Review

Infants of borderline viability: The ethics of delivery room care

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SUMMARY

For more than half a century neonatologists and ethicists alike have struggled with ethical dilemmas surrounding infants born at the limits of viability. Both doctors and parents face difficult decisions. Do we try to save these babies, knowing that such efforts are likely to be unsuccessful? Or do we provide only comfort care, knowing that, in doing so, you will inevitably allow some babies to die who might have been saved? In this paper, we review the outcome data on these babies and offer ten suggestions for doctors: (1) accept that there is a 'gray zone' during which decisions are not black and white; (2) do not place too much emphasis on gestational age; (3) dying is generally not in an infant's best interest; (4) impairment does not necessarily equal poor quality of life; (5) just because the train has left the station doesn't mean you can't get off; (6) respect powerful emotions; (7) be aware of the self-fulfilling prophecies; (8) time lag likely skews all outcome data; (9) statistics can be both confused and confusing; (10) never abandon parents.

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1. Introduction

For over half a century neonatologists and ethicists alike have struggled with ethical dilemmas surrounding infants born at the limits of viability. The odds are against such babies. Most die, and the majority of survivors have long-term chronic health problems. Both doctors and parents face difficult decisions. Do you try to save them, knowing that such efforts are likely to be unsuccessful? Or do you provide only comfort care, knowing that, in doing so, you will inevitably allow some babies to die who might have been saved? The decisions are not black or white. Thus, this domain of clinical decision-making is often referred to as 'the gray zone'.

The delineation of the gray zone has shifted over time. Today, in most developed countries, babies born at 22–24 weeks are considered to be in the gray zone. Over the last 30 years, survival rates at every gestational age down to 22 weeks have improved but the percentage of survivors with disabilities of one sort or another has remained stubbornly unchanged [1]. How, then, should doctors and parents weigh the evidence, the probabilities, and the uncertainties and arrive at a decision together? In this paper, we review the available literature on outcomes for extremely premature infants, on the neuro-cognitive outcomes for survivors, and on the impact of prematurity on the family unit. Finally, we review available guidelines and practice variation across the globe and conclude with our own recommendations.

2. Neonatal survival and neonatal intensive care unit (NICU) morbidity

It is often the case that neonatologists first meet parents as part of a prenatal consultation. At that time, the pregnant woman may be experiencing problems that lead the obstetricians to believe that delivery is likely. Some women go on to deliver the baby. For others, labor is halted and the delivery postponed until outside the gray zone.

Clinicians who provide prenatal consultation are in a unique position. They have to talk about the prognosis for a patient whom they have never seen. They have to make their best guess as to when the delivery will occur, the probability of survival, and predict long-term outcomes, all while trying to determine what the parents need and want to know to make a decision about whether or not to provide life-sustaining treatment. Some parents want detailed information. Others want reassurance. Some trust their doctors. Others don't. Some focus on survival, some on disability, some on the effect that a chronically ill baby might have on their family. The physician who is providing the prenatal consult must try to determine what information, if any, the parent wants and how to convey the needed information effectively. A cookie-cutter approach cannot work in this situation. Nevertheless, there is important prognostic information that a physician should be able to

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provide if the parents indicate that they want to know the odds for particular outcomes.

In a 2008 publication, the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network looked at factors in addition to gestational age that influence outcomes for extremely premature infants. They found that gender, receipt of antenatal corticosteroids, birth weight, and single or multiple birth status better predicted the likelihood of a favorable outcome than gestational age alone [2]. Based on this study, an online calculator was developed to estimate an extremely premature infant’s chances of survival, as well as survival without neurodevelopmental impairment. Although this calculator is useful in providing clinicians with a starting point for prognostication, it describes statistics for the population at large and does not predict the outcome for an individual infant.

The NICHD calculator underscores the importance of taking all factors into account and not instituting hard-and-fast gestational age cut-offs when making decisions about resuscitation and offering intensive care. For example, a 22-week gestation female infant with a weight of 600 g who received antenatal corticosteroids would be more likely to have a favorable outcome than a male, growth-restricted, 24-week twin gestation infant whose mother did not receive corticosteroids. If an arbitrary line were drawn at 23 weeks, the infant with the better likelihood of a favorable outcome would not even be given a chance [3]. Other limitations of this ‘tool’ stem from its use of imprecise data. It is important to recognize that survival and neurodevelopmental outcomes are impacted by a clinician’s prognostication.

