



Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation

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abstract

The anticipated birth of an extremely low gestational age (<25 weeks) infant presents many difficult questions, and variations in practice continue to exist. Decisions regarding care of periviable infants should ideally be well informed, ethically sound, consistent within medical teams, and consonant with the parents' wishes. Each health care institution should consider having policies and procedures for antenatal counseling in these situations. Family counseling may be aided by the use of visual materials, which should take into consideration the intellectual, cultural, and other characteristics of the family members. Although general recommendations can guide practice, each situation is unique; thus, decision-making should be individualized. In most cases, the approach should be shared decision-making with the family, guided by considering both the likelihood of death or morbidity and the parents' desires for their unborn child. If a decision is made not to resuscitate, providing comfort care, encouraging family bonding, and palliative care support are appropriate.

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INTRODUCTION

The anticipated birth of an extremely low gestational age (<25 weeks) infant presents many difficult questions for all involved, including whether to initiate resuscitation after delivery. Variations in practice continue to exist, driven in part by the unclear outcomes of these infants, individual bias with regard to these outcomes, the difficulty in communicating complex information to parents at an extremely stressful time, and the emotionally charged environment that typically exists around the impending delivery of an infant at the lower limits of viability.¹⁻⁹

The topic of antenatal counseling at the borderline of viability (22–24 weeks of gestation) has been addressed in 2 American Academy of Pediatrics clinical reports.^{10,11} Important factors in this area continue to evolve, including improved outcomes, changing attitudes of parents and physicians and other health care providers, and new approaches that

facilitate communication with parents. The present revised clinical report includes new knowledge and understanding gained since the most recent report was published in 2009.

In February 2013, a workshop was convened by the Eunice Kennedy Shriver National Institute of Child Health and Human Development to discuss management and counseling issues surrounding periviable birth. An executive summary of this workshop was published concurrently in multiple journals in May 2014.¹²⁻¹⁴ The intent of the present report was not to revisit issues that were thoroughly discussed at that workshop but to highlight key points relevant to counseling. In addition, whereas previous publications may have provided specific recommendations based on the anticipated gestational age, this statement emphasizes the limitations of that approach and the need to individualize counseling. This report also discusses factors important in communicating with prospective parents and presents ways to assist them with difficult decision-making. The goal of this report was to assist pediatric and obstetric care providers in effectively managing what remains one of the most difficult areas in perinatal medicine.

BACKGROUND

Some infants may be born at such an immature stage of development that the risk of death or severe long-term neurologic impairment is exceptionally high. Initiating resuscitation and offering life support to these newborn infants may be considered futile or not in the best interests of the child, but how to translate these concerns into clinical practice is unclear. Therefore, it is important that parents be involved in decision-making whenever possible. Ideally, shared decision-making and family-centered care should be the goals.

The primary goal of antenatal counseling in this situation is to allow parents to make an informed decision regarding intervention. In addition, counseling can provide parents with knowledge and support that will help them manage what will likely be a difficult aftermath. Effective counseling includes 3 key components: assessment of risks, communication of those risks, and ongoing support. In addition, factors that may influence decision-making need to be carefully considered.

OUTCOME ACCORDING TO GESTATIONAL AGE

Most countries, including the United States, continue to report that survival without significant neurologic sequelae is extremely rare in infants delivered before 23 weeks of gestation, even with full resuscitation and intensive care.¹⁵⁻²⁵ In addition, although improved outcomes for infants born beyond 23 weeks' gestation have been observed in many countries, most have not reported improvement in outcomes for infants delivered at 22 to 23 weeks of gestation.^{15,16,19,22,23} Recent data, however, suggest that survival for infants born at less than 23 weeks' gestation can be improved if perinatal interventions (eg, antenatal steroids, operative deliveries for fetal distress, neonatal resuscitation) are made on the fetus' behalf.^{26,27} Japan has recently reported intact survival rates for infants born alive at 22 weeks of gestation comparable to those born at 23 weeks of gestation, with overall survival rates of 33%.²⁸ A study in the United States found similar rates of survival among newborn infants born at 22 weeks' gestation.²⁹ Therefore, if survival were the only consideration, it would seem reasonable to offer resuscitation and intensive care to all infants born at or beyond 22 weeks of gestation. However, parents and health care providers have to struggle with other considerations, including the fact that

most surviving preterm infants born before 25 weeks' gestation will have some degree of neurodevelopmental impairment and possibly long-term problems involving other organ systems.³⁰ Infants born at 22 weeks' gestation have reported rates of moderate to severe neurodevelopmental impairment of 85% to 90%; for infants born at 23 weeks' gestation, these rates are not significantly lower.²⁹⁻³² The risk of permanent, severe neurodevelopmental and other special health care needs affect both the infant and the family and, for some parents, may outweigh the benefit of survival alone.³³⁻³⁶

