Counseling the periviable pregnant woman presenting at the edge of viability can often be confusing for the patient and frustrating for the clinician. Although neonatal survival rates have improved dramatically over the last few decades, severe morbidity is still common. This is further complicated by the fact that the information provided to the parents regarding the outcomes may not be up to date or completely accurate. The counseling is also frequently influenced by personal beliefs and biases of the medical staff. An evidence-based approach may improve the experience for both the expectant parents and the health care team.

**Key words:** extremely premature infant, neonatal morbidity and mortality, periviable pregnancy


Communication between these many caregivers is often fragmented and uncoordinated. Information relating to neonatal outcome provided to the patient is frequently varied, often conflicting, and even inaccurate because of caregiver differences in beliefs, values, experience, and specific knowledge. Together, these factors can lead to tremendous confusion and frustration for the patient and the caregivers. In this clinical opinion, we will detail some of these problems and describe the development of a program designed to improve the process for counseling and managing the patient at risk for very preterm delivery.

**Scope of the problem**

The problem of prematurity is well known. In 2006, the national preterm birth rate (delivery before 37 completed weeks) was 12.8%. The overall rate has continued to increase over time; however, the rate of births at less than 32 weeks has remained relatively constant for more than 2 decades at approximately 2% of all deliveries. As the gestational age decreases, morbidity and mortality increase dramatically. Nationally in 2001, only 59% of infants born at less than 28 weeks survived to their first birthday. This statistic is compared with 95% delivered between 32 and 35 weeks and 99.7% of those born after 37 weeks.

Survival of these very preterm infants has improved substantially over the past 25 years resulting in progressive lowering of the “limits of viability.” For this discussion we have chosen to define the periviable gestational age range to include fetuses born between 22\(\frac{0}{7}\) weeks and 26\(\frac{6}{7}\) weeks. In 2003, approximately 0.4% of all deliveries in the United States occurred in this gestational age range, amounting to roughly 16,000 infants annually. Within this range, survival improves dramatically from typically less than 10% to more than 80%; however, the same dramatic improvement is not seen for morbidity. Survival is also affected by birthweight, with larger infants having a lower mortality rate at a given gestational age. Infants who survive frequently encounter a number of complications in the neonatal intensive care unit (NICU), including intraventricular hemorrhage (IVH) and periventricular leukomalacia, hearing impairment, retinopathy of prematurity, respiratory distress syndrome and chronic lung disease, necrotizing enterocolitis, and infectious complications. Long-term morbidities include lower IQ scores, increased neu-
Rosensy impairment, increased incidence of learning disabilities, and lower academic performance compared with infants born at term gestations.\(^8\)

**Variations in reported morbidity and mortality rates**

In counseling women regarding morbidities and mortality that frequently occur at these early gestational ages, it is very important for the practitioner to understand how the various rates are derived. Although on the surface establishing mortality rates should be very straightforward, there can be significant clinical variation in how these rates are determined. Differences in populations and resuscitation strategies vary among reports. An important difference can be due to the population denominator used to calculate the mortality rate. Frequently admissions to the NICU constitute the denominator used. Infants who die in the delivery room during the initial resuscitation attempt, or because no resuscitation is attempted, are not included thus artificially lowering the calculated mortality rate for the total population. The mortality rate may be further underestimated by not including those fetuses that die during labor because aggressive obstetric intervention for fetal indications is not planned because of the early gestational age. Just as the mortality rates can be reduced depending on the definition, survival rates can be inflated. These differences in mortality rates are illustrated in Table 1.\(^2\)

