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Prolonging life and allowing death: infants

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Abstract

Dilemmas about resuscitation and life-prolonging treatment for severely compromised infants have become increasingly complex as skills in neonatal care have developed. Quality of life and resource issues necessarily influence management. Our Institute of Medical Ethics working party, on whose behalf this paper is written, recognises that the ultimate responsibility for the final decision rests with the doctor in clinical charge of the infant. However, we advocate a team approach to decision-making, emphasising the important role of parents and nurses in the process. Assessing the relative burdens and benefits can be troubling, but doctors and parents need to retain a measure of discretion; legislation which would determine action in all cases is inappropriate. Caution should be exercised in involving committees in decision-making and, where they exist, their remit should remain to advise rather than to decide. Support for families who bear the consequences of their decisions is often inadequate, and facilitating access to such services is part of the wider responsibilities of the intensive care team. The authors believe that allowing death by withholding or withdrawing treatment is legitimate, where those closely involved in the care of the infant together deem the burdens to be unacceptable without compensating benefits for the infant. As part of the process accurate and careful recording is essential.

Introduction

In a previous paper our Institute of Medical Ethics working party argued that on rare occasions a doctor is ethically justified in assisting the death of a patient, but only when asked to do so by the patient whose terminal suffering cannot be relieved in any other way (1). In a subsequent paper the working party considered the plight of individuals in the persistent vegetative state and concluded that it may be morally justified to withdraw artificial nutrition and hydration in circumstances where the diagnosis and prognosis are beyond doubt, and where doctors, other carers and the family agree that continued survival cannot be in the patient's interest (2). In this paper we consider the particular problems posed by infants whose lives may be prolonged through modern methods of treatment but for whom there is no prospect of recovery without profound disability. While recognising that cultural and national differences exist in the approach to matters relating to 'end of life' decisions (3,4), we, nevertheless, concentrate on the British scene with brief reference to current controversies in the United States.

Key words

Prolonging life; assisting death; neonates; quality of life.

Decisions involving infants

Infants obviously lack the capacity to request the withholding or withdrawing of life-sustaining treatment and they are patients for whom no 'substituted judgment' can be rendered as their present and past wishes cannot possibly be known. If decisions to allow the death of such vulnerable patients are to be justified ethically, three important questions must be addressed: first, in what clinical situations are such decisions appropriate; second, who should be responsible for decisions of such fundamental importance; and third, by what process should they be made so that the interests of the infants are fully protected?

Which infants are involved?

When dilemmas about resuscitation and life-prolonging treatment for infants first came to wide professional and public attention in the early 1970s, the main focus of concern was on infants born with major congenital abnormalities, particularly of the central nervous system (5,6). Since then, advances in prenatal diagnosis and in neonatal intensive care have led to an increase in the relative importance of problems posed by tiny infants whose future quality of life has been severely compromised by the complications of extremely premature birth. Other infants for whom withdrawal of life-prolonging treatment might be considered ethically justified include those whose brains have been damaged by infection, haemorrhage, or by hypoxic-ischaemic encephalopathy. As treatments become increasingly sophisticated,

furthermore, it may no longer be appropriate to talk simply of brain damage; but rather to differentiate between various types of neurological disease in the neonate (7).

For all these infants, irrespective of fine diagnostic distinctions, the basis for any decision to withhold or withdraw life-prolonging treatment is compassionate concern about their future should they survive with devastating brain abnormality or damage. In rare cases, particularly poignant dilemmas arise when the brain remains intact but irreparable damage has occurred to other organs.

