

Ethical Issues in Newborn Care

ANITA CATLIN, DNSc, FNP, FAAN • Section Editor

Benevolent Injustice

A Neonatal Dilemma

Brenda Barnum, BSN, RN

ABSTRACT

There is a little-recognized cohort of NICU patients whose outcomes are the result of a “benevolent injustice” in their healthcare course. Many of these infants are saved by technology; however, they are left both medically fragile and medically dependent, and many of them are required to live in a medical facility. Many of these babies never get to go home with their parents. This emerging cohort of patients may evolve from the difficult ability to prognosticate outcomes for neonates, overtreatment, and acquiescing to parental demands for continued aggressive care. Neonatology is an unpredictable process and one that is never intended to harm, but carries with it the potential of devastating consequences, thus creating a benevolent injustice.

KEY WORDS: benevolent, injustice, neonates, overtreatment, prognostication

“Babies are sweet, unselfconscious, and captivating. Like springtime, they represent hope and a fresh beginning.”^{1(pXI)} Newborn babies and children are among the most vulnerable, protected, and cherished members of our society. They represent the future, vitality, and limitless potential. When a baby is faced with a serious illness—or even death—many believe that there is no question that the life must be saved at all costs. This is especially true in American society, where there is a “belief in a form of vitalism: the idea that a long and healthy life is especially desirable and that each individual is morally entitled to live as long as possible and to be as healthy as possible.”^{2(p1442)} One way to reinforce this value is through healthcare. Neonatal medicine aims to reduce the mortality of infants. In the neonatal intensive care unit (NICU), babies receive high-quality healthcare that in many cases saves lives. Even compared with only a decade ago, fewer and fewer infants are dying.³

As medicine has improved, there have been unintended consequences. “With advanced technology, such as assisted mechanical ventilation, it is now possible to keep some terminally or severely ill or extremely preterm infants alive for prolonged periods of time. The result of such treatment is that dying may be prolonged or the infant may survive with profound

neurologic or other debilitating problems.”^{4(p401)} This type of treatment has created a unique cohort of NICU patients who survive but are medically fragile and technologically dependent. They have extremely long lengths of stay in the NICU, and because they are too fragile to be discharged home, they are transferred to the pediatric ICU (PICU) or to long-term, subacute care facilities, often requiring multiple readmissions to the hospital over their lifetimes.⁵ Many of these babies never get to go home with their parents.

The medical and technological advances made in the NICU have caused some concern. Ethical and moral debates about overtreatment; the threshold of viability, futility, and initiation versus withdrawal of care; best interests of the child; parental rights; and justice are often debated both in the clinical setting and in the literature. “Over time, neonatal intensive care has confronted, clashed with, and in some ways rearranged our consciousness. By developing ways to save the lives of a whole population of babies who once were thought too small to survive, it has changed the way we think about what babies demand of us as a society and about what we owe to them.”^{6(p235)} This article will examine a little-recognized cohort of NICU patients whose outcomes are the result of a “benevolent injustice” in their healthcare course. Many of these infants are saved by technology; however, they are left both medically fragile and medically dependent, and many of them are required to live in a medical facility.

WHAT IS BENEVOLENCE?

In the classic biomedical ethics text, *Principles of Biomedical Ethics*, Beauchamp and Childress define *benevolence* as “the character trait or virtue of being

Address correspondence to Brenda Barnum, BSN, RN, Childrens Hospital Los Angeles, 4650 Sunset Blvd, Los Angeles, CA 90027; barnumbrenda@hotmail.com

Author Affiliation: Loyola University of Chicago, Illinois; and Childrens Hospital Los Angeles, California.

Copyright © 2009 by the National Association of Neonatal Nurses.

disposed to act for the benefit of others.”^{7(p166)} They go on to explain that “promoting the welfare of patients—not merely avoiding harm—expresses medicine’s goal, rationale, and justification.”^{7(p173)} For example, physicians and healthcare workers are benevolent professionals.

WHAT IS JUSTICE?

Justice, as defined by John Rawls, is an equal share or equal opportunity to all. For neonates, this means that all newborns are given access to the NICU. Ethicist Norman Daniels⁸ modifies the classic theory of justice developed by Rawls for the healthcare setting. Daniels maintains that “the central function of health care is to maintain normal functioning. Disease and disability, by impairing normal functioning, restrict the range of opportunities open to individuals. Health care thus makes a distinct but limited contribution to the protection of equality of opportunity.”⁸ These opportunities include, but are not limited to, personal interaction, relationships, jobs, being a participating citizen in society, and even the capacity to think.^{8(p6)} In terms of justice, if it is healthcare’s central aim to maintain normal functioning, or to attempt to restore normal functioning, then, it can be deduced that failure to maintain or restore normal functioning brings harm to the patient—an act of injustice. Because of the fact that many neonates are born prematurely or with congenital anomalies, they have an increased need or claim on the function of healthcare to attempt to restore or optimize functioning. In the benevolent attempts to rescue and save the lives of many neonates, both extremely low birth-weight preterm infants as well as term infants with severe anomalies or diseases, medicine can unintentionally manufacture disabilities in attempts to prevent them. This attempt at justice that causes harm, then, becomes injustice. *Merriam-Webster’s Dictionary* defines *injustice* as “any act that involves unfairness to another or violation of one’s rights.”⁹ A benevolent injustice is teleological in nature in that it is concerned with the outcomes and consequences of these neonates’ healthcare courses. The neonates of interest are those who have a right to healthcare; yet that very healthcare upon delivery may also have negative consequences. Merging Daniels’s theory of justice and healthcare with the definitions of benevolence and injustice formulates the foundation of this healthcare phenomenon—benevolent injustice.

