

# Should artificial resuscitation be offered to extremely premature neonates?

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## Introduction

*“Change’ is scientific, ‘progress’ is ethical; change is indubitable, whereas progress is a matter of controversy.” – Bertrand Russell*

Forty years ago it was generally accepted that a baby born more than two months premature could not survive. Now neonates as young as 22 weeks can be kept alive with medical intervention. This essay will explore the medical, social and legal aspects of artificial resuscitation of extremely premature neonates and argue for a change to a palliative approach towards infants born at the threshold of viability.

## Background

Extremely premature newborns face a number of medical problems, affecting almost all systems of the body. These problems include extreme skin immaturity and fluid balance instability, lung immaturity and breathing problems, malnutrition and gut damage, retinopathy of prematurity, early and late onset infections and brain damage which can lead to a spectrum of long-term neurological sequelae. [1,2]

Infant survival and long-term prognosis improve with increased gestation. According to the largest collaborative clinical audit to date, survival rates of extremely premature infants vary from 1% at 22 weeks to up to 44% at 25 weeks. Before 21 weeks and six days, no published studies record that a baby survived to leave hospital. [3] The fact that almost half of the infants born at 25 weeks survive has been used to justify aggressive intervention in this age group. However, of the children who survived at 25 weeks, only 20% were living with no disability by age six and 22% had severe disabilities, including cerebral palsy. [4,5] Recent Australian data on the outcomes of extremely premature neonates paints a more promising picture, with 71% surviving to eight years and 43.9% having no disability at age eight. The rate of severe disability at age eight was 8.6%. [6] However, this data includes neonates up to 28 weeks and there is no sub-group analysis of survival rates of neonates born at 25 weeks, a group known to have poorer outcomes than extremely premature neonates born at 26 or 27 weeks. [7]

Care for extremely premature newborns is extraordinarily expensive. In 2003, premature newborns accounted for approximately US\$18.1 billion in health care costs in the United States (US), or half of total hospital charges for newborn care. [1] This figure does not account for ongoing costs for the health system and the physical, psychological and emotional impact of raising a child with a disability.

Although there has been much media attention regarding premature newborns over the years, the issue of their care has been given scant attention in the courts in Australia. Legal precedents originate in the United Kingdom, with the Court of Appeal ruling on the issue in 1993. Here they stated that while doctors and parent/s may not undertake actions where the purpose is to end life, they may, in appropriate circumstances, use drugs to relieve pain and distress, even though their use may advance the time of death. [8]

In the US, no court has ever ordered the withholding or withdrawal of life-prolonging interventions over a family’s objections. [9] In 2003, a US court came to a controversial legal decision, permitting physicians to disregard parental preference for palliative care and unilaterally initiate resuscitation when faced with the birth of an extremely premature baby. [10]



In Australia, practice is predominantly guided by local and international guidelines rather than legal decisions.

## The ethical dilemma

As stated, in the last two decades, improved survival rates of extremely premature newborns have resulted in life-saving support being offered to infants of borderline viability. The problem with increased survival rates of extremely premature newborns is that there is a corresponding increase in short- and long-term medical and psychological problems resulting from such a premature birth. This raises the pertinent question of whether neonatologists should be initiating care for these infants in the first place.

## Possible choices

There are a number of frameworks which can help inform the parlous decision of whether or not to initiate treatment. The two prevailing frameworks are:

1. *The Best Interests Standard: Acting in the “best interests of the patient.” Particularly attempting to determine:*
  - degree of suffering involved in the care;
  - futility of further intervention; and
  - likelihood of survival free of serious disability and practical consequences. [11]

The Best Interests Standard is a moral and legal standard for directing the decision-making process when individuals lack decision-making capacity. The interests and welfare of the patient take priority over all other parties. In this particular situation, the interests of the neonate are inextricably linked to that of the parents and therefore their interests must also be taken into account. In Australia, if the Best Interests Standard is maintained, the fiduciary duty of the clinician has been met. In the Netherlands the best interests principle permits active euthanasia of a newborn, as outlined in the Groningen Protocol. [12]

When discussing medical practice, the 19th century physician William Osler wrote: “Errors of judgement must occur in an art which consists largely of balancing probabilities.” [8] The problem with the likelihood of survival free of serious disability is that this likelihood is determined by average survival rates. This is inevitably imprecise in predicting individual survival, or individual disability and suffering

for that matter. Medical practitioners cannot make a completely accurate prediction of the outcome for an individual infant. However, availability of epidemiological data and increasingly reliable diagnostic and prognostic tools have substantially reduced error in diagnosis and prognosis. We are in a better position to determine futility of treatment for premature newborns than ever before.

