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CLINICAL REPORT

Guidance for the Clinician in Rendering Pediatric Care

Hugh MacDonald, MD, and the Committee on Fetus and Newborn

Perinatal Care at the Threshold of Viability

ABSTRACT. In the United States, an increase in the number of births of extremely preterm infants and in their survival potential has occurred over the last decade. Determining the survival prognosis for the infant of a pregnancy with threatened preterm delivery between 22 and 25 completed weeks of gestation remains problematic. Many physicians and families encounter the difficulty of making decisions regarding the institution and continuation of life support for an infant born within this threshold period. This report addresses the process of counseling, assisting, and supporting families faced with the dilemma of an extremely preterm delivery.

INTRODUCTION AND BACKGROUND

The survival rate for infants born preterm has improved over the last 2 decades and is likely to continue to improve. An infant born at the threshold of viability presents a variety of complex medical, social, and ethical decisions. Although the incidence of such births is low, the number of extremely preterm births has increased, and the impact on the infants, their families, the health care system, and society is profound.

The survival rate for infants born from 22 to 25 weeks of gestation increases with each additional week of gestation.^{1,2} However, the incidence of moderate or severe neurodevelopmental disability in surviving children assessed at the age of 18 to 30 months is high (approximately 30%–50%) and does not appear to decrease over the 23- to 25-week gestation period.^{2–9} Many of these infants require prolonged intensive 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 preterm infant, it is essential to inform the prospective parents regarding the expectations for infant survival and 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 preterm infant in the intensive care unit and after discharge from the

hospital. It is often necessary to provide the information in small segments at frequent intervals to help the parents begin to comprehend the issues. They need clear and consistent explanations of the various supportive procedures that will likely be necessary during the first days after the infant's birth. Family members should also be provided with an overview of the potential complications of extreme prematurity and prolonged intensive care. They should be informed of the range of survival rates and of the types and rates of long-term disabilities that can be expected. In providing such information, physicians 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, and they must make provisions for unique qualifiers, such as the presence of intrauterine growth restriction and other factors that affect the risk assessment.

Neonatal survival rates based on birth weight and gestational age from 2 large studies in the last decade are provided in Table 1.^{1,2} These rates do not represent ultimate survival rates, because deaths may occur in the postneonatal period (the postneonatal mortality rate for this group of infants is <3%). The prevalence of a number of neonatal morbidities common to these extremely preterm infants is shown in Table 2.¹

Long-term outcomes of a large collaborative network cohort ($n = 1151$) of extremely preterm infants born in the United States in 1993–1994³ and a population-based cohort ($n = 1185$ [303 survivors]) of infants born in the United Kingdom and Ireland in 1995² have recently been reported. In these 2 studies, neurodevelopmental status at 18 to 30 months of age was assessed with uniform validated tools. Approximately 30% to 50% of surviving children who weighed less than 750 g at birth or whose gestational age was less than 25 weeks had moderate or severe disability, including blindness, deafness, and cerebral palsy. Many infants had more than 1 disability. The incidence of moderate to severe disability did not change significantly between 23 and 25 weeks' gestation, although the survival rate increased over the same gestation range. Outcomes of these populations at school age and beyond are not known; however, data from earlier cohorts have shown an increased incidence of learning disabilities at school age.^{10,11}

The best estimate of gestational age before preterm delivery is often well established and becomes the

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TABLE 1. Neonatal Survival/Morbidity by Gestational Age and Birth Weight

Factor	Mean Survival Rates (%)		Moderate or Severe Disability (%)	
	Wood et al ²	NICHD ¹	Wood et al ²	NICHD ³
Gestational age (wk)				
23	11	30	56	—
24	26	52	53	—
25	54	76	46	—
Weight (g)				
401–500		11	—	*
501–600		27	—	29
601–700		63	—	30
701–800		74	—	28

NICHD indicates the National Institute of Child Health and Human Development.

*Too few infants in study to assess.

