
Panel Discussion

End-of-Life Issues at the Beginning of Life

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Ethical Dilemmas in Decision Making at Limits of Neonatal Viability

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Abstract:

The survival rate for extremely preterm infants has improved over the last two decades. Although the incidence of such births is about 2%, the impact of preterm birth on these infants, their families, health-care providers, and society is profound. The birth of an extremely low birth weight (ELBW) and early gestational age infant poses complex medical,

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social, and ethical challenges to the family and health-care professionals. Survivors have an increased risk of chronic medical problems and disability. It is difficult to make decisions while trying to provide optimal medical care to the infant and supporting the family when delivery occurs at the threshold of viability because outcome at that time is highly unpredictable. Such decisions may have life-long consequences for those involved.

An individualized prognostic strategy appears to be the most appropriate approach. While keeping the patient's best interest as the primary objective, the goal is to reach, through a process of effective communication between the parents and physicians, a consensual decision that respects the parents' wishes and promotes physician beneficence.

Key words: ethics, viability, live birth, preterm birth, low-birth weight.

Viability has been defined as sustaining life outside the womb, with or without medical assistance. It is determined by gestational age, birth weight, and the condition at birth. The definition has been changing with advances in technology because at the present time, an increasing number of lower gestational age infants survive compared to the past. The gestational age at which at least half of the infants survive has decreased from 30 to 31 weeks in the 1960s to 23 to 24 weeks currently. Also, the age at the threshold of viability may vary in different countries depending upon availability of technological advances and other resources. This age can be 23-24 weeks in developed countries compared to 28 weeks or more in developing countries.¹⁻³

With the use of the internet for obtaining information, parents with gravely ill children have a greater opportunity to get involved in decision making and planning medical care. Technology has advanced much more rapidly in curing or at least palliating very premature ill infants than our ability to involve parents (and society) in ethical decision making. With the available endless possibilities it becomes very difficult to make the choice of whether to do nothing or to do everything for a critically ill infant, especially when the outcome is unpredictable. This sometimes leads to prolonged and painful suffering and expensive neonatal intensive care unit (NICU) hospitalizations.⁴

The basic principles of biomedical ethics should guide patient care in the delivery room and in the NICU.⁵ These principles include the following:

- **Autonomy:** Respect of individuals' rights of freedom and liberty to make choices that affect their lives.
- **Beneficence:** All actions should benefit the patient.
- **Nonmaleficence:** Do no harm.
- **Justice:** Treat people equally, truthfully, fairly, and as you would want to be treated.

Parties involved in decision making in the NICU include parents, family members, physicians, nurses, other health-care professionals (social workers and clergy), and the hospital ethics committee. Health care should reflect the neonate's best interests by maximizing benefits and minimizing harm to the infant in any proposed course of action or, in other

words, increasing the benefit-to-harm ratio. Society has an obligation to the patient to allocate resources equitably without discrimination because of disability. Because the neonate is unable to be involved in decisions that will influence him or her for the rest of their life, the principle of autonomy cannot be practiced in its real sense. Instead, surrogates of the patient make highly subjective decisions.⁶

Ethical Considerations

The decision that is considered to be in the best interest of the patient is based on the perception of the parents, medical staff, and others. No reliable markers of outcome for individual infants are available at the time of decision-making shortly before or at birth. We may be guided by data on average survival and risk of disability among survivors. The variable outcome of these infants can influence the perception of parents and health-care team members in different ways, leading to differences in opinion about futility of medical intervention, degree of pain and suffering involved in rendering such care, and the likelihood of survival free of serious disability.⁷

Crisis situation decision making in the delivery room can be difficult for both parents and physicians.⁸ Parents, as opposed to health-care professionals, usually want intervention to save the infant, irrespective of birth weight or condition at birth. Neonatologists are generally in agreement for initiation of resuscitation and intensive care at 24 weeks. Subsequent reevaluation and decision making regarding whether further treatment is futile is often required if there is no improvement in the neonate's condition or if actual deterioration occurs in the NICU. Should we resuscitate an infant with a gestational age of 24 to 26 weeks against parental wishes? Infants have legal rights, and if an infant is resuscitated against parental wishes and subsequently survived with multiorgan damage, the parents would have to bear the consequences for the rest of the child's life. Therefore, is it fair not to comply with their wishes?

