



FROM BIRTH TO DEATH AND BENCH TO CLINIC

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CHAPTER 26

Neonatal Care

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neonatal care

by Alan R. Fleischman

Framing the Issue

Approximately 520,000 babies (12.7%) are born prematurely (before 37 weeks gestation) in the United States each year. A report from the Institute of Medicine published in 2007 estimates that in-hospital charges for preterm infants account for \$18.1 billion dollars in health care costs, half of the the total costs for newborn care in the United States. Dramatic changes in the care of critically ill newborn infants over the last three decades have resulted in the ability to save the lives of the majority of even the sickest and smallest neonates (newborns in the first month of life). Newborns as young as 23 to 25 weeks of gestational age—at the threshold of viability—and weighing 500-600 grams (between about one pound, two ounces, and one pound, five ounces) survive at a rate of close to 50% in most neonatal centers. Yet such infants are at great risk for poor outcomes including cerebral palsy, hydrocephalus, neurodevelopmental delay, and hearing and vision problems. Predicting outcomes in the first days of life is difficult in most circumstances and creates the fundamental dilemma of deciding treatment options in the face of not knowing the future quality of the infant's life.

Doctors and parents are sometimes criticized for aggressively treating these infants or, conversely, allowing them to die. Care for critically ill neonates can be justified based on the increasing survival with good outcomes for some, if not all, of these very tiny patients. But who ought to be permitted to make these choices and determine whether treatment should be provided, withheld, or withdrawn? What constitutes the “best interest” of the infant, and what process for decision-making should be utilized in these hard cases?

History of Decisions in Neonatal Care

Awareness of ethical dilemmas or value conflicts over very premature infants is not new to those responsible for their care. Clinicians first brought this issue to public attention in 1973. Historically, physicians had felt obligated to make treatment decisions based on their personal beliefs about the future quality of life of their smallest patients. At times, professionals shared this decision-making with the family, but often it was thought to be part of the job of the health care provider to make such choices. These decisions were usually made within the privacy of the delivery room, nursery, or pediatric unit. There was little open discussion or even awareness by members of society that value-

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HIGHLIGHTS

- Advances in the care of critically ill newborns over the last 30 years have resulted in the ability to save the lives of the majority of even the sickest and smallest newborns—as young as 23 to 25 weeks of gestational age.
- These tiny infants are at great risk of poor outcomes, but predicting these outcomes is very difficult in the early days of life.
- Ethical dilemmas arise over what is in the best interest of a critically ill newborn when the odds for any particular child are unclear.
- Physicians and parents can disagree over what is in the best interests of a child, and who should have the authority to make that decision is debated.
- The withholding and withdrawing of medical treatment from neonates is a complex process that includes deliberations of parents and clinicians and falls under the jurisdiction of each state's laws concerning child protection.

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EXPERTS TO CONTACT

laden ethical decisions were being made and rationalized as medical judgments. To a large extent, families and society wished these decisions to be private matters because they were considered far too complex and personal for public involvement and debate.

However, coinciding with the evolution of new technology for neonatal intensive care, physicians have recognized a new role as collaborators who provide recommendations for health care decisions that are made jointly by the family and physician, rather than solely by the doctor. In competent adults, respect for a person's fundamental right of self-determination, or autonomy, has resulted in the practice of allowing adults to make health care decisions for themselves, even if the physician disagrees and—more importantly—even if the physician perceives that the decision is not in the adult's best interest. For example, an adult may refuse antibiotics for pneumonia or effective chemotherapy treatments for cancer. The process of such decision-making when it relates to children (or to any individuals who lack the capacity to decide for themselves) invokes the use of a proxy or surrogate. Proxy consent is not based on a patient's choice, but rather on another's perception of the appropriate choice.

Many have argued that the respect for a person's fundamental right of self-determination should be extended to respect for the family as an autonomous unit that makes substituted judgments for members who cannot participate in decision-making. This extension of the principle of respect for persons may occasionally be problematic when applied to neonates, however. Respect for autonomous choices of adults is extremely powerful in that it allows capable adults to refuse treatments despite negative consequences. However, parents' refusals for their infants of treatments deemed beneficial by health care providers do not hold the same weight as competent adults' refusals of treatments for themselves, or as proxy decisions made for other adults if the proxy uses the known wishes of the patient. Parental refusal of a life-sustaining therapy does not relieve the physician from an ethical duty to the child, particularly if the refusal of such treatment puts the child at significant risk.

To preserve the child's future right to autonomous decision-making, the principle known as the "best interest of the child" has supplanted the "respect for persons" principle in regard to deci-

WITHHOLDING TREATMENT IN INFANTS: WHAT THE LAW SAYS

The amendment to the federal child abuse law and subsequent regulations applying to neonatal treatment states,

A new definition of withholding of medically indicated treatment is added . . . to mean the failure to respond to an infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician's reasonable medical judgment will be most likely to be effective in ameliorating or correcting all such conditions. Exceptions to the requirement to provide treatment may be made only in cases in which one of the following applies:

- (i) The infant is irreversibly comatose.
- (ii) The provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant's life-threatening conditions or otherwise be futile in terms of the survival of the infant.
- (iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

These regulations do not mandate unnecessary or inappropriate treatments. They allow physicians to use reasonable medical judgment in making treatment recommendations and to involve parents in the decision-making process. The regulations give responsibility for protecting neonates with potentially handicapping conditions to the individual states; federal involvement is severely limited. While protecting the rights and interest of infants irrespective of underlying condition or potential handicap, the regulations also validate the importance of quality-of-life determinations in the provision of care.

sion-making for infants. This principle supports making a decision solely for the benefit of the infant—sometimes, although rarely, even in conflict with parental beliefs. Determinations of best interest often are made in the presence of massive medical uncertainty as to the outcome of the proposed treatment. Physicians in general have a great deal of difficulty in admitting their lack of certainty as to the benefits of continued treatment or new interventions. Jeff Lyon, in his book *Playing God in the Nursery*, graphically portrays the dilemma of uncertainty: "If it is hard to justify creating blind paraplegics to obtain a number of healthy survivors, it is equally hard to explain to the ghosts of the potentially healthy that they had to die in order to avoid creating blind paraplegics."