TABLE 2. Serious Neonatal Morbidities in Infants With Birth Weight Less Than 750 g in the NICHD Neonatal Centers, 1995–1996¹

Condition	Frequency (%) of Morbidities (Range)
Respiratory distress syndrome	78 (54–97)
Oxygen needed at 28 days after birth*	81 (64–92)
Chronic lung disease†	52 (8–86)
Necrotizing enterocolitis‡	14 (9–38)
Septicemia	48 (30–64)
Grade III intraventricular hemorrhage	13 (6–29)
Grade IV intraventricular hemorrhage	13 (3–26)
Periventricular leukomalacia	7 (2–30)
Growth failure§	100 (92–100)

NICHD indicates the National Institute of Child Health and Human Development.

*Data are for infants alive at 28 days.

†O₂ requirement at 36 weeks' postmenstrual age.

‡Bell's classification stage ≥2.

§Weight <10th percentile at 36 weeks' postmenstrual age.

main basis for subsequent decision making. Clinical assessment to determine gestational age usually is 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 that may alter the prognosis. The accuracy of sonographic measurements and the ability to ascertain malformations, however, may be decreased in the presence of oligohydramnios, such as occurs with ruptured membranes.

Using sonographic weight estimate to assess risk is confounded by the inclusion of infants who are gestationally more mature but growth restricted.^{12,13} Even in ideal circumstances, the 95% confidence limits for a formula-based estimate of fetal weight are plus or minus 15% to 20%.¹⁴ 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 100 to 200 g in birth weight may have major implications for survival and long-term morbidity. This underscores the importance of counseling about the range of possible outcomes. Multiple gestation increases the difficulty of accurate ultrasonic gestational age assessment, and the prognosis for one infant may differ from that of the other(s). Gender and gestational age significantly affect the likelihood of survival for infants weighing less than 750 g. In one large cohort of infants weighing less than 1500 g at birth,¹ a birth weight of 600 g was associated with a survival rate ranging from approximately 15% for a male of 22 weeks' gestational age to 65% for a female of 25 weeks' gestational age. Similarly, at 23 weeks' gestation, the survival rate ranged from approximately 20% for a male weighing 520 g to 60% for a female weighing 740 g.

Obstetric and neonatal physicians, primary care physicians, and other appropriate staff should confer to ensure that consistent and accurate information is provided to the parents. The range of possible outcomes and management options for the mother can then be outlined to the family. If maternal transport is to be considered, the obstetrician should be knowledgeable about the available regional resources and be prepared to provide information to the parents. More detailed counseling can then be accomplished at the receiving unit. Additional 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 there is some uncertainty with any predictive process, because every infant is unique. The prognosis for the fetus may change after birth, when a more accurate assessment of the gestational age and actual condition can be made. Ongoing risk assessment must be individualized depending on the infant's subsequent course and response to treatment.¹⁵

COUNSELING REGARDING THE RISKS AND BENEFITS OF MANAGEMENT OPTIONS

Obstetric Management

When the fetus' prognosis is uncertain, decisions regarding obstetric management must be made by

the parents and their physicians and documented in the obstetric records. Parents should be encouraged to participate actively in discussions regarding delivery, maternal transport, and other management decisions. Counseling about management options and potential infant survival and long-term outcome allows the family to have the information they need to choose a course of action that is 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.¹⁶ Counseling may result in the family choosing not to have active intervention for the delivery and care of the infant. Because the relative benefits of different types of obstetric management are not always known, families should be supported in these often difficult and sometimes controversial decisions.