LIMITATIONS OF GESTATIONAL AGE AS A PREDICTOR

Although gestational age is a strong determinant of outcome, 2 interrelated factors limit the use of gestational age as a predictor of outcome: the rate of fetal development during the early third trimester and the inaccuracy of gestational dating. Between 22 and 25 weeks of gestation, the fetus is in an extremely rapid stage of development of many organ systems essential for extrauterine survival. Thus, each additional day of gestation theoretically increases not only the chance of survival but also the chance for a healthy long-term outcome. However, in most situations, the physician cannot know the gestational age with this degree of precision. Wide variability in an individual woman's ovulatory cycle and vaginal bleeding during the first weeks of pregnancy can make pregnancy dating according to last menstrual period inaccurate. First-trimester fetal ultrasonographic examinations, which have become the gold standard of gestational age assessment,³⁷ typically use mathematical algorithms to report gestational age estimates not only by week but also by days, implying a degree of precision that does not

actually exist. At best, fetal ultrasonographic dating is accurate within 8%, which translates to an accuracy of 4 to 5 days at 8 to 9 weeks of gestation but nearly 2 weeks at 24 weeks of gestation.³⁸ The most precise determination of gestational age occurs with assisted reproductive technologies, in which the date of fertilization or implantation may be accurately defined, giving a more precise date of conception. However, these technologies account for less than 2% of pregnancies.³⁹

Despite the difficulty in using gestational age alone to predict outcome, it is generally agreed that only comfort care should be offered to infants born at less than 22 weeks of gestation and that resuscitation should be offered for infants born at or later than 25 weeks of gestation,^{12–14,40–44} leaving a “gray zone” between 22 and 24 weeks of gestation, within which recommendations vary. However, a common thread shared by all these recommendations is that decisions in individual cases may be guided by considerations other than gestational age.

FACTORS OTHER THAN GESTATIONAL AGE THAT AFFECT OUTCOME

Many factors other than gestational age can affect pregnancy outcome. Preconception and pregnancy-related factors, such as maternal age, health, nutrition, substance use, and even genetics, may alter fetal growth and development and, hence, perinatal outcome. Significant complications during pregnancy (eg, chorioamnionitis, severe preeclampsia, intrauterine growth restriction, placental abruption) are known to affect neonatal outcomes. However, the degree to which any of these factors affects outcome independent of preterm birth is unclear.

Other factors, however, may be useful in refining our estimates of outcome based solely on gestational age. In

a large cohort of extremely preterm infants (22–25 weeks’ gestation) from 19 perinatal centers across the country, several factors in addition to gestational age significantly affected neonatal survival and long-term neurodevelopmental outcome at 18 to 22 months; female gender, antenatal corticosteroids, singleton birth, and increased birth weight (per 100-g increments) were each significantly associated with improved outcomes.⁴⁵ Because the data in this study are now more than a decade old, its contemporary relevance may be limited. One recent study found survival rates and 18- to 22-month outcomes for infants born at 22 to 25 weeks’ gestation to be significantly better than predicted by this model.²⁹ In addition, because these factors do not explain the marked variability in outcomes by center,⁴⁶ their applicability to a specific institutional environment is unclear. Nevertheless, such studies are valuable because they underscore the fact that gestational age should not be the only consideration in discussing prognosis with parents.