## 2. "Baby Doe Rules"

The "Baby Doe Rules" are formally known as the Child Abuse Amendments to Public Law 98-457. These US regulations prohibit anyone from withholding or withdrawing food, water, medications or other treatments appropriate to maintain survival, allowing only three exceptions for withholding life-supporting treatments:

- "The infant is chronically and irreversibly comatose;
- The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions or otherwise be futile in terms of the survival of the infant; or
- The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane." [13]

These regulations are overly prescriptive and have resulted in declined autonomy of parents and medical staff in the US. The option to make individualised and compassionate decisions, such as provision of adequate pain relief and withdrawal of some medications, hydration and nutrition in situations of futility, must be retained. On these grounds, the Baby Doe rules should be rejected.

To return to option one, the Best Interests Standard, it is apparent we have two options – decision making at birth and decision making after the infant has been resuscitated and stabilised.

Decision-making at birth is marred by uncertainty as fetal prognosis is rarely clear-cut at this point. The initiation of resuscitation leads to admission to the neonatal intensive care unit (ICU), which may set off a cascade of expensive and uncomfortable or painful procedures and raise parental expectations about survival. [14] Others contend that denying intensive care a priori, based solely on the age of gestation or birth weight, is contrary to the principle of equity. [15]

Decision-making after initial resuscitation, that is the decision to continue or withdraw treatment, may be viewed as a more justifiable alternative as it allows a better assessment of diagnosis and prognosis. It may further enhance parent and doctor autonomy by conferring a sense of control over the situation. However, many clinicians find it relatively easier to make a decision not to commence treatment rather than to cease it. There may also be reluctance from parents to "turn off life support" for their newborn too, believing they are actively giving up on their child.

## The interested parties

### The Patient

A newborn infant is unable to express an opinion, and its interests are represented by their parents/carers and the medical staff involved in its care. [8] The best interests of a neonate are thus entirely based on the perception of others, namely parent/s or medical staff.

At present time, it is impossible to determine what values and beliefs a neonate has, if any at all. A number of influential philosophers, including Peter Singer, argue that newborns lack consciousness and thus have no interests or independent rights. [9] Although unable to articulate their views, one cannot deny that newborns experience pain and discomfort. Maximising good and minimising harm must be paramount in treatment of the newborn.

### The Carers

The neonatologist is often the default decision-maker. They hold a privileged position having knowledge of diagnosis, likely prognosis and

outcome of the patient. Usually, they will give their assessment of the situation to the parent/s and ask for their consent in the management. In areas of uncertainty, the so-called "grey zone," parents have an increased role in the decision-making process. [16,17] Too much emphasis on parent choice may result in undue stress and burden of responsibility in an already stressful situation. The onus must not rest solely with the parents to decide on commencing or ceasing intervention.

Up to two-thirds of extremely premature births have complications which bring them to the attention of the obstetrician days or weeks before delivery. [11] This allows pre-delivery counselling. This counselling must be accompanied by support and engagement in the decision-making process, preferably by both an obstetrician and neonatologist. Decisions made by parents before birth are not necessarily absolute and binding.

The one principle which underlies guidelines in all advanced countries is *primum non nocere*. This can justify the withdrawal of life sustaining treatment if the continued treatment has a perceived worse outcome than death. There are a number of factors which affect a neonatologist's decision to withdraw treatment including hospital policies in certain countries, individual factors such as gender, age and length of professional experience, religiousness and personal attitude towards sanctity versus quality of life. [14]

The Nuffield Council on Bioethics has made recommendations about resuscitation and continuing intensive care of extremely premature infants. [11] These are shown in Table 1. The Nuffield recommendations reflect modern practice in the United Kingdom.

**Table 1:** Summary of recommendations for the resuscitation at birth of babies born at borderline viability. [11]

Gestation (completed weeks)	Standard	Exceptions
21	No resuscitation (considered as an experimental procedure)	Only as part of research protocol.
22	No resuscitation	At parents' request after prolonged and fully informed discussion of the risks, implications, and the likely outcome.
23	Could not be defined	... precedence (should be given) to parent's wishes. If left to clinicians, the clinical team should 'determine what constitutes appropriate care for that particular baby.'
24	Resuscitation	Unless parents and clinicians agree in the light of the baby's condition that it is not in his or her best interests.
25	Resuscitation	Unless severe abnormality incompatible with any significant period of survival.

In alignment with these recommendations, infants of 24 and 25 weeks are ventilated and intensive care measures implemented. The decision to withdraw assisted ventilation is made only after the infant has been given a chance of life when there has been time to assess progress and response to treatments. As mentioned above, many clinicians find it relatively easier to make a decision to not commence treatment rather than to cease it; thus withdrawal of ventilation may not be undertaken as likely as it should.

