Perinatal Care at the Threshold of Viability

American Academy of Pediatrics
Committee on Fetus and Newborn
American College of Obstetricians and Gynecologists
Committee on Obstetric Practice

SUBJECT REVIEW

The survival rate for infants born prematurely has changed over the last two decades and is likely to change in the future. Currently, the birth of an infant at or before 25 weeks of gestation or weighing less than 750 g presents a variety of complex medical, social, and ethical decisions. Although the prevalence of such births is low, the impact on the infants, their families, the health care system, and society is profound.

The survival of infants born from 23 to 25 weeks of gestation increases with each additional week of gestation. However, the overall neonatal survival rate for infants born during this early gestational period remains less than 40%. Of those who survive, about 40% have moderate or serious disabilities, and many have neurobehavioral dysfunction and poor school performance. Many require prolonged intensive care and long-term care. The commitment for all aspects of care may be extensive, multidisciplinary, lifelong, and costly. Because the families bear the emotional and financial consequences of the birth of an extremely low-birth-weight infant, it is essential to inform the prospective parents regarding the expectations for infant outcome and the risks and benefits of various approaches to care.

Counseling Regarding Potential Fetal Outcomes

Most parents are unfamiliar with the complexities of care required for an extremely premature infant, both in the intensive care unit and after discharge from the hospital. Therefore, it is often necessary to provide the information in small segments at frequent intervals to allow the parents to comprehend the messages. The family can benefit from a clear explanation of the various supportive procedures that will likely be necessary in the infant's first days of life. Family members should also be provided with an overview of the potential complications of prolonged intensive care. Finally, they should be informed of the range of survival rates and of the rates of long-term disabilities that can be expected. In compiling such information, practitioners should consider data reported in the current literature as well as outcomes based on local experience; they should allow for some error in the best estimate of gestational age and fetal weight.

Neonatal survival rates experienced over the last decade in different neonatal units are provided in Table 1. These rates do not represent ultimate survival rates, as deaths may occur in the postneonatal period. The prevalence of a number of morbidities common to these extremely premature infants is shown in Table 2.

It is difficult to counsel parents regarding long-term disabilities because outcomes are only now being reported for neonates born since the use of surfactant became common and who have survived to school age. Recent experience suggests that almost half of the surviving children who weigh less than 750 g at birth experience moderate or severe disability, including blindness and cerebral palsy, and require special education. Many infants have more than one disability. Families should be counseled that, despite the high rate of overall disability, many of these children are educable and can function within their family unit.

The estimation of gestational age before premature delivery forms the main basis for subsequent decision-making. Clinical assessment to determine gestational age is usually appropriate for the woman with regular menstrual cycles and a known last menstrual period that was confirmed by an early examination. Fetal measurements derived through the use of ultrasonography at the time of anticipated delivery should not be used to alter estimated gestational age unless there is a discrepancy of 2 weeks or more between the age derived by menstrual dating and the age derived sonographically or the woman is uncertain about the date of her last menstrual period. Ultrasonography may provide useful information regarding the presence or absence of fetal malformations, but may alter the prognosis. The accuracy of sonographic measurements and the ability to ascertain malformations, however, may be reduced in the presence of oligohydramnios, such as occurs with ruptured membranes.

Even in ideal circumstances, the 95% confidence limits for a formula-based estimate of fetal weight are ±15% to 20%. Thus, an infant estimated to weigh 600 g may have an actual birth weight of less than 500 g or more than 700 g. Even relatively small discrepancies of 1 or 2 weeks in gestational age or
Decisions regarding obstetric management must be made by the parents and their physicians if the neonate’s prognosis is uncertain; the decisions must be documented in the obstetric records. Some decisions, such as the choice of cesarean birth, can result in increased risk of morbidity to the woman.

Few studies have been done to evaluate the influence of obstetric management on the outcome of infants at the threshold of viability. Furthermore, literature on this subject is largely retrospective and often lacks sufficient data regarding potential confounding variables. Despite these limitations, study results have consistently failed to document benefits of cesarean delivery for extremely premature infants. It has even been difficult to document improved outcome with cesarean birth for infants in the breech position who are extremely premature. Furthermore, injuries to the infant can occur during a difficult cesarean birth.

Physicians should avoid characterizing management of uncertain benefit as “doing everything possible.” Rather, they should hold discussions with the family regarding available data and provide an explanation of the risks incurred by management options, including route of delivery. In the case of cesarean delivery, risks to the woman include not only maternal complications such as bleeding, infection, and injury, but also long-term implications for childbearing since a vertical uterine incision is often employed. A vertical uterine incision at these gestational ages may extend into the upper segment and would preclude the option of vaginal birth in future pregnancy. Counseling regarding management decisions such as whether to effect maternal transport should include a discussion of the potential disadvantages of separating the mother from supportive family members and familiar caregivers when benefit for the mother or baby is uncertain.