FACTORS THAT MAY INFLUENCE DECISION-MAKING

Attitudes of Health Care Providers

Both obstetric and neonatal care providers agree that some fetuses are too immature to warrant interventions solely aimed at improving neonatal outcome; these interventions include antenatal steroids, intervention for fetal distress, and delivery room resuscitation. However, there is no general agreement about the gestational age at which proactive management should occur.^{4,47} Proactive institutional practices, particularly the use of antenatal steroids, are associated not only with improved outcomes in periviable infants but also improved outcomes in more mature infants.^{48,49} Conversely, in institutions in which such infants are not fully supported

both before and after delivery (eg, not offering antenatal steroids but offering full resuscitation at birth), mortality rates for infants delivered before 25 weeks of gestation are increased.⁴

Physician attitudes regarding the appropriateness of resuscitation and intensive care are generally much more positive for infants born at 24 weeks of gestation compared with 22 weeks of gestation, but at any given gestational age, wide variation still exists. Data suggest that more experienced physicians tend to encourage shared decision-making with parents.² In addition, attitudes may be changing; whereas earlier studies suggested that obstetricians and neonatologists tended to overestimate morbidity and mortality rates for extremely preterm infants,⁵⁰ that no longer seems to be the case.^{7,8}

Attitudes of Parents

Although outlooks can differ depending on background, most parents who have raised an extremely low gestational age survivor report only modest increases in stress and continue to support aggressive resuscitation for these infants.^{51,52} Although survivors of extreme prematurity can have significant long-term health and developmental problems, former extremely preterm infants generally report better health outcomes than expected,^{53,54} except perhaps during adolescence.⁵⁵ Even though parents report more health care-related concerns, they generally rate the health quality of life of their children fairly high.⁵⁶

Although discussion of survival and long-term outcomes is important in counseling, many parents do not find quantitative predictions of death or morbidity to be central to their decision-making. Instead, religion, spirituality, and hope may be more important factors.^{57,58} There are also cultural differences in terms of preferences for resuscitation of

extremely preterm newborn infants, although these may reflect differences in institutional practices or resources.⁵⁹ Understanding the importance of parental values and experiences is essential to shared decision-making.^{60,61}

Delivery Room Assessment

Given the uncertainty that surrounds the outcomes of these periviable infants, some physicians recommend a “wait-and-see” attitude, suggesting that a skilled resuscitator be present at the delivery to intervene should the infant appear “viable” at birth.⁹ Indeed, this approach was suggested in an earlier edition of the *Textbook of Neonatal Resuscitation*.⁶² However, such decision-making in the delivery room delays the initiation of resuscitation and is prone to error. For example, when experienced neonatologists viewed delivery room videos of extremely preterm births, their ability to predict survival was no better than a coin toss.⁶³ It is recommended, therefore, that decisions regarding resuscitation be well communicated and agreed on before the birth, if possible, and not be conditional on the newborn infant’s appearance at birth. In rare circumstances, the newborn infant could be significantly more or less mature than anticipated, and this assessment could alter decisions made in the delivery room. Parents need to be informed of this possibility.

COMMUNICATION

When an extremely preterm birth is imminent, there is often little time to prepare the parents and to ascertain their wishes regarding resuscitation and subsequent neonatal intensive care. Optimal use of the limited time available, as well as the recognition and management of potential barriers to effective communication, will facilitate a beneficial discussion of anticipated outcomes and options.

Communication With Parents

The primary goal of antenatal counseling is to provide parents with information that will aid their decision-making. This counseling should include not only expected outcomes for the infant but also a discussion of available options (eg, comfort care). This communication needs to be sensitive to the religious, social, cultural, and ethnic diversity of the parents; in particular, for a parent with limited English proficiency, these discussions must include interpretation services, preferably face-to-face. Likewise, an appropriate interpreter may be needed for a parent who has limitations with hearing.

The value of providing statistical information during counseling is unclear, and there is evidence that this information is often misunderstood. Some authors have found that parents of extremely preterm infants who died after birth emphasize emotional and spiritual concerns as more important to their decision-making,⁵⁶ whereas others found that many parents preferred the use of statistics when receiving outcome information.⁶⁴ Regardless of the level of detail provided, it is important to realize that parents prefer to hear a range of outcomes rather than specific numbers.⁶⁰ Because outcomes of extreme prematurity vary widely among centers, institution-specific outcome data may be more applicable than group data from outside institutions. However, because institutional approaches can affect outcomes,⁴⁶ it should be recognized that applying only local data may create a self-fulfilling prophecy. In addition, the number of such infants born at a given institution may be so low that local data may be hard to interpret; therefore, using both local and outside data may be helpful in defining a range of outcomes.