In 2010 the NICHD Neonatal Research Network published morbidity and mortality rates for very low birth weight (VLBW) infants from 20 centers. These were based on retrospective data that had been gathered and analyzed for 9575 infants born between 22 and 28 weeks of gestation form January 1, 2003 to December 31, 2007. Survival rates ranged from 6% for infants born at 22 weeks of gestation to >80% for infants born after 26 weeks of gestation [6].

The data from these studies have been used by many neonatologists as the basis for prenatal counseling. However, this is probably inappropriate. The data were not intended to be used in that way. In fact, on the NICHD website, there is a disclaimer that reads, ‘These data are not intended to be predictive of individual infant outcomes. Instead, the data provide a range of possible outcomes based on specific characteristics.’ [3]. The limitations are clear. Because it was a retrospective analysis, it could only report on what treatments were given and the outcomes. Of note, only 13% of infants born at 22 weeks of gestation were exposed to antenatal corticosteroids. Only 19% were intubated and placed on mechanical ventilation [6]. Thus, the data do not accurately predict what the outcomes would have been if all babies had been intubated and ventilated or if all pregnant women had received antenatal corticosteroids. Furthermore, the NICHD dataset is only one of many that report outcomes for babies at the borderline of viability. A 2009 publication from the Committee of Neonatal Medicine of the Japan Pediatric Society reported survival rates much higher for extremely premature infants than previously described elsewhere. Survival rate ranged from 34% of infants born at 22 weeks of gestation to 77% for babies born at 24 weeks [7].

In Japan, it is the norm to attempt resuscitation in infants born at 22–23 weeks gestation. Fewer deaths occur in the delivery room. It is reasonable that increased attempts at resuscitation may lead to increases in survival rates. Other countries have different experiences. In Switzerland, national guidelines recommend against resuscitation of babies at 23 weeks. Survival rates for such babies are 4% [8]. Survival rates are higher for babies born at 24 and 25 weeks, but are still lower than the survival rates in the USA, Canada, and Sweden.

Survival rates, of course, are not the only consideration. Of the 25 infants born at 22 weeks of gestation in the NICHD cohort, none survived without morbidity. One of the issues, though, is the description of ‘morbidity.’ Morbidity in the NICHD cohort included severe intraventricular hemorrhage, periventricular leukomalacia, bronchopulmonary dysplasia, necrotizing enterocolitis, infection, and retinopathy of prematurity (stage 3 or greater). At 23 weeks, 8% of survivors had none of these morbidities. The percentages at other gestational ages were 9% at 24 weeks, 20% at 25 weeks and 34% at 26 weeks. No long-term outcomes were described [6].

These classifications raise questions about factors that should inform a decision to withdraw life-sustaining treatment. Many premature babies develop sepsis. In most cases, they recover completely without long-term issues. This is also true for necrotizing enterocolitis and bronchopulmonary dysplasia. Whereas these are indisputably events that could complicate a premature infant’s hospital course and have the potential to create long-term consequences, they predict little about what the child will be like in kindergarten or in high school, or as an adult. Which outcomes are most relevant to parents? Which ought to drive decisions?

### 3. Long-term neurocognitive outcomes and quality of life (QOL)

The EPICure study provides follow-up data on academic attainment and special educational needs at 11 years of age. This study followed 307 extremely preterm infants (<25 weeks) born in the UK and Ireland in 1995. It showed that 87% were in mainstream schools, though over half of these children did have special educational needs. Teachers also rated half of the extremely preterm child as having below average educational attainment compared to only 5% of their term gestation classmates [9].

The health-related QOL for extremely premature infants appears to improve as the child ages. Zwicker and Richardson Harris performed a systematic review of this topic, published in 2008. They found that at preschool age, many children born preterm or VLBW performed significantly more poorly than their peers in physical, emotional, or social functioning. However, judgments about the child’s QOL were reported via parent-proxy because of the young age of the children. This reporting could be biased by the parents’ feelings toward — or expectations of — their child. It could also be influenced by the parents’ knowledge of child development and their cultural, social, and education background. In spite of issues with parent-proxy reporting, available evidence suggests that preterm and VLBW children likely have lower QOL than their term and normal birth weight peers [10].

