is widely debated in the context of abortion and the use of human embryos for scientific research.^{34 35} Personhood (and with it the protection of one's interests by society) is believed by some to be fully acquired at conception, and by others to be acquired gradually or stepwise through pregnancy and childhood. Advocates of the latter approach may invoke criteria such as viability, birth, or self awareness as prerequisites for personhood.³⁴ In practice viability and birth are the most widely used and we discuss these below.

A viability criterion of personhood

Obstetric and neonatal practice in the UK and US rests on the premise that when a fetus becomes viable they acquire the status of a person.³⁶ The major criticism of this viability criterion is that the viability of a fetus depends very much on the available technology of the society into which they are born, rather than on any intrinsic worth that they may have.³⁷ If 25 week gestation babies are to be resuscitated against their parents' wishes because they are viable then we might imagine a future in which neonatology has advanced such that fetuses 6 weeks old can be reliably salvaged with little morbidity. To many it would seem absurd for the fetuses of women who suffered an early miscarriage or ectopic pregnancy to be resuscitated and given full intensive care against their wishes.

A birth criterion of personhood

The legal criterion for the acquisition of personhood in the UK and many other countries is birth. In Israel the distinction around birth is particularly clear: here abortion is permitted at any time during pregnancy on maternal grounds, yet neonatal policy is for all viable babies to be given full resuscitation and treatment.³⁸ Where birth is used as the

sole criterion of personhood, women in premature labour may quite frequently feel forced into aborting a wanted pregnancy through doctors' aggressive resuscitation policy, in cases similar to that described above. And unless one views killing and withholding treatment as morally equivalent (a view which some do hold) then such cases argue against a reliance on birth for the acquisition of personhood.³⁹⁻⁴⁰

The gradual acquisition of personhood

Some ethicists reject the view that personhood is acquired suddenly at a given moment in development and argue that personhood develops in a continuous fashion from conception onwards.⁴¹⁻⁴³ If a child born at 25 weeks' gestation is less a person than an older child, then their perceived best interests may not overrule parental autonomy in decisions surrounding their care, and practice which applies to withholding treatment from older children would not be automatically transferred to the child born very prematurely.

Whether the best interests of a very premature child should supersede the wishes of their parents clearly depends on one's view in the widely debated area of the development of moral status; but whichever philosophical stance one takes, the reliance of current practice on viability or birth to define personhood is imperfect.

2. IS RESUSCITATION AT 25 WEEKS' GESTATION IN THE CHILD'S BEST INTERESTS?

If we assume that the 25 week newborn child's interests do supersede their parents' interests regarding their fate, it is still not clear that resuscitation is beneficial for the child. The best available UK data suggest that children born at 25 weeks' gestation have a 40–50% chance of surviving their initial hospital stay—a stay which lasts three months, involves regular potentially painful procedures, reduced maternal contact, and prolonged periods of starvation. At age 30 months 50% of survivors have a significant disability.⁶ In later childhood there is an increased risk of behaviour problems and more minor motor and learning difficulties, and in the context of resuscitation against parental wishes these children may have either reluctant or foster parents.⁴⁴⁻⁴⁷ Although many would feel a 25% chance of life without disability is in the child's best interests, it is at least arguable that it may not always be so. And where there is significant medical uncertainty about the benefits of a given course of action for the child, then parental autonomy should not be subverted.²⁹

3. IS IT IN THE INTEREST OF SOCIETY TO RESUSCITATE VERY PREMATURE CHILDREN AGAINST THEIR PARENTS' WISHES?

Where resources for medical treatment are tightly rationed as in public health systems, resuscitation and intensive care treatment of very premature children with a high chance of early death or disability may not be a justifiable use of such resources.⁴⁸ This may particularly be the case where such treatment is against parental wishes, and the child places an economic burden on both the social and health services of a society. Indeed this "economic justice" criterion is cited by both the Danish Council of Ethics and US ethicists in their recommendations for the management of extremely premature babies.²⁹⁻⁴⁹

BEYOND 25 WEEKS' GESTATION

Published data suggest that children born at 26 weeks' gestation have an improved outcome compared with 25 week births, and estimates of their survival to discharge range from 54% to over 90%.⁷⁻⁸⁻⁵⁰⁻⁵² The long term outcome for such children is less certain, but we would suggest that in countries with a high standard of neonatal care it is in the

best interests of a 26 week gestation baby born in good condition to be resuscitated. Considerations of the child's moral status at 26 weeks' gestation and appropriate resource allocation may in some cultural and financial contexts justify withholding treatment from such children at parents' request.