Understanding morbidity rates and its counterpart intact or normal survival, is even more perplexing. The same problems described previously for mortality rates will affect reported morbidity rates; however, a number of additional factors can have a further confounding influence. Definitions of complications typically vary. For example, all grades of IVH may be included in some reports whereas only severe (grade 3 or 4) cases with a known better correlation with long-term outcome are included in others. Study design is also an important variable. As morbidity rates are gestational age dependent the gestational age range of neonates included in a study will have an impact. If neonates delivered in the periviable gestational age range are analyzed as part of a total population of infants less than 32 weeks or even in a group less than 28 weeks, morbidity will be considerably less than if these very early gestational ages are described as a separate subset. Surrogate end points may correlate only partially or even poorly with an important desired outcome. IVH has been used as a marker for neurologic handicap and cerebral palsy, however, not all infants with IVH will develop these long-term morbidities. Further complicating this issue is the fact that there are varying degrees of severity in conditions such as cerebral palsy. Low APGAR scores have poor predictive value. Many studies report birthweight rather than gestational age. Although at any given gestational age larger birthweights are associated with better outcome,\(^1,4\) inclusion of older infants with intrauterine growth restriction can confound morbidity reports. Length of follow-up will also have an impact on the reported morbidity because evaluation at neonatal discharge compared with school age or even adolescence will report different end points and outcomes.

Further variation in morbidity rates is seen when follow-up is based on examination by a specialist vs telephone surveys of parents. The longer the follow-up period, the greater the likelihood of losing track of study participants, further increasing bias. Changes in obstetric and neonatal care also have a tremendous impact on reported outcomes. In long-term follow-up studies “current” outcomes reflect “old” care. For example, individuals who are currently in their teenage years or young adulthood will have been delivered before the widespread use of antenatal glucocorticoids or neonatal surfactant. Finally, morbidity can be considered significant or not based on who is providing the perspective. Medical professionals often view handicaps more harshly than the patients themselves and their parents,\(^9\) whereas views among the parents of these children can vary as well.\(^10\) The societal impact of the care of these children has received only limited attention, but may become more important as concern over rising medical costs increases and allocation of limited resources becomes a larger issue.\(^11,12\)

### Outcomes of infants delivered during the periviable period

The EPICURE Study\(^2,13\) followed all live born infants between 22 0/7 and 25 6/7 weeks delivered over a 9-month period during 1995 in the United Kingdom and Ireland through 6 years of age. This report provides a representative perinatal mortality rate at each of these gestational ages since the advent of surfactant therapy and routine antenatal corticosteroids. Table 1 shows these rates both as a function of all live births and of NICU admissions. The overall follow-up rate of surviving children at 6 years of age was 78%. The infants were categorized into 4 disability groups: none, mild, moderate, and severe. The severe group was highly dependent on care givers for basic daily needs. Those classified as having a mod-

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**TABLE 1**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Gestational age, wk</th>
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<tr>
<td>Died in delivery room, %</td>
<td>22 (n = 138)</td>
</tr>
<tr>
<td>Died in NICU, %</td>
<td>14</td>
</tr>
<tr>
<td>Survived to discharge, %</td>
<td>1.5</td>
</tr>
<tr>
<td>Intact survival (% of live births)</td>
<td>0.7</td>
</tr>
<tr>
<td>Intact survival (% of discharges)</td>
<td>50</td>
</tr>
</tbody>
</table>

NICU: neonatal intensive care unit.

erate disability were likely to be relatively independent, whereas mild disabilities consisted of neurologic findings with little functional significance. The rates of severe disability and intact survival at 6 years of age are shown in Table 2.13

It is a commonly held belief that morbidity and mortality for extremely premature infants has improved over time and continues to do so. Wilson-Castello et al14 did show significant improvements in survival for infants weighing less than 1000 g when comparing those born in the 1980s with those born in the 1990s, corresponding to the advent of surfactant use. Overall morbidity rates did not dramatically decrease resulting in an increased number of intact survivors as well as an increased number of infants surviving with impairment. Farrow et al14 reported on short-term morbidities based on birthweights during the 1990s in 3 periods roughly corresponding to before, during the transition, and after the routine use of antenatal corticosteroids. Although there was an initial increase in neonatal survival with the initiation of steroids, there was no further improvement in the later years of the study. There was no significant increase in survival without morbidity with the resultant improvement in survival leading to a greater number of infants with short-term morbidity.

