Editorial

Resuscitation of Infants Born at the Limit of Viability

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An emotional and impassioned discussion has erupted in the recent literature over the moral, legal and ethical decision-making authority for the resuscitation of the smallest and most vulnerable infants. It has become increasingly divisive among providers themselves and between providers and families. Although there are no clear moral and ethical precedents for this very difficult area, there are strong and varied opinions surrounding it. The legal system has become endlessly ensnared within the discussion.

Decisions surrounding technological support for the very immature infant are never easy and rarely are clearly right or wrong. Extenuating circumstances exist in nearly every case. Appropriate decisions arise from long and thoughtful discussions; trusting and compassionate relationships between providers and families cannot be enforced by hospital administrations, rules, legislation or a court of law.

We all acknowledge that incredible progress has been made over the last several decades in the medical and surgical care of premature infants. This has evolved without much input from families, until the fairly recent past; however, the family bears the brunt of this burden. The central feature of this dilemma is that extremely low birth weight and extremely low gestational age babies now have a relatively high probability of survival; a survival uniformly accompanied by long-term and complex morbidity. Many of these infants continue to face uncertain outcomes fraught with protracted hazard, pain, suffering, uncertain quality of life and prolonged hospitalization.

NPA, as a multidisciplinary organization with a membership of parents and professionals, supports ongoing exploration and discussion of the decision-making process regarding the resuscitation and treatment of marginally viable infants. NPA proposes a search for common ground for all involved in this issue, including providers, families, professional organizations and institutions. Families are facing an acute tragedy that may affect their ability to enter fully into the decision-making process, and therefore an environment receptive to their needs is imperative. A gap in the time-line of information gathering and understanding usually exists between providers and families and should be acknowledged in the communication process. Constant reassessment of both guidelines and clinical outcomes is imperative for achieving the best long-term outcomes. We urge our physician colleagues to be incredibly honest with themselves and with families about the extremely complex nature of the decision to resuscitate a very immature infant, and all the possibilities it entails. One option for care must be provision of a loving and dignified nonresuscitation. In situations where there is disagreement between families and providers, every effort should be exhausted for resolution, without legal or court intervention, including referral to another provider, if necessary. Parental authority must be honored. As emergent as the decision-making process can seem, it is usually carried out over a time-line from prenatal to intrapartum and neonatal time periods, allowing for gathering of the best information and education of both providers and parents. The final and acceptable resolution can only be orchestrated by careful discussions and complex decision-making between providers and families.

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