A common question that may be difficult to answer is: What should physicians do if the parents' wishes differ from accepted medical care practices? Some parents want full support; others want no resuscitation in situations when their wishes may be different from the accepted standard of care. There

have been examples in the past when an extremely premature infant was resuscitated against parents' wishes and survived and suffered severe neurodevelopmental abnormalities. While the physician was not able to predict the outcome at the time of making that decision and acted in accordance with the state law, the parents had to bear the consequences of having a handicapped child, a responsibility they were afraid of, and thereby did not consent to the medical care.⁹⁻¹²

It may be challenging to define "good or bad and acceptable and unacceptable" outcomes while assigning due importance, both to sanctity of life and quality of life. An extremely premature neonate may suffer several of the following conditions that may be considered as acceptable by some and unacceptable by others. Some of the conditions are mental retardation (mild, moderate, severe), cerebral palsy (nonambulatory, partly ambulatory), vision or hearing loss, home ventilation, later psychiatric disorders, behavioral disorders, learning disabilities, and the need for special education, etc.

When a definite risk of such an outcome is identified while an infant is still on a high degree of medical support, a question may arise as to whether it is proper to withdraw the support or further withhold aggressive treatment. Withholding any escalation of care may prevent parental and physician anxiety and infant pain and suffering, or it might create a feeling of guilt in their mind. More often parents may disagree with the physician's recommendations for withdrawal or withholding of treatment. This action requires continuous reevaluation and confirmation of the clinical findings associated with parental partnership in discussions and decision-making. Parents should be provided with the information about the chances of the infant's survival and outcome, as published in medical literature and evidenced by local hospital statistics.¹³

Generally, physicians seek help from established guidelines and policies in situations where it is otherwise unclear to make a decision. The confusion begins with whether an infant is considered viable, and as a result of that qualification, should receive resuscitation and appropriate intensive medical care. World Health Organization (WHO) defines live birth as "the complete expulsion or extraction from the mother of a product of conception that shows signs of beating heart, breathing movements, pulsa-

tion of the umbilical cord, and movements of voluntarily muscles." Each product of such a birth is considered a live born irrespective of the duration of pregnancy.¹⁴

Because there is no universally accepted definition of viability, several health-care organizations have tried to establish guidelines for the initiation of resuscitation at extremes of gestational age and birth weight. According to the February 2000 American Academy of Pediatrics (AAP) and American Heart Association (AHA) guidelines for resuscitation, noninitiation of resuscitation in the delivery room is appropriate for conditions such as confirmed gestation of fewer than 23 weeks or a birth weight less than 400 grams and a confirmed gestation of 23-24 weeks with assessment of either the infant's condition or parental choice or both. However, they caution about predetermining resuscitation efforts before the baby is born, based on estimated gestational age or birth weight. The International Liaison Committee on Resuscitation (ILCOR) recommends performance of cardiopulmonary resuscitation (CPR) on all infants with a gestational age of 25-26 weeks in absence of major congenital anomalies and possible CPR on infants 23-24 weeks upon parental request. Both AAP (2008) and ILCOR recommend palliative care in infants fewer than 23 weeks. Guidelines from other professional societies in Canada, the United Kingdom, and the Netherlands also place infants from 23-25 weeks in a gray zone where the decision to resuscitate and administer aggressive treatment is left to the individual physician's judgment and parents' wishes.¹⁵ For infants born between 23 weeks and 24 weeks, 6 days gestation and with a birth weight of 500 to 599 grams, survival and outcome are extremely uncertain. This significant degree of uncertainty about outcome could influence the parents as well as the infant for the rest of their lives and should be considered before initiation of resuscitation and continuation of subsequent care.¹⁶ Giving the parents the right to make treatment decisions in collaboration with the health-care team when reasonable medical options exist, including discontinuing support, is consistent with basic legal principles and good medical practice. The family, in collaboration with the health-care team, should make decisions that are in the patient's best interest. Every decision should be made thoughtfully with the best possible informa-

tion provided to parents regarding survival and follow-up statistics for the specific NICU as well as nationwide data. Decisions should be reviewed to ensure adherence to the basic ethical principles of non-maleficence, autonomy, beneficence, and justice and equity. The health-care team should demonstrate compassion, humility, courage, honesty, sensitivity and commitment, and not abandonment. The parents should be assured that the team will abide by their wishes (within reason) and will avoid desperate heroics and callous disregard. When consensus cannot be reached on a treatment plan in the NICU, the medical team should allow time for further clinical observation, ensure that parents fully understand medical information, continue to discuss and explore reasons for differences in choice, and further address their moral, ethical, cultural, and spiritual concerns. While a continued effort is made to achieve a consensus, the medical team may seek opinions from colleagues and other consultants and should involve their hospital's bioethics committee.^{17,18} The decisions of benefits and harm often lie with parents, physicians, and nurses, whose perceptions are influenced by personal values and experience. However, parents are legally and morally responsible for making health-care decisions on behalf of their fetus or infant.^{11,19}

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