

Counselling parents expecting an extremely preterm baby



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Expecting a preterm baby is one of the most difficult and stressful challenges that parents can face. This is particularly so when their infant is expected at the borderline of viability. These parents are often faced with the difficult choice prior to the birth as to whether or not to initiate resuscitation when their baby is born.

The role of the neonatologist, obstetrician and midwife in this setting is to patiently and compassionately guide the parents in making a well-informed and supported decision.

Although babies have survived after birth at 22 weeks gestation, the majority of neonatologists in the Australian setting would not consider resuscitation of such babies appropriate because of the very

poor likelihood of survival free of severe disability. At 23 and 24 weeks gestation, most would ensure parents are provided with the option of palliation or 'comfort care' for their baby as an alternative to neonatal intensive care, with its attendant high-risk of mortality and long-term morbidity. It is evident that parents vary widely in their expectations, past experience, cultural background, religious beliefs and their perception of the potential implications of long-term neurodevelopmental disability for their child and their families. These factors must be considered during counselling.

Outcome

International approaches to resuscitation and intensive care for extremely preterm infants vary considerably and consequently so do the reported rates of survival and long-term disability. The Australian and New Zealand Neonatal Network data for 2003 and 2004 reports survival rates for those babies admitted to neonatal intensive care units of approximately 40 per cent for 23 weeks gestation and 60 per cent for 24 weeks gestation. The consensus in our State of Tasmania is to quote preterm infant survival data from the experience of our own neonatal intensive care unit.

The data from the Victorian Infant Collaborative Study Group found that of the survivors born at 23 or 24 weeks gestation in the 1997 cohort, assessed at two years of age, the incidence of severe disability (unlikely ever to walk, blindness, or major intellectual deficit) was 33 per cent.¹ The likelihood of freedom from any neurosensory disability as assessed in this same cohort was 33 per cent for 23-week infants and 50 per cent for 24-week infants. The likelihood of severe disability in those infants offered intensive care at less than 25 weeks gestation in Victorian cohorts from the 1990s remained largely static despite increasing survival rates.^{1,2}

Discussion of the increased risk of death or major neurosensory disability is obviously important. For some parents, particularly when delivery is imminent, this may be all that can be discussed without overwhelming them with information. It is more difficult to discuss the increased risk of more subtle deficits in higher functioning and behaviour that may be problematic later in life, as it is primarily the likelihood of the major adverse outcomes (therefore death or severe disability) that influences parental decision-making regarding resuscitation. Imparting information on the minutiae of neonatal intensive care and the finer points of long-term neurodevelopment may be unhelpful for some parents, but is not infrequently requested by others. Unfortunately, there is not always an opportunity to counsel parents before the delivery of an extremely preterm infant, either because the delivery is precipitous, or the mother is too distressed or unwell in labour to make any informed decision.

'Discussions with parents expecting to deliver an extremely preterm baby need to be compassionate but frank regarding the risks.'

After appropriate counselling regarding the risks associated with extremely preterm birth, especially at 23 and 24 weeks gestation, parental requests for their baby may be categorised broadly into three groups: non-resuscitation, resuscitation and undecided.

Non-resuscitation, palliation and comfort care

There are those who do not wish for their baby to be resuscitated. These parents must be given some knowledge of what to expect following delivery with the 'comfort care' approach, as it is not uncommon for babies at the borderline of viability to be active and breathing at birth. They can survive for some hours despite the absence of resuscitation. The assistance of a midwife who is experienced in this aspect of care of the extremely preterm infant is invaluable. Whenever possible, the attending midwife should be present during counselling of the parents.

Parents not infrequently vacillate in their decision for comfort care for their extremely preterm baby. Parents have been known to change their decision after the birth and request resuscitation. This highlights the need for careful counselling and ensuring appropriate supports are in place. This may include ensuring the close proximity

of a neonatologist in the event that concerns arise after the birth. This also applies if there is any uncertainty regarding the true gestational age.

Resuscitation and intensive care

Some parents request that resuscitation and intensive care support be initiated despite the risks of morbidity and mortality. Many neonatologists in the setting of resuscitating extremely preterm babies would, however, limit the extent of resuscitation to preclude the use of adrenaline or external cardiac compression. Those extremely preterm babies not responding to intubation and effective ventilatory support alone at the time of birth almost invariably have a poor outcome.

Undecided

Despite careful counselling, there are some parents who find it too difficult to make a decision as to whether to choose comfort care or resuscitation for their extremely preterm baby. In this setting, it is best to avoid pressuring parents to make a choice. These parents rely on the neonatologist to make a judgement as to the appropriateness of resuscitation at the time of birth. When grappling with this difficult proposition, many neonatologists will initiate basic resuscitation and then decide whether or not to continue with intensive care support based on the baby's early progress and apparent maturity. Of key importance is the close engagement of the parents in any decisions regarding the appropriateness of ongoing care. Careful guidance with empathy is needed.

Consensus

Many international groups have agreed to a common approach to the care of the extremely preterm infant at birth. In Australia, neonatal intensive care units and parent representatives in New South Wales and the Australian Capital Territory reached the consensus that, given the risks, it was an acceptable option, with the consent of the parents after appropriate counselling, not to commence resuscitation for infants born at less than 26 weeks gestation.³

Caring for parents and their extremely preterm baby is one of the most challenging aspects of neonatal medicine. Discussions with parents expecting to deliver an extremely preterm baby need to be compassionate but frank regarding the risks. Non-resuscitation must be provided as an acceptable option for parents with the support of their clinicians. Regardless of the final outcome, these parents need ongoing support, both in the short and long-term.

References

1. Doyle LW and the Victorian Infant Collaborative Study Group. Neonatal intensive care at borderline viability – is it worth it? *Early Hum Devel.* 2004; 80:103-113.
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