CONCLUSIONS

In an era of fast improving neonatal care, the ethical management of fetuses or children at the threshold of viability is increasingly complex. Those born before 24 weeks' gestation would have inevitably died in the past but can now be salvaged, yet may also be legally aborted, bringing into focus the debate over their moral status. In the UK women can sanction the killing of their child in utero at 23⁺6 gestation, but a day later they may not be permitted to let the child die at birth without medical intervention. If we agree that the fetus in utero is not morally distinct from the baby ex utero, then current practice rests on a premise that the fetus suddenly becomes a person at 24 weeks' gestation; a view which has no physiological or philosophical basis. In the context of current practice regarding the resuscitation of children born very prematurely, termination of pregnancy for maternal indications at close to 24 weeks' gestation may seem inappropriate. However it is equally important to offer couples greater flexibility in resuscitation decisions at 24–25 weeks' gestation. Children born at this gestation should not be resuscitated against their parents' wishes. Although the "personhood" of such children is widely debated, whatever their moral status it is not unequivocally in their interests to be resuscitated. To do so against the wishes of their parents may be both an unnecessary subversion of parental autonomy and an inappropriate use of healthcare resources.

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REFERENCES

- 1 Abortion Act 1967 (c87). Norwich, UK: Her Majesty's Stationery Office.
- 2 **World Health Organisation**. Unsafe abortion: global and regional estimates of incidence of and mortality due to unsafe abortion with a listing of available country data. Geneva: World Health Organisation, 1997.
- 3 **Royal College of Obstetricians and Gynaecologists**. The care of women requesting induced abortion. London: RCOG Press, 2000. http://www.rcog.org.uk/guidelines/induced_abortion.html (accessed 1 June 2002).
- 4 The Children Act 1989 (c41). Norwich, UK: Her Majesty's Stationery Office.
- 5 **McHaffie HE**, Fowlie PW. Life, death and decisions: doctors and nurses reflect on neonatal practice. *Cheshire: Hochland and Hochland*, 1996:190–204.
- 6 **Wood NS**, Marlow N, Costeloe K, *et al*. Neurologic and developmental disability after extremely preterm birth. *EPIcure study group. N Engl J Med* 2000;**343**:378–84.
- 7 **Yu VY**. Developmental outcome of extremely preterm infants. *Am J Perinatol* 2000;**17**:57–61.
- 8 **Sutton I**, Bajuk B. Population based study of infants born at less than 28 weeks' gestation in New South Wales, Australia in 1992–3. *Paediatr Perinat Epidemiol* 1999;**13**:288–301.
- 9 **Bengtson JM**, VanMarter LJ, Barss VA, *et al*. Pregnancy outcome after premature rupture of the membranes at or before 26 weeks' gestation. *Obstet Gynecol* 1989;**73**:921–7.
- 10 **Dowd J**, Permezel M. Pregnancy outcome following preterm premature rupture of the membranes at less than 26 weeks' gestation. *Aust N Z J Obstet Gynaecol* 1992;**32**:120–4.
- 11 **Rib DM**, Sherer DM, Woods JR Jr. Maternal and neonatal outcome associated with prolonged premature rupture of membranes below 26 weeks' gestation. *Am J Perinatol* 1993;**10**:369–73.