Quality of life

To those familiar with neonatal intensive care it is not surprising that concern about quality of life is an important, perhaps the most important, element in these decisions. The legacy of abnormal development or prolonged intensive care that parents fear most is 'brain damage' and what this could mean for their child. As a criterion for decisions to forego life-sustaining treatment, quality of life has been severely criticised, particularly in the United States. Such judgments have been labelled as discriminatory against the handicapped and equivalent to the 'social judgments' that involve invidious discrimination on the grounds of such morally irrelevant criteria as race and colour (8). But it can be argued that quality of life predictions are necessary and inevitable if doctors and parents are to seek, on behalf of the infant, the least detrimental of several burdensome treatment options when it becomes apparent that none will be of real benefit. Furthermore, if we are to help families to cope with the tragedy of having a child with severe abnormalities or brain damage, quality of life judgments are important components of the detailed medical and ethical analysis that properly must precede any decision to withdraw treatment. To leave them out is to ignore the practical realities of caring for children with catastrophic impairments and to undervalue the importance of compassion in patient care. The alternative is to relegate doctors and nurses to acting purely as technicians and require them to use life-sustaining treatments indiscriminately without regard to the consequences for child or family.

In this context it is perhaps worth emphasising what 'quality of life' does *not* mean. To paediatricians it does not mean a judgment about the infant's inherent value or 'social worth' to the community. Nor does it imply that these medical decisions primarily rest upon consideration of the likely *financial* costs of long term care to the family, hospital or state. To a paediatrician, taking account of quality of life means being *concerned on behalf of an infant patient* about his or her capacity for future health, development and well-being, about the potential ability to reciprocate in human relationships, and about the human costs to the child and family that will accrue with survival.

Resources

Economic cost is not a quality of life issue. However, whether a treatment or its consequences can be afforded is an important but separate ethical judgment related to policy which must be determined away from the bedside. It is unrealistic to think that the staff of an intensive care unit can simply ignore the problem of finite human and financial resources and ever-increasing demands. Doctors, nurses and others, should be prepared to contribute to discussions on financial and other costs as any decisions they make could have adverse consequences for others. The prolonged care of totally dependent children is very expensive and inevitably uses public as well as private resources. If life is prolonged in infants who will be unable to engage in meaningful relationships with others, this must encroach on the resources available for the care and support of the much greater number of severely disabled children who can form and sustain such relationships.

Who should decide?

In most circumstances decisions to withhold or withdraw treatment are made through individual case-by-case analysis of the medical facts and sensitive informed discussions between the responsible doctor and the parents, or in the absence of parents, an appropriate surrogate. Parents are likely to make concerned and loving decisions in their child's interests if given the facts and treatment options accurately, sensitively and objectively. If possible, they should have adequate time for reflection and perhaps for consultation with family members, their family doctor, clergy and others as they wish.

While doctors and parents can be viewed as partners in decision-making for infants, it must be emphasised that any decision to withhold or withdraw life-sustaining treatment is primarily a *medical* decision for which the doctor bears ultimate responsibility. Nevertheless, good practice imposes an important duty on doctors to take careful note, not only of the wishes of the family, but of the views of the nurses and other key members of the intensive care team. Like doctors, nurses are accountable for their own practice in the care of patients. By the nature of their work and their frequent and prolonged contacts with parents at the cotside they may be in a better position to understand the true feelings and wishes of grieving parents that may not have found expression during more formal discussions with the medical staff.

When it is clear that there will be no benefit from further intensive treatment and where it seems beyond reasonable doubt that, with survival, the infant will be seriously impaired, there will usually be agreement to withhold or withdraw a life-sustaining procedure such as assisted ventilation. Sometimes parents may disagree with the staff and request

withdrawal of treatment earlier than indicated, or occasionally they may insist that treatment be continued long after the doctors and nurses believe it to be futile. Parental wishes should be respected as far as possible but there will be circumstances when they cannot be justified medically, ethically or legally. Even loving parents can make choices, perhaps based on strong religious convictions, that conflict with their child's interests, or are eccentric for other reasons. The doctor (or someone else) may have to intervene and act as an advocate for the infant. An infant's interests become inextricably interwoven with the interests of the family and a major part of a doctor's 'clinical wisdom consists of responsibly weighing interests and creatively resolving apparently irreconcilable conflicts' (9). For doctors, nurses and parents alike the emotionally charged atmosphere that surrounds abnormal birth or catastrophic illness can lead to snap judgments that, on reflection, are seen to be hasty and ill-advised. Parents may view the future either unduly pessimistically or over-optimistically and it may be difficult for them to understand the complexities of the condition or the treatment choices, particularly when the time available for discussion and questions is limited by circumstances. Conflicts may arise among the various people involved. Most of these can be resolved by discussion or through the help of some arbitrating procedure such as referral to an Institutional Ethics Committee (IEC), as in the United States, but occasionally it will become necessary to seek court opinion.