At school age, the literature is somewhat lacking. There are data to support the notion that preterm and VLBW infants experience more academic, motor, physical, and behavioral difficulties, including ADHD. These challenges likely impact QOL, but QOL has not been studied directly [10].

In adolescents, evidence suggests that parents of VLBW, extremely low birth weight (ELBW) or extremely low gestation age (ELGA) teenagers perceive that their children had lower health-related QOL than term peers, but that the teens themselves did not. Parents may have a broader, more realistic view, and, in the case of children with severe impairments, parent-proxy reporting may be the only assessment option available. By young adulthood,
there was no significant difference between preterm and term young adults. However, measures of objective QOL and physical functioning were significantly lower for the preterm groups [10]. Quality of life is one of the major factors used in determining life-and-death decisions for infants at the edge of viability. The AAP Committee on the Fetus and Newborn uses ‘poor quality of life’ as the basis for non-initiation or withdrawal of intensive care for high-risk newborns [11]. The issue is the interpretation of QOL. In reality, QOL is a subjective term and can only be truly determined by the individual. As mentioned above, recent studies of children and young adults who were born prematurely and who were ELBW perceive their own QOL despite their disabilities, to be the same as their term peers [12].

Perhaps the most important finding in the studies by Zwicker and Saigal is the indication that having a biological impairment does not automatically translate into having a poor QOL. Conversely, it is also reasonable that individuals without impairment may feel that their QOL is low. The general public and medical staff view the QOL as lower than the individuals with the medical impairments themselves. All things considered, the affected individuals’ perception is what matters most [12]. For former extremely premature infants, the view on their own health-related QOL seems to improve as they transition into young adulthood. It is debatable, though, whether this finding represents true improvement in QOL, adaptation of the individual to his/her own limitations, or simply a shift from parent to child reporting [10]. It is important to keep in mind that QOL studies are rather heterogeneous and difficult to interpret, as there is no consensus even on the definition of QOL, particularly for children [12].

The question remains ‘Does having a disability translate into a poor QOL?’ The term ‘quality of life’ should only refer to subjective assessments by an individual about himself or herself. Parents can report on their own QOL as parents of a disabled child. Older children with cognitive capacity can report on their own QOL, but other objective measures of hearing, vision, motor function, or intellectual ability should not be taken as measures of QOL. They should be taken as measures of, say, sound, sight, physical ability, and the like.

4. Familial impact

Much of the anxiety of neonatal clinicians regarding the resuscitation of infants born at the borderline of viability lies in the fear that if the baby survives, the burden of care for the infant will be greater than the family would wish to endure. But is this a valid concern? It appears as though the impact of the premature child on the overall psychosocial well-being of the family diminishes over time. Early on, in the neonatal period, having a VLBW infant leads to heightened levels of psychological distress. This includes symptoms of depression or anxiety, as well as difficulty concentrating and making decisions. However, by 8–12 months of age, mothers of VLBW infants show few differences from mothers of term infants with regard to psychological and emotional well-being [13]. It may be that the differences in psychological and emotional well-being result from having a sick newborn in the NICU rather than from prematurity itself.

An apparent difference between mothers of ‘high risk’ VLBW infants (diagnosis or signs of bronchopulmonary dysplasia or birth weight <1500 g) and the ‘low risk’ VLBW and term population seems to become evident around age 2–3 years. Mothers of high risk VLBW infants reported more symptoms of clinically significant depression and general distress, higher parenting stress scores, and greater financial, family, personal, and total stress scores [13]. This could be related to the fact that performance scores at 2 years of age are more predictive of long-term outcomes, and perhaps parents lose hope that the child will be able to ‘catch-up’.

Follow-up as soon as the VLBW cohort reached school age showed similar findings, with the high risk VLBW mothers reporting significant levels of stress. Also, mothers of all VLBW children had lower levels of educational attainment compared to mothers of term children. There was no difference, however, between the three groups with regard to sense of parenting competence, divorce rate, parenting/marital satisfaction, family cohesion, and psychological distress symptoms. Mothers of children in the high risk VLBW group actually reported more personal growth and mastery [14]. This study and others demonstrated that lower birth weight, low socio-economic status, and neurosensory impairment of the child predict a more negative impact upon the family [15–17].

