VIEWPOINT

Is intensive care for very immature babies justified?

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Neonatal intensive care is generally considered justified in the majority of very premature infants, but there is some concern about the effectiveness of the techniques used at the margins of viability (22–24 wk of gestation). The controversy that exists in this area is largely due to a lack of agreed endpoints for geographically based populations where all live births are considered. Evaluation of outcome must also take the quality of neurological function in surviving infants into consideration, and in reviewing these data the reader is struck by the few reports providing information on a high proportion of survivors. To inform this debate, the “best data” for analysis are reviewed based on a number of criteria for quality of survival and outcome studies. Based on these data sets, <25% of babies born alive at 24 wk and below survive without major disability.

Conclusion: An objective review of “best data” will provide the basis of an informed debate on whether providing intensive care for all very immature babies is appropriate in developed countries.

Key words: Disability, neonatal intensive care, neonatal outcome, severe prematurity

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We are now in the fifth decade of neonatal intensive care and it is timely to take stock of what we are doing and ask whether the results are fully justified in terms of outcome. Many of us work in a cash-limited public health service where we are asked to justify value for money in the services we provide. Although this is not the primary consideration of providing excellent healthcare it is an important factor in terms of equity of services.

I have become increasingly uncertain about whether it is right to provide intensive care for all babies referred to our service. Reflection on this issue requires accurate information that can be agreed and debated, but these data are not readily found. The information required and issues for discussion can be posed as a series of questions, which I have sought to answer below.

What is described here is a personal view based on my experience of providing neonatal intensive care for critically ill babies for over 25 y.

What is the outcome of the extremely tiny baby?

There are many confounding factors in determining the true survival and neurodevelopmental outcome of very immature babies (Table 1).

- a. Many studies refer to the infant’s birthweight rather than gestational age. Low birthweight introduces the variable of growth retardation, which is known to be associated with significantly increased mortality (1). Accurate assessment of gestational age by early ultrasound assessment is now widely available in developed countries and studies should be reported using gestational age as the main variable.
- b. Survival data relating to the modern era of neonatal intensive care are clearly important. The two major innovations in recent years that have improved survival are wide uptake of the use of antenatal corticosteroids and postnatal surfactant therapy. There have been many reports of improvement in survival world-wide when studies of cohorts born in the 1980s are compared with those born in the 1990s (2–5). Studies of babies born before 1990 are unlikely to include a high proportion of babies benefiting from these forms of treatment.
- c. Selection bias of survival data is a major confounding variable. In their systematic review, Evans and Levene (6) showed that when studies reporting the outcomes of surviving babies only admitted to the neonatal unit (Grade C studies) were compared with outcomes of all those delivered in the hospital labour ward, including stillbirths and deaths, before admission to the neonatal unit (Grade A studies), there was...
a 100% difference in the reported survival in infants of 23 wk and a 56% difference in infants of 24 wk when Grade C was compared with Grade A.

d. Most survival data are reported from individual centres or from a number of centres usually representing academic institutions of excellence. This may bias the reported figures possibly related to the referral of the most complicated (highest risk) cases which might cause the figures to reflect this adverse risk, or, alternatively, may influence the admission criteria to reflect an enhanced rate of survival. Staffing levels in centres of excellence may not reflect levels in more “average” centres.

e. Large numbers of multiple births, differences in racial characteristics and lethal congenital malformation rates have all been reported to influence the survival figures.

If we are to debate the justification for neonatal intensive care we must agree on a database to reference the debate. For this reason, I have reviewed the English language literature for survival studies that fulfil all the following criteria:

- Birth cohort largely during or after 1990
- Cohorts expressed by gestational age
- Ascertainment of all live-born infants including those who were not offered intensive care
- Reported survival to at least one year of age
- Cohorts where there is a clearly defined geographical base

I have reviewed the literature to estimate the “best evidence” of survival for groups of babies born alive based on all of the above five criteria. It is my view that this best evidence reflects the realistic survival figures that can be debated widely amongst professional and lay people.

Only seven studies fulfilled these five criteria (5, 7–12); the overall survival rates for these seven studies by gestational age are shown in Fig. 1. At 24 wk, the survival rate in only 26% and is only above 50% at 26 wk.

Adverse outcome of survivors can be measured by those described as having “major disability”, the definition of which may vary somewhat from study to study but generally includes cerebral palsy affecting independent locomotion, intellectual impairment with DQ or IQ <70, deafness requiring hearing aids or children registered as blind.

Additional variables that are necessary when considering quality of outcome data are the age at which follow-up data are ascertained and the completeness of the data. A number of investigators have shown that studies with incomplete ascertainment data are the most likely to miss children with significant disabilities (13, 14).

