

## OBSTETRICS

# Caring for the pregnant woman presenting at periviable gestation: acknowledging the ambiguity and uncertainty

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Care of the pregnant woman threatening to deliver at the edge of viability presents an enormous challenge to both the obstetric and neonatology staff. In the relatively narrow gestational age range of 22<sup>0/7</sup> to 26<sup>6/7</sup> weeks, neonatal mortality is initially almost universal but decreases rapidly with advancing gestation. Surviving neonates are at considerable risk for a number of severe morbidities.<sup>1-4</sup> Patients presenting at these early gestations are often frightened and usually ill equipped to completely comprehend the information presented and the impact of the decisions that must be made on the lives of their unborn child, themselves, and their families. They are often distracted by pain. Medications used in initial treatments can adversely affect their ability to concentrate and comprehend. In addition, these decisions must be made with little time for reflection in the presence of progressive labor or deteriorating maternal or fetal condition. Multiple care providers are typically involved and may include physicians practicing obstetrics, maternal-fetal medicine, neonatology, as well as nurses from each of these disciplines.

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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

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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.<sup>5</sup> 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.<sup>6</sup>

Survival of these very preterm infants has improved substantially over the past 25 years resulting in progressive lowering of the "limits of viability."<sup>1</sup> For this discussion we have chosen to define the periviable gestational age range to include fetuses born between 22<sup>0/7</sup> weeks and 26<sup>6/7</sup> 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.<sup>7</sup> 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.<sup>2,3</sup> Survival is also affected by birthweight, with larger infants having a lower mortality rate at a given gestational age.<sup>4</sup> 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-

TABLE 1

**Intact survival at gestational ages 22-25 weeks as a function of total deliveries or NICU discharges<sup>2</sup>**

Outcome	Gestational age, wk			
	22 (n = 138)	23 (n = 242)	24 (n = 382)	25 (n = 424)
Died in delivery room, %	84	46	22	16
Died in NICU, %	14	44	50	40
Survived to discharge, %	1.5	11	26	44
Intact survival (% of live births)	0.7	5	12	23
Intact survival (% of discharges)	50	42	45	53

NICU, neonatal intensive care unit.

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rosensory impairment, increased incidence of learning disabilities, and lower academic performance compared with infants born at term gestations.<sup>8</sup>

### 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 straight forward, 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.<sup>2</sup>

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,<sup>1,4</sup> inclusion of older infants with intrauterine growth restriction can con-

found 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,<sup>9</sup> whereas views among the parents of these children can vary as well.<sup>10</sup> 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.<sup>11,12</sup>

### Outcomes of infants delivered during the periviable period

The EPICURE Study<sup>2,13</sup> 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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