- 12 **Farooqi A**, Holmgren PA, Engberg S, *et al*. Survival and 2-year outcome with expectant management of second-trimester rupture of membranes. *Obstet Gynecol* 1998;**92**:895–901.
- 13 **Major CA**, Kitzmiller JL. Perinatal survival with expectant management of midtrimester rupture of membranes. *Am J Obstet Gynecol* 1990;**163**:838–44.
- 14 Human Rights Act 1998. Norwich, UK: Her Majesty's Stationery Office.
- 15 [1981]1 WLR 1421, CA.
- 16 [1997]1 WLR 242.
- 17 **Goss JA**, Shackleton CR, McDiarmid SV, *et al*. Long term results of pediatric liver transplantation. *Ann Surg* 1998;**228**:411–20.
- 18 *Pierce v Soc of Sisters* (1925) 268US510, 535.
- 19 *Meyer v Nebraska* (1923) 262US390, 399.
- 20 *Parham v JR* (1979) 442US584, 602.
- 21 *Quilloin v Woolcott* (1978) 434US246, 255.
- 22 *Jehovah's Witnesses of Wash v King Co Hosp* (1967) 390US598.
- 23 *Bowen v American Hospital Association* (1986) 476US610.
- 24 *State v Messenger* 561NW2d463 (Mich Ct App 1997).
- 25 **Royal College of Paediatrics and Child Health**. Withholding or withdrawing life saving treatment in children. London: Royal College of Paediatrics and Child Health, 1997.
- 26 **British Association for Perinatal Medicine**. Fetuses and newborn infants at the threshold of viability: a framework for practice, July 2000.
- 27 **Canadian Paediatric Society; Society of Obstetricians and Gynaecologists of Canada**. Management of the woman with threatened birth of an infant of extremely low gestational age. *CMAJ* 1994;**151**:547–51.
- 28 **Allen MC**, Donohue PK, Dusman AE. The limit of viability—neonatal outcome of infants born at 22 to 25 weeks gestation. *N Engl J Med* 1993;**329**:1597–601.
- 29 **Pinkerton JV**, Finnerty JJ, Lombardo PA, *et al*. Parental rights at the birth of a near-viable infant: conflicting perspectives. *Am J Obstet Gynecol* 1997;**177**:283–8.
- 30 **McHaffie HE**, Laing IA, Parker M, *et al*. Deciding for imperilled newborns: medical authority or parental autonomy? *J Med Ethics* 2001;**27**:104–9.
- 31 **Van der Heide A**, Van der Maas PJ, Van der Wal G, *et al*. The role of parents in end-of-life decisions in neonatology: physicians' views and practices. *Pediatrics* 1998;**101**:413–18.
- 32 **Cuttini M**, Rebagliato M, Bortoli P, *et al*. Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal unit policies in Europe. *Arch Dis Child Fetal Neonatal Ed* 1999;**81**:F84–91.
- 33 **de Leeuw R**, Cuttini M, Nadai M, *et al*. Treatment choices for extremely preterm infants: An international perspective. *J Pediatr* 2000;**137**:608–15.
- 34 **Gillon R**. Is there a 'new ethics of abortion'? *J Med Ethics* 2001;**27**(Suppl 2):ii5–9.
- 35 **Robertson JA**. Ethics and policy in embryonic stem cell research. *Kennedy Inst Ethics J* 1999;**9**:109–36.
- 36 **McCullough LB**, Chervenak FA. *Ethics in obstetrics and gynecology*. Oxford: Oxford University Press, 1994:224–8.
- 37 **Campbell AV**. Viability and the moral status of the fetus. *Ciba Found Symp* 1985;**115**:228–43.
- 38 **Gross ML**. Avoiding anomalous newborns: preemptive abortion, treatment thresholds and the case of baby Messenger. *J Med Ethics* 2000;**26**:242–8.
- 39 **Glover J**. Causing death and saving lives. London: Penguin, 1990:92–112.
- 40 **Rachels J**. Active and passive euthanasia. *N Engl J Med* 1975;**292**:78–80.
- 41 **Strong C**. The moral status of pre-embryos, embryos, fetuses and infants. *J Med Philos* 1997;**22**:457–78.
- 42 **Glover J**. *Causing death and saving lives*. London: Penguin, 1990:126–8.
- 43 **Tooley M**. *Abortion and infanticide*. Oxford: Oxford University Press, 1983.
- 44 **Jongmans M**, Mercuri E, de Vries L, *et al*. Minor neurological signs and perceptual-motor difficulties in prematurely born children. *Arch Dis Child Fetal Neonatal Ed* 1997;**76**:F9–14.
- 45 **Wolke D**. Psychological development of prematurely born children. *Arch Dis Child* 1998;**78**:567–70.
- 46 **Marlow N**, Lynne R, Cooke RWI. Outcome at 8 years for children with birth weight of 1250 g or less. *Arch Dis Child* 1993;**68**:286–90.
- 47 **Hobbs GF**, Hobbs CJ, Wynne JM. Abuse of children in foster and residential care. *Child Abuse Negl* 1999;**23**:1239–52.
- 48 **Zupancic JA**, Richardson DK, Lee K, *et al*. Economics of prematurity in the era of managed care. *Clin Perinatal* 2000;**27**:483–97.
- 49 **Danish Council of Ethics**. *Debate outline: extreme prematurity, ethical aspects*. Copenhagen: EuroLingua, 1995:28.
- 50 **Cooper TR**, Berseth CL, Adams JM, *et al*. Actuarial survival in the premature infant less than 30 weeks' gestation. *Pediatrics* 1998;**101**:975–8.
- 51 **Draper ES**, Manktelow B, Field DJ, *et al*. Prediction of survival for preterm births by weight and gestational age: retrospective population based study. *BMJ* 1999;**319**:1093–7.
- 52 **Lorenz JM**. The outcome of extreme prematurity. *Semin Perinatal* 2001;**25**:348–59.