The Law and Neonatal Care

In response to growing interest in these difficult decisions, in 1984–1985, the U.S. Congress amended the federal child abuse law specifically to make each state's child protection agency responsible for overseeing the withholding and withdrawing of medically indicated treatments from neonates. The law details the physician's responsibility to use reasonable medical judgement to make recommendations for care of critically ill neonates. Furthermore, the federal regulations strongly urge the formation of infant care review committees (which the American Academy of Pediatrics calls infant bioethics committees) to facilitate decision review and to assist in the interaction among physicians, the family, the hospital, and the state (see box, "Withholding Treatment in Infants: What the Law Says").

Ethical Considerations

Physicians and parents caring for neonates at the threshold of viability in delivery rooms and neonatal intensive care units each have obligations to advocate for the best interest of the infant based on the principle of beneficence—the obligation to

maximize benefits and avoid harms. However, what constitutes the best interest of such critically ill neonates is most often uncertain. American neonatologists tend to deal with this uncertainty by considering it far worse to let an infant die who could have lived a life of reasonable quality than to save an infant who becomes devastatingly disabled. They argue that parents' decisions are not child-centered, but take into account the effect of the choice on their marriage and their other children, as well as financial considerations, emotional concerns, and their views on the value of life with a disability or cognitive impairment.

However, some (including the author) have argued that those who will bear the burden of the decision—namely, the family—ought to have the major role in making it. Parents are given broad authority in our society to make virtually all decisions for their children regarding nutrition, clothing, housing, education, religion, and medical care. Society's deference to parental choice promotes the value of family integrity, ensures the availability of an identifiable decision-maker, and acknowledges the legitimate role parents play in shaping their children's futures. Parents search for meaning in the life crisis they face with the birth of an extremely premature infant and seek mastery and

RESOURCES

Web sites

- www.marchofdimes.com -- March of Dimes. Professionals and Researchers section includes fact sheets, statistics, medical references, publications, and links.
- www.aap.org – American Academy of Pediatrics. Neonatal care page includes general resources, policy guidelines, and publications.
- www.nuffieldbioethics.org – Nuffield Council on Bioethics. Publications page includes the full report, "Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues," available for PDF download.

Recent news

- Nicholas Bakalar, "Prematurity May Lead to Adult Problems," *New York Times*, September 15, 2008.
- Saquib Rahim, "Multiple Births Raise Ethical, Medical Issues," *Washington Post*, August 19, 2007.
- Aida Edemariam, "Against All Odds," *Guardian*, February 21, 2007.
- Jacqueline M. Duda, "Early Arrivals: A Growing Problem," *Washington Post*, February 6, 2007.

- Hilary Waldman, "When Doctors Deliver Anguish: With Tiniest Premies, A Huge Ethical Issue," *Hartford Courant*, November 19, 2006.

Further reading

- Eric C. Eichenwald and Ann R. Stark, "Management and Outcomes of Very Low Birth Weight," *New England Journal of Medicine*, April 17, 2008.
- Hilde Lindemann and Marian Verkerk, "Ending the Life of a Newborn: The Groningen Protocol," *Hastings Center Report*, January-February 2008.
- John A. Robertson, "Extreme Prematurity and Parental Rights after *Baby Doe*," *Hastings Center Report*, July-August 2004.
- Tracy K. Koogler, Benjamin S. Wilfond, and Lainie Friedman Ross, "Lethal Language, Lethal Decisions," *Hastings Center Report*, March-April 2003.
- Alan R. Fleischman et al., "Caring for Gravely Ill Children," *Pediatrics*, October 1994.
- Jeff Lyon, *Playing God in the Nursery*, Norton, 1985.
- American Academy of Pediatrics, "Guidelines for Infant Bioethics Committees," *Pediatrics*, August 1984.

control over the experience. They desire respect and consideration of their views and values. In the face of uncertainty about the best interest of an individual child, society generally defers to parental decision-making, which values the intimate role parents play in the lives of children. However, parents' authority to control their children's lives is not absolute. Society recognizes that children may have interests independent of their families and limits to parental authority may be justified when necessary to protect the child's well-being.

Difficult Choices

In the final analysis, these are very difficult choices. When faced with a lack of certainty as to

what is in an infant's best interest, the physician's obligation is to share with the family a clear understanding of the various treatment options and make a recommendation consistent with what the treatment team believes is in the child's best interest. Decisions should be collaborative, with the child's interest at the center of the analysis but with parents responsible for the choice unless they are making a decision clearly against the best interest of the child. The physician's values should not be imposed inappropriately, and continued treatment should not be forced when hope for benefit is uncertain. Prolonging an infant's life should not be viewed as an end in itself, but should be weighed against the probable quality of the future of that life. 🌳