Some decisions, such as the choice of cesarean birth, can result in an increased risk of morbidity to the woman. Few studies have been performed 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 preterm infants.^{17,18} It has even been difficult to document improved outcome with cesarean birth for infants in the breech position who are extremely preterm.^{19,20} However, in one study, the opinion of the obstetrician regarding the potential viability of an extremely preterm fetus, as measured by the willingness to perform cesarean delivery, was found to have a major impact on the likelihood of survival of the fetus to birth.²¹

Physicians should avoid characterizing management of uncertain benefit as “doing everything possible” or “doing nothing” so as not to place a value on the judgment. 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 those incurred during the perioperative period but also long-term implications for childbearing, because a vertical uterine incision is often made. A vertical uterine incision at these gestational ages may extend into the fundus, thus precluding the option of vaginal birth in a future pregnancy. Counseling regarding management decisions, such as whether to use 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 infant is uncertain versus potential advantages of ensuring that the infant is delivered in a setting with maximum expertise in caring for an extremely preterm infant should the infant be more mature and/or larger than anticipated.

Neonatal Management

Decisions regarding the extent of resuscitative efforts and subsequent support of the neonate are com-

plex and often involve ethical considerations.^{22–25} The *Textbook of Neonatal Resuscitation*, 4th edition, suggests that noninitiation of resuscitation for newborns of less than 23 weeks’ gestational age and/or 400 g in birth weight is appropriate.²⁶ Parents should be counseled that decisions about viability and neonatal management made before delivery may need to be altered in the delivery room and beyond depending on the condition of the neonate at birth, the postnatal gestational age assessment, and the infant’s response to resuscitative and stabilization measures. Decisions regarding the extent of continuing support require frequent reevaluations of the infant’s condition and prognosis^{15,23} and reconsideration with the parents.

When a decision is made to withhold resuscitation, discontinue resuscitation, or forgo other life-supporting treatments, the family should be treated with compassion, focusing on their needs. Humane and compassionate care must be provided to the nonviable or dying infant and the family. This includes careful handling, maintaining warmth, avoidance of invasive procedures, and unobtrusive monitoring—sometimes called “comfort care.”

When medical support is discontinued or death is inevitable, time and opportunity should be provided for the parents and other family members to hold, touch, and interact with the infant before and after the infant dies. Simple personalizing acts, such as naming the infant; obtaining a photograph, footprint sheet, crib card, name band, or even a lock of hair; and recording birth weight and other measurements may be important to the parents and should be provided. Clergy and supportive family and friends should be encouraged to have access to the infant in a setting that maintains dignity.

Support should be provided to the family by physicians, nurses, and other staff beyond the time of the infant’s death. This may include referral to perinatal loss support groups, repeated telephone contact, other simple acts of condolence, and a conference with the family to review the medical events surrounding the infant’s death and to evaluate the grieving response of the parents.

FUTURE INVESTIGATION

There is a continuing need for additional investigations into the prevention of preterm birth, the treatment of preterm labor, life support of the extremely preterm infant, and the impact of obstetric and neonatal management on the survival potential, short-term morbidities, and long-term disability rates of extremely preterm/extremely low birth weight infants. In addition, studies of optimal counseling and bereavement management and the societal impact of extremely preterm births would enhance support of families. Continued research on this subset of pregnancies and infants by multicenter trials with reliable and validated methods of data collection and analysis and long-term follow-up of the survivors is imperative to provide an improved basis for ongoing assessment and decision making for physicians and families.

SUMMARY

The threatened birth of an extremely preterm infant presents complex medical, social, and ethical issues for a family and the involved physicians; therefore, it is important that:

- Decisions regarding all aspects of management of the birth and subsequent care of the infant are based on frequent reevaluations of the fetal/infant's condition and prognosis and are made jointly by the parents and the physicians;
- Parents receive appropriate information about maternal risks associated with delivery options, potential for infant survival, and risks of adverse long-term outcomes;
- Parental choice regarding management of the delivery and subsequent care of the infant is respected within the limits of medical feasibility and appropriateness;
- Physicians become knowledgeable about contemporaneous local, referral center, and national comparative data regarding survival and long-term outcomes associated with extremely preterm birth; and
- Future investigations of interventions in the management of extremely preterm delivery and/or subsequent care of the infant include evaluation of infant survival and long-term neurodevelopmental status as primary study outcomes.

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