In Australia, a consensus statement exists regarding decision-making

about newborns of borderline viability. This framework considers the gestational “grey zone” to be between 23 and 25 weeks. The guidelines make recommendations in alignment with the Nuffield recommendations but essentially leave initiation of treatment to the discretion of parents and treating clinicians for newborns at the threshold of viability. [18,19] These guidelines can be interpreted on a case-by-case basis according to comprehensive postnatal assessment of the child’s general health. Factors such as availability of resources, planned pregnancy, assisted conception, maternal age and illness and fetal conditions or compromise all play a part in the decision of whether to initiate resuscitation.

Australian and international surveys of obstetricians and neonatologists about their management decisions in extremely premature infants have shown significant variation in the use of intensive care in the extremely premature. [20,21] Lorenz *et al.* [22] compared management strategies in the US to those in the Netherlands. Near universal initiation of intensive care (US) compared with selective initiation of intensive care (Netherlands) was associated with 24.1 additional survivors per 100 live births, 7.2 additional cases of disabling cerebral palsy per 100 live births and a cost of 1,372 additional ventilator days per 100 live births. Unfortunately this study did not report on less disabling neurological complications or other sequelae.

## Discussion

A newborn has a right to good quality of life, not simply a right to life. Imposing prolonged suffering upon a child, justified under a belief in the sanctity of life, reflects clinicians’ or parents’ beliefs rather than the best interests of the newborn. Parents, clinicians and the community as a whole must conclude that their obligation to a newborn is to act in their best interests. In a case where tests indicate a prognosis of severely disabling cerebral palsy, the right action ought to be to withdraw treatment and institute palliative care measures.

Orzalesi *et al.* examined four ethical principles as they apply to extremely premature newborns. [14] These principles, given equal priority, tend to conflict with each other. Presented with a neonate who does not possess autonomy, priority must be given to the autonomy of the surrogate decision-makers (the parent/s and treating clinicians). Beneficence and non-maleficence prescribe the duty to benefit and not to harm other people. They must be viewed in terms of the larger picture. Most diagnostic and therapeutic acts involve some form of harm in the short-term. Therefore beneficence in the long-term must take priority. With increased diagnostic and prognostic reliability, and assuming one views severe disability as an undesirable trait, the initiation of often painful treatment to prolong the life of a child with significant likelihood of severe disability would be harmful and clearly contravenes this principle. [14]

Justice in this situation implies fairness of treatment from an economic standpoint, in terms of allocation of resources where resources are finite. [14] It costs AU\$2,740 per day to keep a baby alive in a neonatal ICU in Australia. In a large number of cases, this cost may increase substantially over time as a result of the patient’s developmental conditions relating to prematurity. [23] It would be wrong to keep a child alive with a very poor prognosis when these resources could be used to keep children with the prospect of a reasonable life alive. When 1.4 billion people live on less than US\$1.25 per day, and

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thousands of healthy babies are born each day but go on to die before their first birthday due to preventable disease, one cannot morally justify spending such large amounts of money on a child of borderline viability. Approaching the study by Lorenz *et al.* from this utilitarian perspective, it is difficult to justify an additional 1,372 ventilator days which only result in 24.1 additional survivors per 100 live births, a significant number of which will have neurological sequelae. One can easily recognise that beds made available for newborns with a better chance of survival (such as those born at >25 weeks) would result in more survivors, with a better long-term prognosis.

Further on the principle of distributive justice, there remains significant geographical inequality with premature newborn care. A notable disparity exists between survival and disability outcomes between newborns born in tertiary neonatal centres and those born in rural and remote centres, a relevant point in a large country such as Australia. [7]

## Conclusion

The decision to resuscitate extremely premature newborns is a relatively new ethical dilemma brought about by advances in neonatal intensive care within the last half century. Continuing medical and technical advances in neonatal intensive care will result in ongoing revisions of current medico-legal and ethical guidelines. Decision-making regarding refusal, initiation and withdrawal of intensive care will remain a process which occurs between doctors and parent/s, taking into account the newborn’s best interests, parental autonomy and the clinical judgement of the treating neonatologist. To determine the correct moral decision, the neonatologist should consider their duties of beneficence and non-maleficence and the shared duty of distributive justice.

A paradigm change to a more palliative, holistic approach is, in many places, already embedded in the neonatal ICU. This necessarily incorporates physical, psychological and spiritual aspects of the dying process that the infant and the family are experiencing. Neonatologists who are not comfortable with this approach and attempt to save every child born before 25 weeks are doing a disservice to the patient, their family and the community in general.

Opportunism must not override compassion. Whilst there are the knowledge, skills and appropriate technology available to keep an extremely premature newborn alive, it would be prudent to consider the short- and long-term ramifications of such a decision on the child, their family and the health care system.

The widely practised approach of treating all potentially-viable newborns is resource intensive and will result in short- and long-term physical, psychological and emotional distress. An alternative approach involving default non-initiation of treatment in newborns born under 25 weeks gestation, with treatment being the exception rather than the rule, would benefit from wider discussion and debate.

## Conflict of interest

None declared.

## Correspondence

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