Supplementing verbal information with written information improves

parental knowledge of long-term outcomes and may reduce parental anxiety.⁶⁵ Visual aids, such as pictures, graphics, and short messages about resuscitation and complications associated with extreme preterm birth, enhance parental knowledge regarding survival and morbidities, although 1 study found that they did not seem to alter parental desire for resuscitation.⁶⁶ Also, although the use of visual aids improves the understanding of inexperienced parents, those who have previously had experience with a preterm birth gained little from the aids.⁶⁷ If written or other visual aids are used, the level of comprehension and literacy of the parent needs to be considered.

Regardless of the issues discussed and decisions made during initial counseling, ongoing support should be provided. Parents will benefit from additional discussion either before or after delivery, regardless of whether the newborn infant receives resuscitation or intensive care. Addressing parents’ questions and concerns for a dying infant or the uncertain future of their extremely immature newborn infant will assist them during this difficult time.

Developing and Improving Communication Skills

In any institution, even those with training programs, the threatened birth of a periviable infant occurs infrequently enough that less experienced clinical staff and learners have limited opportunities to observe and to improve their communication skills. Therefore, when such an opportunity presents itself, an effort should be made to include these individuals in the process, with appropriate supervision. This involvement should be conducted in a manner that is respectful and not burdensome to the parents, and the roles of all present should be made clear. In addition to direct observation, simulated counseling

sessions can mirror the real-life clinical situation and may assist individuals in developing and improving their communication skills.^{68,69}

Communication Among Providers

Good communication among health care providers promotes optimal decision-making. Whenever possible, obstetricians and neonatologists should discuss each case together before, during, and after discussions with the prospective parents. In addition, with consultation from related service providers (eg, family support, social work, clinical ethics, palliative care, chaplaincy), health care institutions should develop policies and procedures that will not only frame discussions with parents but also inform staff and physicians.⁷⁰ Such guidance can be effectively used to counsel parents and to improve communication and consistency between service providers.⁷¹

A general approach to communication is suggested in the latest edition of the American Academy of Pediatrics/American Heart Association *Textbook of Neonatal Resuscitation*:

“Meeting with parents prior to a very high-risk birth is important for both the parents and the neonatal care providers. Both the obstetric provider and the provider who will care for the baby after birth should talk with the parents. Studies have shown that obstetric and neonatal perspectives are often different. If possible, such differences should be discussed prior to meeting with the parents so that the information presented is consistent. Sometimes, such as when the woman is in active labor, it may seem as if there is inadequate time for such discussions. However, it is better to have some discussion of potential issues, even if brief, with the baby’s family than to wait until after the baby is born to initiate such conversations. Follow-up meetings can take place if the situation changes over subsequent hours and days.”⁴³

CONCLUSIONS

1. Fetal gestational age, as currently estimated, is an imprecise predictor of neonatal survival, but

22 weeks of gestation is generally accepted as the lower threshold of viability.

2. Although most infants delivered between 22 and 24 weeks’ gestation will die in the neonatal period or have significant long-term neurodevelopmental morbidity, outcomes in individual cases are difficult to predict.
3. Outcomes of infants delivered at 22 to 24 weeks of gestation vary significantly from center to center.
4. Because of the uncertain outcomes for infants born at 22 to 24 weeks’ gestation, it is reasonable that decision-making regarding the delivery room management be individualized and family centered, taking into account known fetal and maternal conditions and risk factors as well as parental beliefs regarding the best interest of the child.
5. Attitudes vary not only between providers and parents but also among physicians and staff. Ongoing interdisciplinary communication and written policies and procedures can promote consistent, timely, and effective counseling.
6. Optimal decision-making regarding the delivery room management can be promoted through joint discussions between the parents and both the obstetric and neonatal care providers whenever possible.
7. Factors to consider when communicating with parents include their ability to comprehend the situation, language preference, cultural and/or religious considerations, and family support structure. If the parent has limited English proficiency, an interpreter should be used. Visual aids and outcome data based on local institutional experience may be helpful when

communicating concepts such as mortality and morbidity.

8. Optimal use of the limited time available, as well as the recognition and management of potential barriers to effective communication, will facilitate an effective discussion of anticipated outcomes and options.
9. Clinical learners may benefit from observing these prenatal counseling sessions. In addition, other educational tools, such as simulations, can be used to help them gain experience with such situations.
10. When a decision is made not to resuscitate a newborn infant, comfort care is appropriate, as is encouraging the family to spend time with the dying/deceased newborn infant. Providing religious, psychosocial, and/or palliative care support may assist families at this difficult time.

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