I have applied the following criteria for high quality outcome data:

- Birth cohort largely during or after 1990
- Cohorts expressed by gestational age
- At least 85% of the original surviving cohort assessed

Five studies were found, in which the above criteria are met (4, 5, 11, 15, 16). The interpolation of the survival data from Fig. 1. and the morbidity data from these five studies expressed as a combination of mortality and morbidity by gestational age are presented in Fig. 2. It is my view that these data are most informative of the true outcome figures for babies born very immaturely.

Over 50% of babies born at 26 wk survive without major disability, whereas less than 25% of babies born alive at 24 wk are considered to be without major disability. This does not take into account the evidence for “minor” disability amongst a further 25% of the survivors of 25 wk of gestation and below (9).

Has survival improved in the modern era?

A number of studies have reported improved survival rates in recent years (2–5). These studies have compared outcome in the modern era (post-1990 when wide use of
Antenatal corticosteroids and postnatal surfactant were used) with babies born in the 1980s. I am not aware of any studies that have reported improved survival or better outcome when two successive cohorts, both born in the 1990s, have been compared.

There has traditionally been an argument in neonatal medicine that because we struggled with babies of 26 wk in the late 1980s we have improved our techniques so that now 26-wk intact survival is common. This reasoning is now being used to justify aggressive management of 22–24 wk infants. Without good evidence to support the proposition that intact survival has been increasing in recent years, it is likely that we are near the limits of viability for the conventional treatments that are currently available. Significant numbers of babies surviving intact below 23 wk will require different technologies that are not currently available and which, in any case, will need very careful evaluation of their safety before being introduced.

What is the moral and ethical obligation to treat these babies intensively?

It has been argued in Acta Pædiatrica that we have a moral obligation to treat all very premature babies, referred to as “micropreemies” (17). What remains unclear is how these babies should be treated. Treatment can involve comfort care in the knowledge that we are easing their passing from birth to death in a caring, loving and supportive manner, ensuring that the babies do not suffer. In these cases, full nursing care is just as good a management strategy as launching the entire panoply of intensive support. What do the parents want and have we primed their expectations by giving them few options other than accepting intensive care as the only treatment available? If full intensive care is started, how long should this be offered and has termination of treatment been discussed with the parents? Have formal review times and rules for stopping treatment been set?

It is my premise that if parents are told that the chances of their 23- or 24-wk infant surviving without major disability is <20% rather than the survival figure of 44% published by an individual referral centre (15) for a similarly immature infant, then agreement to intensive care at that gestational age may be less generally accepted.

Does death represent the only measure of failure?

Survival rates for very immature infants may be used to calibrate the quality of care and if league tables are published of results comparing different intensive care units then this impression may be reinforced. Survival is clearly not the only, or, arguably, the most important measure of outcome, as a surviving infant with multiple and severe neurodevelopmental disability may be viewed as a medical, social and economic disaster. Quality of outcome should therefore be measured as the number of surviving intact children emerging from the intensive care environment.

“Intact survival” may also be a misleading term as it is increasingly recognized that children who were thought to be normal in the sense that they had no major neurodevelopmental disability at a young age are now being shown to have cognitive, behavioural and dyspraxic problems at school age and beyond (9, 18, 19). Although these may not be considered to be major problems, they do represent very considerable burdens of care and stress to the families and challenges to the provision of their education.

It is always tragic for a family when their baby is born very immature. They are faced with weeks or months of intensive care, loss of the anticipation and excitement of a normal birth and persistent and pervasive anxiety about their child’s future. Not all families want neonatal intensive care for the baby who is very immature and with only a small chance of intact survival. Unfortunately, there is still a view amongst the medical profession that a patient’s death during treatment is a failure rather than taking a more holistic view that this may be the best outcome for the patient and the family. It is often my experience that the nursing view is more compassionate to a range of outcomes with a “good death” being entirely acceptable and one to draw professional satisfaction from.

A way forward

The development of neonatal intensive care during the past forty years has been a great success story for modern medicine. Many babies now survive to lead normal lives as a result of this development in treatment techniques. It is only when babies are born near the limit

![Combined Mortality and Morbidity](image)
of viability that it becomes more difficult to justify whether what we are doing is appropriate. Reviewing the outcome data for these babies causes me considerable anxiety regarding whether the outcome for babies born at 23 and 24 wk justifies the aggressive forms of therapy that are brought to bear.

I am not suggesting cessation of care for these babies, but merely a more objective approach to initiating a general debate within society as to whether this is good use of resources. There will always be appropriate arguments for instigating intensive care for some very immature infants, but perhaps it should be viewed as an experimental therapy with properly informed consent rather than the automatic process that it often becomes. It is too easy to start the carousel of intensive care for baby and family rather than reserve this for the minority who truly understand what this treatment entails.

References


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