Once the child has reached adolescence, the familial impact of an infant born at ELBW seems to lessen and by young adulthood it has practically resolved. At adolescence, even though more parents in the ELBW group felt that their child’s health adversely affected their own emotional health and that of other children in the family, they also felt that their ELBW child brought their family closer together. Both positive and negative effects on marriage were higher in parents of the ELBW group [18]. By young adulthood, there were no significant differences in scores between the ELBW group and the normal birth weight group with respect to marital disharmony, family dysfunction, maternal mood, anxiety, social support, depression, and maternal physical and mental health. Results did not appear different when ELBW young adults with neurosensory impairment were excluded. Having an ELBW young adult did still carry a significant negative impact on the jobs and educational training opportunities for parents. Increased feelings of self-worth were implied by significantly more mothers of ELBW young adults with neurosensory impairment reporting that they felt better about themselves for having managed their child’s health [19].

Although an extremely premature infant could negatively impact the emotional well-being of the family initially, in the long run, as the child grows, the overall negative effects seem minimal. In reality, the potential impact on the family is a positive one.

5. Guidelines and policies

Various governing bodies and professional societies across the globe have attempted to provide a framework for clinicians faced with difficult decisions regarding an infant born at the borderline of viability through policy statements or clinical guidelines. The Institute of Medicine defines clinical practice guidelines as ‘systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances’ [20]. The variation among differing countries, all with access to advanced medicines, technologies, and equipment is impressive. Decision-making is of course considerably different in countries with much more limited access to resources.

In 2012, the Canadian Pediatric Society released a new position statement entitled ‘Counseling and Management for Anticipated Extremely Preterm Birth’. They recommend a ‘non-interventional’ approach at 22 weeks, since survival is uncommon. From 23 to 25 weeks, treatment plans should be individualized for each infant and family. At 23 and 24 weeks, active treatment is appropriate for some infants. Active treatment is appropriate for most infants of 25 weeks’ gestation. They do not recommend cesarean section for fetal indications prior to 24 weeks, but state that antenatal corticosteroids should be administered when active management is considered. For all extremely preterm infants, they recommend ongoing face-to-face discussions with parents and obstetrical and
neonatal care providers and that decision-making should be an informed and shared process [21].

The updated Canadian Pediatric Society position statement was universally accepted. Opponents criticized the policy for being too simplistic, for utilizing inaccurate completed weeks of gestation as the framework for recommendations, and for not giving appropriate consideration to QOL. These critics argue for personalized counseling and individual treatment plans tailored to each baby and family [22].

In the USA, the most recent policy from the American Academy of Pediatrics was released in 2009. This policy recognizes the limitations of gestational age and avoids its use as a sole criterion when making recommendations. Recommendations are broader and less directive; if the medical team believes that there is no chance of survival, resuscitation is not indicated. If a good outcome is very unlikely, parents should be given a choice. If a good outcome is reasonably likely, resuscitation should be initiated and continually re-evaluated [23].

In 2006 in the UK, The Nuffield Council on Bioethics published their full report on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues. Their proposed guidelines include having a pediatrician present at the delivery of all babies born below 26 weeks of gestation. At 25 weeks, intensive care should be initiated unless there is a severe abnormality. Below 25 weeks of gestation, the clinical team should discuss with the parents in a ‘thorough and frank fashion’ the national and local statistical evidence for survival and the range of disabilities. ‘The healthcare team should make it clear that statistics indicate that most babies born below 25 weeks of gestation will die’. Between 24 and 24\(\frac{6}{7}\) weeks a baby will be offered full invasive intensive care unless the parents and the clinicians agree that it is not in the child’s best interests. Between 23 and 23\(\frac{6}{7}\) weeks, prediction is difficult and precedence should be given to the wishes of the parents. If clinicians judge that the treatment is futile, they are not legally obliged to proceed. Between 22 and 22\(\frac{6}{7}\) weeks, standard practice should be to not resuscitate a baby, unless resuscitation is demanded by parents even after appropriate counseling. Below 22 weeks of gestation, no baby should be resuscitated unless for research purposes and informed consent is obtained from the parents. They recognize that the welfare of the infant is directly linked with the ability of the parents to provide care; therefore the views of the parents are paramount [24,25].

