Clinical Report—Antenatal Counseling Regarding Resuscitation at an Extremely Low Gestational Age

abstract

The anticipated delivery of an extremely low gestational age infant raises difficult questions for all involved, including whether to initiate resuscitation after delivery. Each institution caring for women at risk of delivering extremely preterm infants should provide comprehensive and consistent guidelines for antenatal counseling. Parents should be provided the most accurate prognosis possible on the basis of all the factors known to affect outcome for a particular case. Although it is not feasible to have specific criteria for when the initiation of resuscitation should or should not be offered, the following general guidelines are suggested. If the physicians involved believe there is no chance for survival, resuscitation is not indicated and should not be initiated. When a good outcome is considered very unlikely, the parents should be given the choice of whether resuscitation should be initiated, and clinicians should respect their preference. Finally, if a good outcome is considered reasonably likely, clinicians should initiate resuscitation and, together with the parents, continually reevaluate whether intensive care should be continued. Whenever resuscitation is considered an option, a qualified individual, preferably a neonatologist, should be involved and should be present in the delivery room to manage this complex situation. Comfort care should be provided for all infants for whom resuscitation is not initiated or is not successful. Pediatrics 2009;124:422–427

INTRODUCTION

The anticipated delivery of an extremely low gestational age infant presents difficult ethical issues for caregivers and parents. Despite previously published guidelines,1–4 no consensus exists on this subject, and it remains one of the most controversial and emotionally charged areas in perinatology. Antenatal treatment decisions at an extremely low gestational age are complex, because they affect both the mother and the fetus, and the balance between risk and benefit may be quite different for each. For example, a cesarean delivery performed for fetal indications increases morbidity to the mother but may or may not benefit the infant. Uncertainty also exists regarding the timing of antenatal interventions, such as corticosteroid administration and fetal monitoring. These difficult decisions should optimally be made by the parents and their obstetrician, in collaboration with a neonatologist, after a thorough discussion of all currently available information.2

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KEY WORDS

prematurity, resuscitation, ethics, antenatal counseling.

ABBREVIATION

NRP—Neonatal Resuscitation Program

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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In addition to decisions about antepartum care and mode of delivery, parents and their physicians also must decide whether to initiate resuscitation for an infant born at an extremely low gestational age. The approach to counseling parents about decision-making regarding resuscitation of these infants should be comprehensive and consistent. The purpose of this revised clinical report (previously titled “Prenatal Care at the Threshold of Viability”) is to offer guidance for clinicians providing antenatal counseling to parents in this situation.

BACKGROUND

Most clinicians agree that some infants are so immature that initiating resuscitation is futile, whereas others are sufficiently mature such that not initiating resuscitation is unacceptable. Uncertainty exists, however, for infants between these 2 extremes, when it is unclear whether resuscitation is in the infant’s best interest. For these infants, selective resuscitation on the basis of parental preference is often considered to be an appropriate option, and general guidelines for decision-making are commonly based on estimated gestational age. The Nuffield Council on Bioethics suggests that infants born from 22 0/7 through 23 6/7 weeks’ gestation should be considered candidates for selective resuscitation. They also state that from 24 0/7 through 24 6/7 weeks’ gestation, the “normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit unless the parents and the clinicians are agreed that in light of the baby’s condition it is not in his or her best interests to start intensive care.” The Neonatal Resuscitation Program (NRP) considers the group appropriate for selective resuscitation on parental request may include an infant born at 23 to 24 weeks’ gestation. The International Liaison Committee on Resuscitation suggests that resuscitation is not indicated for an infant born at <23 weeks’ gestation or with a birth weight less than 400 g but also recommends, “In conditions associated with uncertain prognosis, when there is borderline survival and a relatively high rate of morbidity, and where the burden to the child is high, the parent’s views on starting resuscitation should be supported.” A recent summary of international guidelines concluded that an individual approach consistent with parents’ wishes should be considered for infants born at 23 to 24 weeks’ gestation.