The process of decision-making

LEADERSHIP AND COMMUNICATION

Doctors have a particular responsibility to take all necessary steps to establish a diagnosis and prognosis as accurately as possible and to consider the various treatment options available, their likely outcomes and how these might affect the future life and health of their patient. They also have a responsibility to ensure that good communication exists between themselves and the parents, and between themselves and the other members of the intensive care team so that clinical decisions and other important information affecting the care of the child are properly shared. The doctor in clinical charge must exercise responsive leadership by not only being prepared to take difficult decisions but also by ensuring that they are soundly-based medically, ethically and legally. He or she should provide all the staff involved with opportunities to reflect on the issues and express their views. This is particularly important when individual members disagree or are uncomfortable about the ethics or legality of the decisions taken.

SUBSTITUTED JUDGMENT/BEST INTERESTS

The difficult and troubling task for parents and staff is to act as responsible and competent proxy decision-makers for the infant. It is impossible to predict exactly how an infant with a particular disability might view the options for treatment and the prospects for the future. Nevertheless, from the perspective of one in the patient's condition, there must be a careful attempt to assess the benefits and burdens of each action proposed in the light of what any 'reasonable person' would wish as regards quality of life. The agonising debate required to reach a decision in these cases, while time-consuming and emotionally demanding, has the additional value of providing some comfort and reassurance to the parents and the staff that the decision taken was correct and in the infant's best interests.

DISCRETION

It has to be acknowledged that what makes a life 'worth living', and what counts as a benefit or burden, and the relative ratio between the two, will vary with the circumstances and in the perceptions of different individuals. In this kind of medical decision-making some discretion is necessary. Underlying the Baby Doe regulations in the United States was the view that making quality of life judgments for others is morally unacceptable and that the traditional discretion awarded to parents and paediatricians in deciding the treatment of disabled infants was inappropriate and should be curtailed (10). However, it is worth pointing out that the exceptions to required treatment contained in the Baby Doe guidelines (for example, 'irreversible loss of consciousness', treatment that is 'virtually futile and inhumane') undoubtedly contain implicit quality of life judgments. We believe that quality of life judgments are unavoidable unless one adopts the view that 'life' has absolute value in itself and that every patient must be treated with every available technology until death is certain. Making judgments in good faith in circumstances where there is some uncertainty about outcome will inevitably lead to the occasional 'wrong' decision, but the alternative is to impose inappropriate treatment on many in order to eliminate bad decisions in a few cases.

Protections

OPENNESS

In the absence of legislation to limit discretion, are there sufficient safeguards to protect the interests of the infant? Apart from a combination of trustworthy doctor and loving parents (or committed surrogate) which gives a considerable protection, there is the importance of open decision-making and growing multidisciplinary participation in patient care. Nowadays it is unusual for such decisions to be made paternalistically by only one doctor in the privacy of the family home. They are usually made by consultation and consensus in large hospitals,

usually in an intensive care unit staffed by nurses, junior doctors and others whose views are all relevant to the moral decisions taken on behalf of patients. In the process of establishing the facts of diagnosis and prognosis doctors consult with specialist colleagues in the same way as the family consult with their own advisers. The nurses who provide the hour-to-hour care at the cotside are in almost constant communication with parents as together they watch anxiously over the condition of the infant, and become fiercely protective of his or her interests. In modern hospitals, frequent staff changes and shift systems sometimes make it difficult to maintain continuity and consistency in patient care. But by such a process of consultation through which an appropriate environment is established, the decisions taken should be both medically and morally consistent.

