

Advocating for equality for preterm infants

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Threatened extremely preterm delivery at the border of viability represents a complex situation for families, caregivers and the fetus. Decisions about the appropriate level of active intervention are complicated by concerns regarding morbidity and mortality risks to the mother and infant, the stress of a potentially long neonatal intensive care stay and uncertainty regarding the infant's outcome. In our opinion, this process is aided by a consistent approach across caregivers and, ideally, health care institutions. However, evidence that extremely preterm infants are devalued relative to older patients with a similar or worse prognosis¹ suggests the potential for a discriminatory approach toward these infants.

The Fetus and Newborn Committee of the Canadian Paediatric Society recently published guidelines for counselling and management for anticipated extremely preterm birth.² The American Academy of Pediatrics has published a similar statement,³ which one of us (D.B.) was involved in crafting. Similar to most previous guidelines, the Canadian Paediatric Society's recommendations for active intervention in the delivery room² are based primarily on the relationship between gestational age and the risks of morbidity and mortality. Although morbidity and mortality rates increase as gestational age at birth declines, both are influenced by many factors and differ substantially between institutions and at each gestational age from 22 to 25 weeks, with substantial overlap across this range.

Another concern with this approach is the acknowledged limitation in accurately estimating gestational age. Even with early ultrasound evaluation, the error rate is plus or minus 5 days,² which represents a 10-day time frame. The Canadian Paediatric Society statement recommends nonintervention for an infant born at 22 weeks, 6 days estimated gestational age (recommendation 10), whereas active treatment is recommended for some infants at 23 weeks, 4 days (recommendation 12), even though the actual gestational age for these 2 infants may well be reversed. We are not aware of any other area in medicine in which life-sustaining interventions are arbitrarily provided on the basis of the patient's *estimated* age or whether an event

(birth) happens shortly before or shortly after midnight (e.g., at 22 weeks, 6 days v. 23 weeks, 0 days). This approach also does not fully consider other factors that affect infant outcomes, including birth weight, sex, multiple gestation and antenatal corticosteroids.^{3,4}

In particular, the role of antenatal corticosteroids for extremely preterm infants remains unclear. However, in addition to the studies referenced by the Canadian Paediatric Society, data from a large retrospective cohort have suggested a significant benefit of antenatal corticosteroids for infants born at 23 weeks gestational age and some benefit at 22 weeks.⁵ In contrast to the Canadian Paediatric Society statement, we advocate for routine antenatal administration of corticosteroids whenever there is a risk for extremely preterm birth and newborn survival is possible, not just "when active management of the neonate is considered," as plans sometimes change suddenly, resulting in a lost opportunity for the infant to benefit from corticosteroids.

The role of cesarean delivery at 22 to 25 weeks' gestational age is also unclear, as there are substantial morbidity risks to the mother and her future children, including an increased risk of uterine rupture or preterm birth with subsequent pregnancies, and uncertain benefits to the fetus. We agree that such a decision should be made by the obstetrics team following appropriate discussion with the family. Although randomized controlled trials are not available, lim-

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KEY POINTS

- The decision to provide active intervention to extremely preterm infants at the border of viability is difficult but should not be discriminatory.
- Current methods of estimating gestational age are not sufficiently precise for this to be the sole basis for decision-making.
- The error of a self-fulfilling prophecy inherent in withholding active intervention in the delivery room because it is assumed to be futile should be avoided.
- Reported neurodevelopmental disability rates in populations of surviving infants are not sufficient criteria for withholding active intervention in the delivery room.
- Providing antenatal steroids and active intervention initially and then re-evaluating the appropriateness of such intervention with the parents thereafter should be the default approach to care when the infant's best interests are unclear.

ited evidence suggests that cesarean delivery is associated with reduced mortality at 22–25 weeks gestational age.⁶ It should also be noted that a decision regarding the mode of delivery is separate from the decision to provide life-sustaining interventions to the infant.

Using the relationship between estimated gestational age and outcome as the primary basis for life-and-death decisions is problematic for several other reasons. As noted by the Canadian Paediatric Society, variation in infant survival rates across institutions is partly due to the use of different active management strategies. Unfortunately, the field of perinatology has long struggled with this self-fulfilling prophecy: withholding active intervention for some infants who are not “expected” to do well, then using their poor outcomes as justification for this decision.

Furthermore, studies often report neurodevelopmental outcomes for these infants using terms such as “bad,” “poor” and “severe,” without considering the families’ perspectives. For example, cerebral palsy at 18–24 months has been cited as evidence of a “severe adverse neurodevelopmental outcome,” even though many surviving preterm infants with cerebral palsy (or other types of “poor” outcomes) become happy, well-adjusted and productive individuals who are grateful they received active intervention.^{7–9} We feel that many publications about infant neurodevelopment de-emphasize the positive outcomes of surviving preterm infants. We all wish such infants were universally free of sequelae, but the presence of a disability does not mean that active intervention was a mistake.

Finally, as the Canadian Paediatric Society acknowledges, review of the literature for groups of infants is of little value in prognosticating for a specific infant. Statistics cannot tell parents how their infant is going to do. A more appropriate approach may be to provide them with the range of possibilities while acknowledging our uncertainty regarding their infant.

We recognize that extremely preterm infants face serious challenges. This is also true for infants with other diagnoses who receive intensive care but do not seem subject to the same degree of selectivity regarding active intervention at birth. We recognize that the birth of some

preterm infants occurs so early in gestation or is associated with such important complications (e.g., severe asphyxia) that limiting active intervention may be the best option. However, in our opinion, extremely preterm infants should be treated like all other patients who cannot tell us what they want: if there is a reasonable opportunity for a reasonable quality of life, then the default position should be to provide appropriate antenatal and postnatal care, including life-sustaining interventions in the delivery room. The appropriateness of continuing these interventions can then be re-evaluated with the family and withdrawn if mutually decided upon.¹⁰ We have a responsibility to provide parents with information and options not shaded by our biases or smothered in probabilities that hide our ignorance. Making a reasonable decision for each extremely preterm infant requires all of our knowledge, compassion and communication skills to avoid a discriminatory approach.

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