However, caution has also been expressed against using these general guidelines for managing specific cases, and individualized decision-making is encouraged. The NRP states that “these uncertainties (regarding the accuracy of antenatal gestational age and birth weight estimates) underscore the importance of not making firm commitments about withholding resuscitation until you have the opportunity to examine the baby after birth.” The importance of individualized decision-making is also emphasized by a statement from the summary of international guidelines: “...because of the uniqueness of every pregnancy and neonate, to protect mothers and infants from futile treatment, as well as incorrect withholding of life-sustaining treatment, the specific circumstances of every individual situation must always be kept in mind.” It is clear that individualized decision-making is required for this complex issue, and many factors have to be considered when providing antenatal counseling to parents.

FACTORS TO CONSIDER WHEN COUNSELING PARENTS

Infants born at an extremely low gestational age have a high mortality rate, and a substantial percentage of survivors have serious neurodevelopmental disabilities. Estimated gestational age has served as the basis for estimating these risks for parents because of its strong association with outcome. However, there are limitations of using estimated gestational age alone for antenatal counseling purposes. One limitation is that the length of gestation is rarely certain to the precise day, except when conception occurred via in vitro fertilization. Another limitation is that many other factors influence the outcome of infants besides gestational age. Data from the National Institute of Child Health and Development Neonatal Research Network have been used to create an algorithm predicting outcome that considers birth weight, gender, use of prenatal steroids, and singleton pregnancy in addition to estimated gestational age. Each of these factors individually improves outcome for infants by as much as 1 additional week of gestation from 22 through 25 weeks’ gestation. These data were averaged from multiple centers with a wide variety of outcomes, and the healthiest infants (those not requiring mechanical ventilation) were excluded from the analysis. Nevertheless, these data indicate that a decision regarding resuscitation should not be made on the basis of gestational age alone. Because this study included only infants born at a perinatal center, the impact of delivery outside a perinatal center was not evaluated. Because preterm infants born at a perinatal center have better outcomes than those transported after delivery, this should be considered when providing parents of infants born outside a perinatal center with estimates of morbidity and mortality risks.

Studies show that clinicians who provide perinatal care, patients (later in life), and parents differ in their
interpretation of outcomes of extremely preterm birth. Obstetricians and neonatologists tend to overestimate morbidity and mortality rates for extremely preterm infants, which leads to underutilization of proven therapies, creating a self-fulfilling prophecy.\textsuperscript{30,31} In addition, neonatal nurses and neonatologists generally view disabilities in surviving infants more negatively than do parents of surviving infants or the children themselves as adolescents.\textsuperscript{32} Most families who have a surviving preterm infant with a disability do not believe that there has been a negative impact on the family, although this is not the case for all families.\textsuperscript{33,34} Finally, adolescents who themselves were surviving extremely preterm infants generally have the same self-perceived quality of life as their control peers who were of normal birth weight, despite having more physical disabilities.\textsuperscript{35–37} These observations highlight some of the challenges in providing guidance to parents in this complex situation.

In the United States, many neonatologists are concerned about the impact of the Born-Alive Infants Protection Act of 2001\textsuperscript{38} on antenatal counseling, because this federal legislation specifies that a born-alive infant’s legal status does not depend on gestational age, birth circumstances, or “whether anyone happens to want him or her.” However, this legislation does not specify when resuscitation efforts must be initiated in the delivery room and recognizes that perceived medical futility is a justification for noninitiation of resuscitation. Although a universal definition of medical futility does not exist, a therapy is generally considered futile if it is very unlikely to benefit the patient.\textsuperscript{39}

The antenatal consideration of noninitiation of resuscitation for an extremely low gestational age infant is a unique ethical dilemma in that the patient has not yet been seen or examined. This fact distinguishes this decision-making process from essentially all others in medicine that involve the noninitiation of life support. Therefore, whenever resuscitation is considered an option, a qualified individual should be involved and present in the delivery room to manage this complex situation. Whenever possible, this individual should be a neonatologist.