WHAT IS A “BENEVOLENT INJUSTICE?”

A benevolent injustice occurs when the well-intentioned treatment efforts of a physician or a medical team produce an outcome that limits the potential of a patient or renders them technologically dependent.

“In neonatology, as in the rest of medicine, we use many treatments whose efficacy has not been established in clinical trials. Some of these therapies may be useless and others may actually be harmful.”^{10(p1076)} Many of these neonates are left with subsequent morbidities and disabilities that are a direct result of medical treatment. Thus, a paradox arises—attempts to save the neonate’s life, correct malformations, or restore health can initiate new health problems, increase morbidities, or cause further harm to the health of the patient.

CASE STUDY OF BENEVOLENT INJUSTICE

The following case study is an example of a preterm neonate with multiple congenital anomalies who survived with profound debilitating and neurologic issues.

Baby V was born at 36 weeks’ gestation to an 18-year-old mother who received little prenatal care and a 39-year-old father. Baby V was born with a severe cloacal anomaly that consisted of an omphalocele, bladder exstrophy, urethral exstrophy, gonad exstrophy, imperforated anus, and severe bilateral hip dysplasia. There were no obvious external sex organs. Baby V was breathing on its own and would only desaturate during examination, likely due to pain. The parents wanted everything done for Baby V. On day of life 1, Baby V was intubated and placed on a mechanical ventilator for pain management and to undergo major corrective surgery for the defects. By examination, surgeons felt Baby V was male, and this was later confirmed by the test for chromosomes. Because of the extreme deformities, the surgeons and family felt it would be easier to assign Baby V the gender of female although she was chromosomally male.

Over the course of the next year, in the NICU, Baby V underwent multiple bowel surgeries, central line placements, and diagnostic tests and procedures. She suffered from chronic lung disease because of prolonged intubation and never successfully extubated. She received a tracheostomy for long-term airway security and remained dependent on a ventilator. She was total parental nutrition dependent for over 8 months and eventually underwent a gastrostomy tube placement for long-term feedings. She suffered multiple bouts of fungal and bacterial sepsis, central line infections, respiratory tract infections, and skin breakdown from multiple stoma sites and vesicostomy. During 2 separate, severe, and acute episodes of sepsis, she was placed on high-frequency ventilation, suffered prolonged periods of hypoxia, and was placed on high doses of inotropic drugs to support her blood pressure. Both times, the physicians asked for her to be made a Do Not Resuscitate, but the mother refused—the parents continued to want everything done.

Baby V had multiple surgical complications, including feeding intolerance. She suffered from

seizures. She was extremely developmentally delayed and minimally interacted with her parents or staff. She continued to survive despite her many setbacks, and she celebrated her first birthday in the NICU. She was, eventually, weaned to a home ventilator, but because of her fragile medical state, she was not able to be cared for at home by her mother, who was trying to finish high school and earn her General Education Development Test. The parents started having relationship difficulties, and both parents began to visit Baby V less and less. At approximately 18 months of age, Baby V was transferred to the PICU. Her NICU length of stay was more than 540 days. After approximately 6 weeks in the PICU, she was transferred to a long-term, subacute care facility where she was managed on her home ventilator. She never exceeded the mental capacity of a 2-year-old. She was deaf from the high doses of ototoxic drugs she received in her lifetime. She never walked, never talked, never ate by mouth, and required 24-hour subacute care. Baby V was readmitted to the hospital 3 to 5 times per year for the next 9 years. She ultimately died during a readmission to the PICU from a severe respiratory tract infection at the age of 10 years.

THE BENEVOLENT INJUSTICE COHORT

“Because of neonatal intensive care, lives of infants are saved and parents are given children who would not have previously survived. But rarely has the underside of this success been examined, specifically when technology is used to save marginally viable infants who are left with severe residual morbidities.”^{11(p269)} There has been little research in the literature addressing this cohort of neonates with extremely long hospitalizations and comorbidities, many of whom are never discharged home; instead, like Baby V, they end up “living on the unit.”^{5(p742)} There were only 2 published reports found in the literature regarding this special cohort of patients.

