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Outcome following extremely preterm birth

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KEYWORDS

Extreme prematurity;
Survival;
Child development

Summary

Survival and later morbidity after extremely preterm birth are key issues to factor into the care of women and their children at borderline viability. Whereas we have robustly collected information on survival that shows some increases at 24–25 weeks of gestation, few data suggest any change in morbidity. Of babies born before 26 weeks of gestation around one quarter grow up with serious disability. Mild disabilities are common amongst the remainder. Overwhelmingly the major adverse outcome following extremely preterm birth is cognitive impairment, something that may not be apparent until school age, when we make increasing demands on children to perform. Despite these problems studies of very preterm/very low birthweight children as adults seem to indicate good adaptation and integration into society.

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Introduction

The instigation of neonatal care following birth at borderline viability has always been attended with public and professional anxiety over the eventual outcome for such children, and these arguments have often been advanced as a reason for not supporting neonatal intensive care. However, there have been dramatic changes in the mortality and major neonatal complication rates over the past 50 years such that when examined the balance sheet has always been found to be in favour of the application of intensive support for such children.

More recently some doctors have taken the view that there may be some groups for whom the institution of intensive care may not be in the child's best interests, based around the high mortality and risk of serious longer-term problems that have been reported in babies of extremely

low gestations, usually 25 weeks or less. This has led to international variation in practice with some national recommendations that intensive care should not be offered for such infants unless the parents request it, most overtly from the Netherlands. In most countries, however, such decision making is not subject to strict national guidance and a risk-based approach is undertaken for each delivery. Such an approach demands a careful assessment of risk and communication of this risk to the future parents so that a joint considered approach may be made.

In this paper I will address what is currently understood about longer-term outcomes for this vulnerable group and what the potential for longer-term improvements in these outcomes might be.

Mortality and survival

Single neonatal units frequently claim high rates of survival at very low gestations, but these statements frequently have wide confidence intervals in view of the small numbers

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included. Hence epidemiological or collaborative data provide a more reliable estimate of survival in the population. In 1995 in the British Isles we reported perinatal outcomes for babies born at 25 weeks or less (Fig. 1).

It is critically important that accurate denominators are used when interpreting survival data at low gestational ages. Furthermore comparisons between populations are difficult as small changes in the proportion of deliveries considered stillborn will make considerable differences to the eventual proportion of survivors, if considered as a percentage of livebirths, for example. Trying to establish trends in survival since 1995 is problematic, therefore, unless one views consistently collected data. Data from the Trent Neonatal Survey are frequently used to counsel women. Considering gestation-specific survival rates for low gestations demonstrates a three-fold increase in survival rates at 24 weeks of gestation over 8 years against a background of little change at 23 weeks and lesser increases in survival at 25 and 26 weeks (Fig. 2).

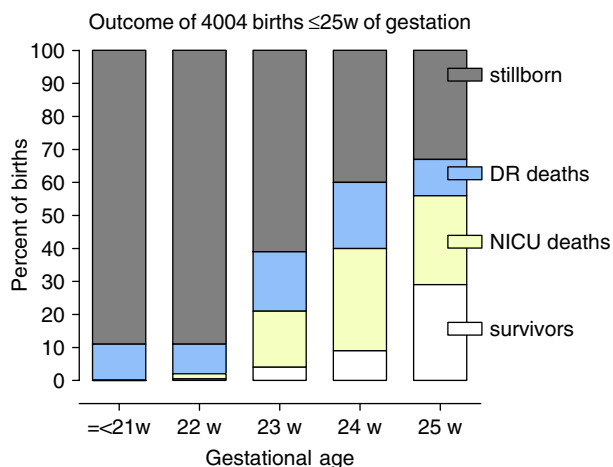


Figure 1 The outcome of 4004 births at 21–25 weeks gestation in the UK and Ireland in March–December 1995 (the EPICure study).

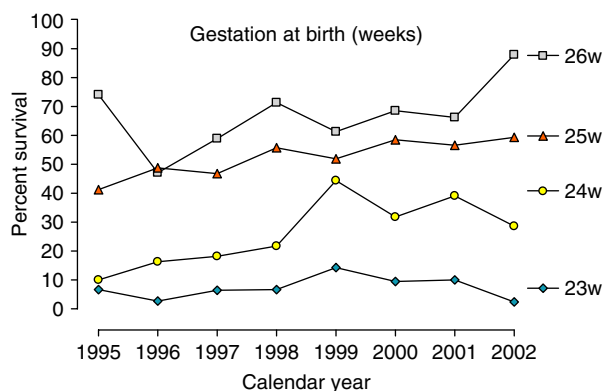


Figure 2 Gestation specific survival Trent Region, UK, 1995–2002, for fetuses alive at the onset of labour. Data from the Trent Neonatal Survey with permission.

Morbidity after discharge

Neonatal morbidity is high among extremely preterm children, particularly in terms of chronic respiratory disease, ultrasound-detected brain injury, retinopathy of prematurity and other common neonatal complications. Where these are particularly severe, for example with bilateral parenchymal infarction, prognosis is relatively easy to determine but for the majority of children the issue is one of risk assessment.

Although there are many studies of longer-term outcome after very preterm birth (<32 weeks) or very low birth-weight (<1501 g) the proportion of children born at borderline viability in each study are relatively few. There have been a range of recent studies that have looked at large populations of extremely preterm babies, often seeded within larger epidemiological cohorts, for example EPICure (UK and Ireland), EPIPAGE (France), EPIBEL (Belgium), EFTOL (Denmark) and VICS (Victoria, Australia). Not all have yet reported later outcomes but these are awaited.

Outcomes for the children in each study varies. This variation is difficult to explain as practice concerning resuscitation and end-of-life decisions will impact both on the survival rates and rates of serious morbidity, but decision-making processes are rarely explicit. Furthermore, population differences in social and demographic factors may lead to differences in population risk that explains at least some of the variation in outcome. International comparisons may also be confounded by poorly validated or differently defined outcome measures; for example it is not possible simply to translate developmental scales, they must be standardised on the local population, poorly standardised tests will lead to differing cut points when making classifications of outcome.

Overall disability

Many outcome studies combine domains of disability in their reports of outcome. This is particularly common when reporting outcomes from randomised trials. Most studies report outcome between 18 months and 24 months correcting for prematurity.

There is little consensus over the classification of a “poor” outcome. The commonest grouping comprises:

- Cerebral palsy (CP)
- Developmental quotient (DQ) <70
- Blindness
- Hearing aids

Some studies add to these epilepsy and hydrocephalus, although by themselves they may not by themselves always be ‘severe’ disabilities. Some studies qualify their reporting of CP as ‘non-ambulant CP’ indicating more severe disability, and there is a range of tests that can be used to identify children with low developmental scores, both by direct assessment (Bayley Scales and Griffiths’ Scales are the commonest) and by parent assessment of development (e.g. the Ages and Stages Questionnaire) or cognitive function (e.g. PARCA-R). The value of these consensus standards is in their comparability but it is not assumed that these

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