Management options

Once potential outcomes are reviewed with parents, available management options range from aggressive obstetric and neonatal interventions to neonatal palliative comfort care. With a plan for aggressive therapy, glucocorticoids are given to improve neonatal outcome. Intrapartum fetal monitoring is used. Cesarean section is performed as indicated for malpresentation or nonreassuring fetal status. Once delivered, full NICU support includes resuscitation with nasal continuous positive airway pressure or mechanical ventilation, surfactant administration, and placement of central vascular catheters as indicated. If comfort care is chosen and aggressive interventions are declined, glucocorticoids may be withheld with administration at a later gestational age when aggressive interventions are planned. Fetal monitoring is not routinely performed, and vaginal delivery is planned regardless of fetal presentation. After delivery, the neonate is kept warm and comforted with no invasive or painful procedures. The parents are allowed and encouraged to hold and interact with the infant and pastoral services are offered as desired.

Any number of intermediate management plans can be established that incorporate various aspects of full intervention and comfort care allowing for flexibility in decision making. On the obstetric side, glucocorticoids can be given and intrapartum fetal monitoring may be provided while deciding not to proceed with a cesarean section in the presence of fetal malpresentation or fetal distress. Although this may seem counterintuitive, glucocorticoids are known to improve neonatal outcome, whereas intrapartum fetal monitoring allows for more conservative interventions to improve neonatal outcome short of incurring the potential maternal morbidity associated with cesarean section when there may be only limited benefit for the infant. Such conservative maneuvers include maternal position change, fluid bolus, maternal oxygen therapy, and amnioinfusion. Aggressive intervention can be initiated and later withdrawn in the NICU if there is a poor response or severe neonatal morbidities develop such as IVH or necrotizing enterocolitis.

An intermediate management approach is neither simple nor straightforward and requires clear and compassionate communication of the limitations of this option. Avoiding a cesarean section if indicated may lead to delivery of an infant that is compromised resulting in greater neonatal morbidity than if a cesarean section had been performed. In addition, the neonatologist is often not able to accurately predict either short- or long-term morbidity based on the initial response to resuscitation in the delivery room in terms of predicting NICU or long-term outcomes.15 This may lead to prolonged and undesired interventions in the face of a poor prognosis or nonintervention in an infant that could fare well. Although “intermediate” management plans allow flexibility, it is important to understand that ultimate management decisions are not always straightforward.

Beliefs and knowledge of medical staff and parents

In addition to understanding the potential variations and biases in the objective measures of neonatal outcomes, it is important to be familiar with beliefs and biases of medical care providers, as well as those of the prospective parents. Value
systems, moral tenets, and religious beliefs vary between individuals and can have a tremendous impact on how the counseling is delivered and how it is perceived. It is also important to realize the ultimate management decisions can have an impact on the remainder of the family as well.

Physicians practicing obstetrics tend to systematically underestimate survival of infants delivered preterm. Haywood et al.16 found that obstetric providers underestimated survival at all gestational ages before 36 weeks with the difference between actual and physician estimates becoming progressively larger as the gestational age decreased. Before 26 weeks, physician estimates were less than half of the actual survival rates. In another survey, respondents were asked to state the gestational age at which they would recommend various perinatal and neonatal interventions.17 The mean gestational age below which the obstetrician would not provide a given intervention was 23-24 weeks. The range at which the interventions would be recommended was surprisingly wide. Some respondents reported a willingness to proceed with cesarean section at a gestational age of 20 weeks, whereas others would withhold it up to 28 weeks. Some recommended neonatal resuscitation as early as 18 weeks, whereas others would withhold it until after 27 weeks.