In Switzerland, guidelines were updated in 2011, but maintain the recommendation that, at <24 weeks’ gestation, care should generally be limited to palliative care. Obstetric interventions for fetal indications are usually not indicated unless parents insist. Between 24 and 24\(\frac{6}{7}\) weeks they feel that it is difficult to determine whether the burden of obstetric interventions and neonatal intensive care is justified. After 25 weeks, intensive care is generally indicated [26]. Ongoing dialogue among all care providers and the family is crucial, and the parents should not carry the full responsibility for decision-making. Cost should be evaluated at a societal level, but economic considerations should never interfere with an individual case. Cost should refer not simply to economic costs but also to the emotional and physical burden of therapy [25].

Several countries do not provide specific guidelines, but general principles that should be paramount in caring for infant of borderline viability. In Germany the overriding message is ‘if there is any chance, it is necessary to do everything to sustain survival’. German physicians seem to emphasize an individual approach as opposed to placing weight on statistics. In Singapore, they consider it a medical duty, with the parents’ consent, to identify infants who could benefit from treatment: ‘If there is good reason to treat, resuscitation is mandatory, otherwise it should be withheld. In France, caring for neonates can mean withholding or withdrawing life-sustaining treatment and even arresting life. The position of the parents is different in that doctors and parents have their own special roles in the care of the newborn and if parents establish trust with the physician, they do not request to be the decision-maker [25].

The International Federation of Gynecologists and Obstetricians define infants between 22 and <28 weeks as having ‘threshold viability’. They state that it is ethical to initiate intensive care at birth until the infant can be properly assessed and appropriate consultation can occur between staff and family. The International Liaison Committee on Resuscitation states that ‘a do-not-resuscitate order is an evidence-based justified choice in a newborn of <23 weeks or 400 g’. If there is an uncertain or inaccurate diagnosis or prognosis, a therapeutic trial with the option of subsequent withdrawal can be considered [26]. The Working Group on Prematurity of the World Association of Perinatal Medicine published a statement on infants at the margin of viability and recommended that ‘The short-term goal is to prevent imminent death.’

- The long-term goal is to minimize morbidity and maximize functional status.
- Clinical intervention should be initiated and continued only so long as these goals are reasonably expected to be accomplished.
- For the fetus or neonate at 22 weeks of gestation and earlier, when gestational dating is secure, the short-term goal of preventing imminent death cannot usually be achieved by any means, including resuscitation, cesarean delivery, and neonatal intensive care.
- At 22 weeks of gestation or earlier, when gestational dating is secure, cesarean delivery should not be offered, and should be denied if requested, because the woman will undergo the clinical risks of surgery with no potential for clinical benefit for the fetal or neonatal patient [27].

6. Conclusions and recommendations

These facts about survival, short-term morbidity, long-term neurocognitive sequelae, and the impact on families can only get us so far. Ultimately, each perinatologist and neonatologist who deals with these issues will have to develop a personal approach to decision-making. With that in mind, we offer ten suggestions as one tries to help families navigate through the gray zone.

1. Be okay with the gray. Complex decisions deserve complex individualized analysis for each case and scenario. Attempting to create broad, overreaching, black-and-white guidelines for all extremely premature infants is taking the easy way out. Decisions about infants at the borderline of viability must enter into the gray zone, so proper due diligence regarding decision-making is awarded to the tiniest of humans. This means, however, that the treatment plan for the infant born to a mother in preterm labor at 23 weeks might not be decided before the baby is born. It also means that two 22\(\frac{5}{7}\) week gestation infants born on the same day, but with different characteristics, might not be managed in exactly the same way. That’s okay.

2. Do not place too much emphasis on gestational age. If every fetus came with a stamped ‘conceived on’ date, then gestational age might carry a bit more weight. Given the imprecision of dating methods at up to ±2 weeks, the utility of gestational age decreases substantially. Even if every infant was conceived by artificial methods and gestational ages
were exact, other factors greatly impact both survival and long-term outcomes.

(3) **Dying is usually not in an infant’s best interest** – at least not right away. Whereas long-term outcomes, QOL, and the burden of care are clearly important, if the infant is not allowed a ‘trial of life’, s/he will never have the opportunity to confront these future obstacles in care. It is hard to argue that death without a proper chance at life is ever in the best interest of an infant.

(4) **Impairment does not necessarily equal poor QOL.** To high functioning adults, the thought of being blind, deaf, or having any degree of cognitive impairment would easily equate to a poor QOL. However, as former ‘preemies’ and ELBW infants reach young adulthood, their self-reported QOL scores equal those of their normal birth weight counterparts. Perhaps there is an element of blissful ignorance or denial, but this goes to show that one cannot be the judge of someone else’s QOL.