**COMMUNICATIONS WITH THE PARENTS**

The purpose of antenatal counseling is to inform parents and assist with decision-making. These discussions should be sensitive to the culture of the family and appropriate for the family’s level of understanding of complex issues. Translation services should be used if the family is not proficient in English. Parents should be given the most accurate prognostic morbidity and mortality data available for their infant. In some situations, these may be hospital-specific data,\textsuperscript{40,41} and in other situations, regional or national data may be more appropriate.\textsuperscript{19} Parents need to be informed that despite the best efforts, the ability to give an accurate prognosis for a specific infant either antenatally or immediately after delivery remains limited.\textsuperscript{40–45} Parents should be told that even with resuscitation and intensive care, many infants born at an extremely low gestational age die within the first few days after delivery.\textsuperscript{41} Parents also need to recognize that infants who survive the first few days are likely to survive until hospital discharge, but prediction of long-term neurologic outcome remains limited.\textsuperscript{42} It should be made clear to parents that if resuscitation is attempted and successful, situations may occur later in which it is reasonable to consider withdrawing treatment.\textsuperscript{46} If the parents’ preferences regarding resuscitation are either unknown or uncertain, both the Nuffield Council on Bioethics and the NRP suggest that resuscitation should be initiated pending further discussions.\textsuperscript{3,4} Two surveys of parents have indicated that the vast majority of parents prefer resuscitation to be initiated even when there is great uncertainty about the outcome.\textsuperscript{67,48} Parents should also be told that if the decision is not to initiate resuscitation or if resuscitation is unsuccessful, their infant will be provided comfort care and they will have the opportunity to hold their infant after delivery.

The most effective method of communicating complex information to parents is unknown.\textsuperscript{41,49} Some have suggested providing written information, because parents often forget what they have been told.\textsuperscript{50} When considering noninitiation of resuscitation for an infant, established ethical principles require that the parents be fully informed about their infant’s prognosis and care options.\textsuperscript{46,51} Whenever possible, these conversations should involve both parents at the same time, and parents must have adequate time to ask questions and consider the content of the discussions. Ideally, the neonatologist and the obstetrician should speak with the parents together and present a consistent approach. More than 1 conversation may be necessary and decisions may need to be altered if the pregnancy continues. It is important to realize that what physicians think parents hear and understand during these discussions may not reflect what the parents later report being told.\textsuperscript{52,53}

Opinions differ on whether counseling of parents should be directive.\textsuperscript{51} The traditional approach has been to give parents outcome data in a nondirective manner and ask them to decide whether they want their infant resuscitated. Others have argued that this places an unfair burden on parents, who may later regret their decision.
regardless of what it was, and experience feelings of guilt. In addition, parents can rarely be as informed as physicians about the complexities of prolonged hospitalization and the long-term outcome for these infants. Still others have suggested the degree to which counseling should be directive is in part related to the characteristics of individual parents. Although no consensus exists on this point, antenatal counseling may be of little value unless some degree of direction is provided to parents. After appropriate discussions, conflicts may still exist between parents and physicians regarding whether to initiate resuscitation. Further discussions will usually resolve these conflicts, but for unusual cases, referral to an ethics committee may be necessary.

CLINICAL IMPLICATIONS

1. Whether to initiate resuscitation of an infant born at an extremely low gestational age is a difficult decision, because the consequences of this decision are either the inevitable death of the infant or the uncertainties of providing intensive care for an unknown length of time with an uncertain outcome.

2. Each hospital that provides obstetric care should have a comprehensive and consistent approach to counseling parents and decision-making.

3. Parents should be provided the most accurate prognostic data available to help them make decisions. These predictions should not be based on gestational age alone but should include all relevant information affecting the prognosis.

4. It is not possible to develop specific criteria for when the initiation of resuscitation should or should not be offered. Rather, the following general guidelines are suggested when discussing this situation with parents.
   a. If the physicians involved believe that there is no chance of survival, resuscitation is not indicated and should not be initiated.
   b. If the physicians consider a good outcome to be very unlikely, then parents should be given the choice of whether resuscitation should be initiated, and clinicians should respect their preference.
   c. When the physicians’ judgment is that a good outcome is reasonably likely, clinicians should initiate resuscitation and, together with the parents, continually re-evaluate whether intensive care should be continued.

5. Whenever resuscitation is considered an option, a qualified individual should be involved and present in the delivery room to manage this complex situation. Whenever possible, this individual should be a neonatologist.

6. Comfort care should be provided for all infants for whom resuscitation is not initiated or is not successful.

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