An obstetrician’s willingness to actively intervene on behalf of the fetus has been shown to have an impact on outcome. Bottoms et al.18 evaluated the relationship between perinatal outcome and willingness to intervene for infants weighing <1000 g. The stillbirth rate was reduced to nearly zero and the neonatal death rate was lower in those infants where the obstetrician was prepared to perform a cesarean section compared with those who were not. In the subgroup of infants at less than 800 g or 26 weeks’ gestation, both major morbidities and intact survival were higher in the delivery of those infants in which the obstetrician was willing to perform a cesarean section. The number of infants surviving with major morbidity was significantly increased because of the overall increased survival rate. Redmond and Gonik19 used cesarean section rates from Michigan state birth certificate data to estimate the threshold at which obstetricians actually intervened. From 1995-2000, the cesarean section rate for infants delivered at 24 and 25 weeks was 40% to 50% with no change during this time frame. At 23 weeks, the cesarean rate significantly increased from 16% to 28% during this same time frame, suggesting that there was a lowering of the threshold at which obstetricians were willing to aggressively intervene.

A survey of neonatologists viewing regarding the use of resuscitation of the periviable newborn reported nearly universal agreement that resuscitation was futile at or before 22 weeks’ gestation. There was also broad agreement that full resuscitation was clearly beneficial at 26 weeks and later. With increasing gestational age from 23-25 weeks there was a clear switch from the belief that resuscitation was futile to clearly beneficial. At 23 weeks nearly a third of the respondents believed resuscitation was futile and only 2% thought it was clearly beneficial. At 24 weeks, only 1% believed resuscitation to be futile but only approximately a third thought it was clearly beneficial. At 25 weeks, three quarters of respondents reported that resuscitation was clearly beneficial. This leaves a large proportion of neonatologists viewing the benefit of resuscitation between 23 and 25 weeks as not clear cut.20

Parental attitudes regarding perinatal interventions should also be considered. Saigal et al.9 used a series of clinical vignettes to compare attitudes addressing quality of life measures on a scale ranging from a state of perfect health on one end to death on the other as it related to progressively increasing impairment. They compared adolescents, their parents, and neonatal caregivers. The health care providers consistently rated the quality of life worse than the parents and the adolescents. This was particularly apparent in the scenarios with the worst impairment where the health care providers rated the most severe outcomes as “worse than death.” The authors concluded that these attitudes could affect...
the counseling and care given in the NICU. In a particularly poignant letter to the editor regarding this publication, parents of disabled children related their experiences with the NICU care. They reported their counseling to be slanted toward aggressive intervention with little information regarding outcomes and limited opportunity to participate in decision making. “Instead of being encouraged to limit care many of us were threatened and made to feel like criminals for questioning even the most extreme medical measures.”

Attitudes regarding management of the patient with the potential perivable delivery are varied and frequently divergent. There are not only differences between health care providers and the prospective parents, but there is also considerable variation within these groups. Ultimately, parents should be the principle focus regarding decision making surrounding care of their extremely premature infant. To make appropriate decisions for their situation, they deserve accurate information that is as unbiased as possible. In most situations parental care choices should be honored and supported.22,23

A standardized approach to counseling

In an effort to improve clarity and consistency of the counseling process for both patients and staff, we developed a set of guidelines in a systematic multistep fashion.24 Education regarding outcome of the infants was provided to all health care providers (physicians and nurses from both the NICU and the Obstetric units). An evidence-based data sheet outlining mortality and morbidity rates at the various gestational ages was developed for this process. The reported mortality rates included those from our own institutional data, those from the Vermont Oxford Neonatal Network, and a composite of available literature.24 A composite range of neurologic morbidity rates was summarized from recent publications. Tyson et al25 have subsequently developed an estimator (www.nichd.nih.gov/neonatalestimates) that provides more individualized survival and morbidity estimates using gestational age and 4 additional clinical variables (estimated fetal weight, gender, singleton or not, and steroid administration) based on outcomes from the NICHD neonatal research network.