(5) **Just because the train has left the station doesn’t mean you can’t get off.** Just because the decision was made to attempt resuscitation at 23 weeks in the delivery room, it does not mean that the baby is automatically committed to a tracheostomy, gastrostomy tube, and home ventilator at the age of 6 months. Discussions about the care of extremely preterm infants must be ongoing. Parents and the medical team are welcome to alter the course of treatment at anytime, should complications arise. It must be remembered that withdrawal of care is ethically equivalent to the withholding of care.

(6) **Respect powerful emotions. They reveal moral truths.** It is clear that parents serve as the best surrogate decision-makers for an extremely premature infant (at least most of the time anyway). They should be appropriately informed about what the infant may endure and they should play an active role in decision-making. However, not all of the burden should fall on the parents. It is appropriate for the medical team to be somewhat directive. Making the decision to resuscitate an infant at the borderline of viability is not the same as obtaining informed consent prior to a surgical procedure and should not be met with the same rigor. Childbirth is a highly emotionally charged event and typically there is not the luxury of time. Even if all available outcome data were eloquently described to parents in the most dismal of settings, it is still quite likely the parents would request to have ‘everything’ done. Emotion and feelings of parental duty will overrule logic without direction and guidance from the medical team.

(7) **Be aware of the self-fulfilling prophecy.** Several of the available policies and practice guidelines cite low survival rates as the premise for not recommending resuscitation at 22 weeks’ gestation. If resuscitation is never attempted at 22 weeks, then of course no infants will survive at 22 weeks, adding merit to the original recommendation. Thus, a self-fulfilling prophecy is created. This may or may not explain the increased survival rates seen in the Japanese population and should be taken into account when making decisions about infants at the borderline of viability. In the 1950s, the survival rate at 26 weeks was close to zero, because resuscitation was not even attempted. Today, it is >80%. Granted, size and state of embryologic development likely play a greater role at 22 weeks.

(8) **Time lag likely skews all outcome data.** An infant admitted to a NICU today does not receive the same care as an infant born in 1995, or even in 2013 for that matter. By the time data can be collected, analyzed and published, advances in neonatal care undoubtedly will have occurred. Progress in neonatal care may not be as dramatic today as it was in the second half of the 20th century, but nonetheless long-term follow-up data must be interpreted cautiously when applied to an infant born today.

(9) **Statistics can be both confused and confusing.** Available outcome studies and calculators describe population statistics but do not predict the individual outcome for a specific infant. A father could be told that 26% of infants born at 23 weeks’ gestation survive, but there is no way to predict whether his daughter will be one of the 26 of the 100 who survive. For parents, ultimately statistics become an all-or-none retrospective phenomenon. If their child lives, survival is 100%. If there child dies, survival is zero. There is no such thing as 26% survival for an individual baby.

(10) **Above all, never abandon parents.** Parents of babies in the NICU are on an emotional roller-coaster. They may behave badly. Some get angry. Some don’t visit their babies. Others can be intrusive or critical of staff. Parents need the support and guidance of doctors and nurses. The parents who are the most difficult to get along with are often the ones who need support the most.

### Practice points

- Decision-making for infants of borderline viability is a complex and intricate process. Narrow, black-and-white guidelines are insufficient for this purpose.
- Gestational-age estimates are thwart by inaccuracies and should not be the primary basis for decision-making.
- ‘Quality of life’ can only be described by those living the life. It cannot be implied by objective measures or reported by others.
- Survival statistics vary from country to country and are dependent upon the societal and practice norms regarding resuscitation of infants at the borderline viability.
- A limitation of the interpretation and application of long-term outcome data lies in the fact that it does not reflect the current standard of care and lags behind clinical advances.
- Population statistics cannot be used to predict the chances of survival for an individual infant.
- Discussions between the family and care team should be frequent and ongoing to continually weigh the benefits versus burdens of care for the extremely premature infant.

### Research directions

- Investigation into the use of neuroimaging and other evaluations to better predict long-term neurocognitive disability in ‘micro-preemies’.
- Development of an international database of extremely premature infants to delineate outcomes and negate the effects of variation in practice between countries.
- Ongoing evaluation of the QOL for former ‘micro-preemies’ and their families.
- Effective antenatal strategies and public health initiatives to prevent prematurity.
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References