BOOK REVIEW

Bioethics

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This is a collection of 15 papers from “philosophers, social scientists, and academic lawyers” concerned with “the field of bioethics itself”, “bioethics’s role in contemporary society”, and “specific issues”, including some—such as the role of the pharmaceuticals—not often addressed in such collections. They have all been commissioned for the volume either by or through the Social Philosophy and Policy Foundation, located in the USA, on whose behalf Cambridge University Press has published it in the UK. Perhaps, then, it is not surprising that it should be so parochial: all the contributors are from North America, and the focus of the book is very much on bioethics and on society as that discipline and that entity respectively are understood and thought about in the USA. In

some cases, of course, that is fine, because extrapolation from the American to the more general case is no less obvious than it is easy; in others, however—and it would be unfair of me to single out particular contributors, as my worry is addressed to the editors, and, even more, to the publishers—the material is very closely tied to the specificities of the circumstances and realities of the USA.

Academically rigorous though the collection is, therefore, it is not easy to see exactly whom it is intended to address: clearly not, for instance, MA/MSc students on healthcare ethics courses in the UK. Certainly this anthology is a very different *sort* of anthology from, say, Blackwell’s 1999 *Bioethics: An Anthology*. Unlike most such collections, which are intended to be used as textbooks, this one appears to be aimed very much at academics working in the broad field of bioethics. Again, that is in itself no bad thing. But the difficulty with this particular example is that its interest even for that constituency would seem quite limited: it lies more in its constituting something of a collective position statement from the Social Philosophy and Policy Foundation rather than as forming even a specialist anthology offering a range of views and

material conveniently collected together. For the entire collection—even those articles that are somewhat more questioning of common liberal positions than others—assumes both the validity and the value of a basically liberal outlook. However much infused by the spirit of a Rawlsian egalitarianism, the fundamental assumptions and attitudes of the politics and the philosophy of liberalism remain unquestioned. Differences, disagreements, and suggestions are all matters of adjusting the basics of that tradition rather than subjecting it to any fundamental critique—let alone rejecting it altogether. Again, then, the impression is that of a parochialism, and of one which is no less intellectual than social and geopolitical.

Those interested in seeing how the land lies within the field of bioethics as a growth industry in the USA, and/or in seeing what liberal assumptions amount to as they pan out in American bioethics, might well find this a useful anthology. Those with less specialised (or indeed quite different) concerns, however, are unlikely to find it very illuminating.

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