ETHICS COMMITTEES

In attempting to reach a compromise over the Baby Doe regulations, and to avoid intrusive review by federal investigators, American paediatricians proposed the use of Institutional Ethics Committees within the major hospitals to ensure a broader forum for discussion of the issues involved (11). These committees, and particularly some of the individual members, can be very helpful to the staff in an extremely taxing and poignant aspect of their work. We believe that ethics committees should remain advisory and not be asked or expected to take decisions on individual cases, a pitfall some American committees have not managed to avoid. The final decision should remain the prerogative of the doctor in clinical charge. There is always the danger that a committee, being relatively remote from the realities of abnormal birth and intensive care, will end up making a decision that is more protective of other interests than those of the individual child and family (12). Many British neonatologists already use a multidisciplinary group informally to discuss difficult cases at length and some are considering the formation of a more formal committee structure quite distinct from the *research* ethics committees already established in major hospitals. Apart from a role in educating both committee members and staff, and in reviewing hospital practices and developing policy, a formal forum for the regular discussion of these complex problems can also provide 'ethical comfort' and possibly some legal protection for the doctors who bear the ultimate responsibility. Whether ethics committees ensure better decision-making is less certain, but the need for them should diminish as good multidisciplinary practice continues to evolve.

RECORDS

A final protection is to insist that all decisions and actions taken are accurately recorded in such a manner that the decision-making process can be reviewed. Full explanation of the circumstances and reasons for any decision to withdraw treatment can do much to demonstrate and justify the *trustworthiness* that must remain a key component in medical decision-making.

Legal implications

One legacy of legislation in the United States has been the widespread but mistaken belief among American paediatricians that the law requires that all infants be treated intensively until death is certain (13). As a result, terminally ill infants have received overly aggressive and futile treatment for long periods at great cost, both human and financial. The Baby Doe regulations simply require that States wishing to receive federal funds for child protection services must have established a mechanism to review suspected cases of 'medical neglect'. To paediatricians and parents it may seem offensive to have their carefully considered decisions to withhold or withdraw life-prolonging treatments subject to scrutiny as 'child abuse'. They have, nonetheless, retained considerable discretion in decision-making.

The same is true in the UK. One lawyer, somewhat cynically, has described the current position thus: 'In so far as the tradition has been for the courts in the United Kingdom to allow themselves to be led by the medical profession, it is not necessarily surprising that both appear to pay lip service to the sanctity of life while leaving a vast discretion to the doctor in charge in consultation with the parents' (14).

Some examples of this 'vast discretion' are given below but the fact remains that for any decision to withhold or withdraw life-prolonging treatment, the legal position of the doctor remains somewhat unclear in the absence of any testing in court. A neonatologist will remain legally vulnerable as long as it is thought unwise (and probably impossible) to detail all the circumstances where it is 'legal' to allow a baby to die.

Recent court decisions give some idea of how English law currently views the responsibilities of doctors for making decisions about life-prolonging and life-saving treatment for children. They are consistent with the view expressed earlier, *viz* that quality of life judgments are proper components of the decision-making process.

For example, in *Re B* heard by the Court of Appeal in 1981, surgery was authorised to correct congenital intestinal obstruction in an infant with Down's Syndrome in the face of parental objection because, in the judges' opinion, the infant's life was not so 'demonstrably awful' that the infant should be allowed to die (15).

In 1989, in *Re C*, a High Court judge agreed that a very seriously handicapped infant should be permitted to die and that no further attempts should be made to prolong her life. She was four months old,

hydrocephalic, blind, and with severe cerebral palsy. This decision was appealed by the Official Solicitor who was unhappy with the judge's use of the phrase 'treat to die' which might be interpreted as giving authority for taking active steps to end the child's life. In their judgment, the Lords of Appeal agreed that Mr Justice Ward had 'failed to express himself with his usual felicity' and that the original decision had been too restrictive on the exercise of the doctors' 'normal clinical discretion'. They accepted that the goal of any treatment should be to ease the baby's suffering rather than a short prolongation of her life (16).