Parents should be encouraged to actively participate in discussion regarding maternal transport and other management decisions. Counseling about management options and potential outcome allows the family to more easily choose a course of action that is both medically appropriate and consistent with their own personal values and goals. Whenever possible, a nondirective approach needs to be used; in some circumstances, however, directive counseling may be appropriate. Counseling may result in the family choosing a noninterventional approach to delivery and management. Because the benefits of different types of obstetric management have not been delineated, families should be supported in such decisions.

Counseling Regarding the Risks and Benefits of Management Options

Obstetric Management

Decisions regarding obstetric management must be made by the parents and their physicians if the neonate’s prognosis is uncertain; the decisions must be documented in the obstetric records. Some decisions, such as the choice of cesarean birth, can result in increased risk of morbidity to the woman.

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<td>Factor</td>
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<td>23</td>
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<tr>
<td>25</td>
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<tr>
<td>Weight (g)</td>
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<tr>
<td>501–600</td>
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<td>601–700</td>
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* Rates were reported by the National Institute of Child Health and Human Development neonatal centers.


100 to 200 g in birth weight may have major implications for survival and long-term morbidity. This underscores the importance of counseling about range of possible outcomes. Furthermore, multiple gestations increase the difficulty of accurate gestational age assessment, and the prognosis for one infant ultimately may differ from that of the other(s).

Ideally, the obstetric and neonatal physicians, primary care physicians, and neonatal nurses should confer before recommendations are made to the parents. The range of possible outcomes and management options can then be outlined for the patient and her family. If maternal transport may be needed, the obstetrician should be knowledgeable about the available regional resources and be prepared to provide basic information to the parents if the specific clinical circumstances warrant. More detailed counseling can then be accomplished at the receiving unit. Additional medical opinions and input from other important sources such as clergy, social workers, and the institution’s bioethics committee may be offered to the parents. Counseling should be sensitive to cultural and ethnic diversity, and a skilled translator should be available for parents whose primary language differs from the language of the care providers. It should be emphasized that the prognosis for the newborn may change after birth since a more accurate assessment of the newborn’s gestational age and condition may be made at that time.

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<table>
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<th>TABLE 2. Serious Morbidities in Infants With Birth Weight &lt;750 g Experienced by the NICHD Neonatal Centers, 1989–1990*</th>
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<tbody>
<tr>
<td>Condition</td>
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<tr>
<td>Respiratory distress syndrome</td>
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<tr>
<td>Ventilator support at 28 days†</td>
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<tr>
<td>Chronic lung disease†</td>
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<tr>
<td>Necrotizing enterocolitis</td>
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<td>Septicemia</td>
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<tr>
<td>Grade III intraventricular hemorrhage</td>
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<td>Grade IV intraventricular hemorrhage</td>
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<tr>
<td>Seizures</td>
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<tr>
<td>Periventricular leukomalacia</td>
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* NICHD indicates the National Institute of Child Health and Human Development.
† Data are for infants alive at 28 days.
‡ Data are for survivors.

Neonatal Management

Ethical decisions regarding the extent of resuscitative efforts and subsequent support of the neonate are complex.\textsuperscript{12-14} Parents should understand that decisions about neonatal management made before delivery may be altered depending on the condition of the neonate at birth, the postnatal gestational age assessment, and the infant’s response to resuscitative and stabilization measures. Recommendations regarding the extent of continuing support depend on frequent reevaluations of the infant’s condition and prognosis.

When a decision is made not to resuscitate the infant or to discontinue resuscitation, the family should be treated with dignity and compassion. This should include the acknowledgment of the birth of the infant. Humane and compassionate care must be provided to the infant, including careful handling, maintaining a neutral thermal environment, and gentle monitoring of vital signs.

When medical support is discontinued or death is inevitable, time should be allowed for the parents and other family members to hold, touch, and interact with the infant if they desire to do so, both before and after the infant has died. Naming the infant and obtaining a photograph may be important to the parents, and a crib card and name band should be provided. Birth weight and other measurements should be provided to the family as well. Clergy and other family and friends should be allowed access to the infant in a setting that maintains the dignity of both the family and infant.

Support should be provided to the family by physicians, nurses, and other staff beyond the time of the infant’s death. Perinatal loss support groups, intermittent contact by phone, and a later conference with the family to review the medical events surrounding the infant’s death and to evaluate the grieving response of the parents may be considered.

Summary

The survival rate for infants at the threshold of viability has been improving. However, there are insufficient data regarding the costs of initial and ongoing care of these infants and the long-term outcome of survivors. Furthermore, there has been little study of the impact of obstetric management on the survival rates of extremely low birth weight infants and on long-term morbidities. Continued research on these issues is imperative, and physicians need to remain informed of changing statistics.

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