After staff education these same providers were surveyed as to how they believed the patient should be counseled at the various gestational ages from 22 through 26 weeks. The 5 available responses at each gestational age ranged from strongly encouraging intervention to strongly discouraging life support (Figure 1). Based on this education, discussion, and survey results, we developed consensus management strategies to be used at each specific gestational age from 22 through 26 weeks (Figure 2). In general health care professionals recommended against aggressive resuscitation before 24 weeks and promoted it after 25 weeks. At 24 weeks, there was no clear consensus. These recommendations serve as a guide for the counseling physician who is encouraged to consider each patient’s clinical situation, personal beliefs, and preferences. The process often begins with the obstetrician on admission and, depending on the clinical situation, the neonatologist may see the patient anywhere from shortly after the initial obstetric assessment to 24-48 hours after admission. The consensus management strategy sheet (Figure 2) and a table outlining morbidity and mortality rates used to counsel the patient are often given to them for further review. The recommendations were not meant to dictate a course of management but rather to provide patients with a framework to begin their individual decision-making process based on a general consensus of the medical and nursing staffs. For example, after counseling, a patient’s desire for full resuscitation at

<table>
<thead>
<tr>
<th>Weeks</th>
<th>Obstetric care</th>
<th>Neonatal care</th>
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<tbody>
<tr>
<td>&lt;23</td>
<td>Tocolysis as indicated. No steroids. No C/section for fetal indications.</td>
<td>NICU care not offered. Comfort care provided.</td>
</tr>
<tr>
<td>230/-236/7</td>
<td>Tocolysis as indicated. Steroids not recommended. C/section for fetal indications not recommended.</td>
<td>NICU care not recommended because of high mortality and high neurologic disability rate. Comfort care provided.</td>
</tr>
<tr>
<td>240/-246/7</td>
<td>Tocolysis as indicated. Steroid use if mother/family choosing NICU care at &lt;26 wk. C/section may be declined or chosen after review of clinical outcomes. Majority of medical staff does not recommend C/section for fetal indications.</td>
<td>NICU care may be declined and comfort care provided or NICU care may be chosen by the mother/family after review with the medical staff of the probable and potential clinical outcomes. Majority of medical staff does not recommend NICU care.</td>
</tr>
<tr>
<td>250/-256/7</td>
<td>Tocolysis as indicated. Steroid use if mother/family choosing NICU care at &lt;26 wk. C/section may be declined or chosen after review of clinical outcomes. Majority of medical staff does recommend C/section for fetal indications.</td>
<td>NICU care may be declined and comfort care provided or NICU care may be chosen by the mother/family after review with the medical staff of the probable and potential clinical outcomes. Majority of medical staff does not recommend NICU care.</td>
</tr>
<tr>
<td>260/-266/7</td>
<td>Tocolysis as indicated. Steroids as indicated. C/section for fetal indications strongly recommended.</td>
<td>NICU care provided in the majority of cases.</td>
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</table>

23 weeks is honored despite the fact this is not generally recommended by the medical staff. On the other hand, if comfort care is chosen at 25 weeks, this parental choice is also honored despite the general staff recommendations for NICU care.

Patient perception of the process obtained through surveys at 3 days and 6-18 months after counseling have been overwhelmingly positive. Women report the counseling information to be understandable, useful, and consistent. Once a management decision was made after counseling, most patients were comfortable they had made the right decision for themselves and their families.24,26

We recognize that these periviability decisions can be very emotional and that the specifics of our approach may be controversial. We also believe our periviability counseling process has resulted in a substantial improvement in the care of pregnant women because it emphasizes an evidence-based approach and consensus decision making. The bottom line remains that infants delivered in the periviable gestational age range will face high mortality and the majority will develop some degree of significant neurologic handicap. Parents deserve this discussion delivered in a consistent and understandable fashion. They will then hopefully have the information necessary to make an informed decision that is right for them.

REFERENCES