This case only came to attention because the baby, for reasons unconnected with her medical condition, had been made a ward of court before birth, but it provides further insights into how judges view these treatment dilemmas. Mr Justice Ward referred to Baby B noted earlier and also indicated his agreement with the kinds of criteria that have been used (and published) by neonatologists during the past two decades: 'In as much as one judges, as I do, intellectual function to be a hallmark of our humanity, her functioning on that level is negligible if it exists at all. Coupled with her total physical handicap, the quality of her life will be demonstrably awful and intolerable within the B test'.

In *Re C* the issue was about life-prolonging as distinct from life-saving treatment, that is, it was about a baby who was dying. In a subsequent 1990 case, that of *Baby J*, the Official Solicitor appealed a decision by Mr Justice Scott Baker that doctors should not be required to ventilate and therefore save the life of a 'gravely ill child', should he suffer a collapse, on the basis that: 'a court is never justified in withholding consent to treatment which could enable the child to survive a life-threatening condition, whatever the quality of life which it would experience thereafter' (17).

However, this submission was not accepted by the Court of Appeal which took the view that there can be some circumstances where the quality of life would be so intolerable that treatment, without which death would ensue, could be withheld even though the child was not dying. Lord Donaldson emphasised the need to avoid looking at the problem from the point of view of the decision-makers, but instead to look at it from the point of view of the patient.

'... even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive'.

This case is also important as it involved an infant born prematurely at 27 weeks gestation who, after weeks of intensive care and many complications was known to have suffered brain damage. It was therefore more typical of the infants who cause increasingly frequent and difficult medical, moral and legal dilemmas for the staff of neonatal units.

In a 1992 case, also confusingly called *Baby J*, the Court of Appeal held that the courts would not order a doctor to treat a patient if, in his clinical judgment, to do so would not be in the patient's best interests (18). This infant, aged 17 months, was profoundly handicapped and in the care of foster parents following a fall at the age of one month. He was microcephalic, blind and suffering from cerebral palsy and epilepsy. A consultant paediatrician had recommended that it would be inappropriate to intervene intensively, for instance by using mechanical ventilation should the infant suffer a further life-threatening event. This view was supported in the High Court by the health authority and the Official Solicitor but challenged by the local authority in charge of the child and by the child's mother. The Court of Appeal decision left the health authority and the doctor free to treat the child according to their best clinical judgment, but as noted by one judge, this did not mean that in no circumstances should mechanical ventilation be used, since the clinical situation might change, and Lord Donaldson stressed that, although no one could dictate to the doctors which treatments to apply, co-operation between parents and doctors was essential.

From such judgments and others it is possible to get some indication of how the courts might respond to the facts of an individual case, although judicial decisions are by no means predictable. Uncertainty remains about where the line of 'demonstrably awful', 'negligible intellectual function' or 'intolerable quality of life' might be drawn and who exactly should draw it. It is precisely in this area that there must be room for medical and parental discretion. We believe that it would be unwise to follow the American precedent and introduce legislation in an attempt to limit this discretion. Those involved in critical patient care might then feel compelled to consider their own interests before taking decisions related to the best interests of their patients. This would merely create new dilemmas and would not necessarily lead to any improvement in the current, admittedly imperfect, process of decision-making.

Consequences

It must be remembered that it is the parents who usually bear the consequences of these clinical decisions and that the supports and services available to help families to cope are often unsatisfactory or inadequate. On the death of an infant parents experience acute and profound grief, perhaps with feelings of guilt at the tragic outcome of a pregnancy that promised so much. For many families the long term consequences of an infant surviving with

grievous handicap are likely to be even more devastating as the crushing burdens and 'chronic sorrow' of long term care become all too apparent. Supportive care and counselling will be necessary not only in the hospital but within the community, perhaps for many years but certainly long after the staff in the neonatal unit have turned to other problems. It is part of the wide responsibility of the intensive care team to facilitate access to these services, perhaps with the help of the social worker or hospital chaplain. Members of the team can also be influential in lobbying for improved services for disabled children and their families both locally and nationally.

It would appear that with the more open and ongoing discussion of the ethical issues relating to prolonging life, even in countries where there is a tendency to wait for a virtually certain prognosis of impending death before withdrawing treatment, there has been a swing towards a more deliberated approach to decision-making in intensive care units (4,19). Consideration of the relative benefits and burdens in each individual case influences the judgment made. In addition, an increasing tendency to resuscitate smaller and more immature infants has made it necessary for neonatologists to countenance withdrawal of treatment when there are clear indications of severely adverse outcomes.

Summary

Doctors may decide to withhold or withdraw treatment and by so doing legitimately allow or assist death when it is agreed between the informed parents (or surrogate) and the members of the intensive care team that continued treatment will lead to unacceptable burdens without compensating benefits for the infant. The responsibility for such a decision ultimately rests with the doctor in clinical charge but he or she has a duty to share the decision-making process with those closely involved in the care of the patient. In assessing the benefits and burdens, quality of life judgments are unavoidable if the decision-makers are to act in the best interests of the child. In reaching a decision, considerable latitude should be expected and tolerated. If the decision-making is informed, thorough and properly shared, and recording is accurate and careful, the process itself will help to mitigate the long term consequences for both parents and staff.

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References

(1) Institute of Medical Ethics. Assisted death. *Lancet* 1990; 336: 610–613.
(2) Institute of Medical Ethics. Withdrawal of life-support from patients in a persistent vegetative state. *Lancet* 1991; 337: 96–98.
(3) Rhoden N K. Treating Baby Doe: the ethics of uncertainty. *Hastings Center report* 1986; 16: 34–42.
(4) Ryan C A, Byrne P, Kuhn S, Tyebkhan J. No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *Journal of pediatrics* 1993; 123, 4: 534–538.
(5) Lorber J. Results of treatment of meningomyelocele: an analysis of 524 unselected cases with special reference to possible selection for treatment. *Developmental medicine and child neurology* 1971; 13: 279–303.
(6) Duff R S, Campbell A G M. Moral and ethical dilemmas in the special care nursery. *New England journal of medicine* 1973; 289: 890–894.
(7) Coulter D L. Neurologic uncertainty in newborn intensive care. *New England journal of medicine* 1987; 316, 14: 840–844.
(8) U S Commission on Civil Rights. *Medical discrimination against children with disabilities*. Washington D C: U S Government Printing Office, 1989.
(9) Stanley J M. Appleton International Conference: developing guidelines for decisions to forgo life-prolonging treatment. *Journal of medical ethics* 1992; 18 [suppl]: 1–22.
(10) Weir R F. The government and selective non-treatment of handicapped infants. *New England journal of medicine*, 1983; 309: 661–663.
(11) American Academy of Pediatrics. Committee on Bioethics: treatment of critically ill newborns. *Pediatrics* 1983; 72: 565–566.
(12) Campbell A G M. Baby Doe and forgoing life-sustaining treatment: compassion, discrimination or medical neglect? In: Caplan A L, Blank R H, Merrick J C, eds. *Compelled compassion*. New Jersey: Humana Press Inc, 1992.
(13) Kopelman L M, Irons T G, Kopleman A E. Neonatologists judge the 'Baby Doe' regulations. *New England journal of medicine* 1988; 318: 677–683.
(14) Wells C. 'Otherwise kill me': marginal children at the edges of existence. In: Lee R, Morgan D, eds. *Birthrights: Law and ethics at the beginnings of life*. London: Routledge, 1989.
(15) *Re B* 1981, 1, WLR 1421, 1424.
(16) *Re C* 1989, NLJ Law Reports: 613.
(17) Re J 1990. Court of Appeal Oct 19. *Bulletin of medical ethics* 1990; 63: 22–23.
(18) Re J 1992. TLR 12-06-92. *Bulletin of medical ethics* 1992; 79: 5–6.
(19) Jayes R L, Zimmerman J E, Wagner D P, Draper E A, Knaus W A. Do-not-resuscitate orders in intensive care units. *Journal of the American Medical Association* 1993; 270, 18: 2213–2217.