Catlin^{5,11} reports (from the National Healthcare Cost and Utilization Project-Kid’s Inpatient Discharge Data stratified, random sample population of pediatric discharges) that there were “680 newborns during the year 2003 who were reported to be hospitalized for greater than 179 days. Of the 680 children, 44% were discharge to home normally, 27% went home with home health nursing care, 13% were transferred to long-term care facilities, and 16% died in the hospital.”^{5(p743)} Out of this sampling, 29% of the patients, or roughly 200 babies, were either sent to subacute, long-term care facilities or died. Catlin also created a research survey tool for healthcare respondents in the same sample year of 2003, termed LONGTERM.⁵ In this survey, the data outcomes were even more staggering. Out of “422 infants hospitalized for greater than 179 days, 32% were

discharged to home normally, 25% were still hospitalized in the NICU or PICU, 13% were transferred to long-term care facilities, and 30% of described infants died in the hospital.”^{5(p743)} Out of this sampling, 68% or roughly 331 babies remained hospitalized, were sent to subacute, long-term care facilities, or died. These numbers may seem statistically insignificant considering that nearly 4 million babies were born in 2003, but to the lives of these children, their families, and the medical staff that cared for them, these numbers are drastically high and underrepresented.⁵

Smith and Uphoff¹² poignantly describe the cases of 2 neonates who would fall into the benevolent injustice cohort. Both had extremely long lengths of stay and, throughout their healthcare course, remained both acutely and chronically ill. They go on to discuss that not only does this cohort of patients exist, but the wake left by their prolonged hospitalizations is large. There are many complex issues that surround these patients and their ultimate outcomes. There are social, familial, financial, parental employment, sibling, caregiver fatigue and moral distress, lack of community support, and marriage issues—none of which are easily resolved. Ultimately, there are more questions than answers when providing care for this special cohort of infants.

RECURRENT THEMES IN THE LITERATURE

There are 3 recurrent themes that emerge in the literature as to how this cohort of NICU patients evolves: poor prognostication, overtreatment, and acquiescing to parental demands for continued aggressive care.

Poor Prognostication

Despite our epidemiological advances in the field of neonatal medicine, prognostication continues to prove problematic in the neonatal community. “Because birth weight is so powerfully correlated with outcome, many proposals for deciding when to start or stop treatment have focused on this easily obtainable prognostic measurement.”^{13(p640)} However, Meadow et al¹³ determined that after the most critical period of the first 72 hours of life, the odds or chances of survival to discharge between extremely low birth-weight preterm infants 600 g or less and low birth-weight infants greater than or equal to 1 kg equalize. “The prognostic accuracy of birth weight as a predictor of survival disappears by 4 days of age. Prognosticating neurodevelopmental outcome, disability, and lifetime cost for survivors remains difficult.”^{13(p643)} In a separate study, Meadow et al¹⁴ discovered that many infants who ultimately die but initially pass the critical 72-hour period actually have transient periods of improvement. Because of the fact that these infants are not sick their entire

lives, these infants are said to “cloak themselves,” hiding their ultimate outcomes with every day that they survive and making prognostications of their potential survival or outcomes increasingly difficult. The ultimate reality in an inexact science such as medicine is that there are limitations to prognostication, which can make decision making for clinicians and parents very difficult.

Overtreatment and Acquiescing to Parents' Demands for Treatment

“The dramatic increase of technical power in neonatal medicine has made possible an unprecedented form of extremism.”^{15(p973)} This extremism is often seen in the form of overtreatment. The physician's overwhelming obligations to save and prolong life can at times cloud all sensibilities. Overtreatment tends to go hand in hand with physicians acquiescing to parents' demands.

The societal and legally supported opinion is that parents should be able to make decisions for their children because they follow a “best interest” standard. “However, what is in the best interest of the child is often debatable. There are times when good families and good physicians disagree about the appropriateness of continuing or stopping life-sustaining treatments.”^{16(p1219)} It is the nature of parenting to hope endlessly for a child, to never give up, and to do everything possible to save that child's life. “Many of us have witnessed parents demanding continuation of futile aggressive care that may be painful and induces suffering to the newborn with a life-threatening condition for reasons not part of infant-centered, best-interest considerations.”^{17(p475)} Even in the face of potentially life-altering morbidities to the patients, the parents will continue to choose aggressive treatment. These reasons include denial, overwhelming grief, religious beliefs, a sense of failure, the hope for a miracle, the inability to let their baby go, or the fear of how the loss of the baby will change their marriage or family life.¹⁸ Whatever the reasons, overly demanding parents place neonatologists in precarious positions when they feel they must continue to provide aggressive care that they may deem futile or no longer of benefit to a critically ill newborn. For fear of litigation, many neonatologists will acquiesce to these parental demands or refusals.

CONCLUSION

“It has been said that we practice medicine in an age of miracles and wonders. This is easy to see in the world of the NICU. Yet, despite the many successes, there are also failures, and contemporary neonatology may be either a blessing or a curse.”^{16(p1219)} It is clear that an entire cohort of patients, much like Baby V, who remain both acutely and chronically

ill, with prolonged hospitalizations and comorbidities, are an increasing reality in the NICU. “The old saw that our technology has outrun our ethics has never been more true than in the case of the imperiled newborns.”^{1(pIX)}

Physicians have a code of ethics that makes responsibility to their patients as paramount. This responsibility is considerably complex when considering the fate of a neonate. The reality of the NICU is that the same technology that is used to save a neonate's life may also be the cause of severe comorbidities and life-altering, adverse side effects. Neonatologists and parents are attempting to benevolently make decisions in neonates' best interests, which, unfortunately, can be quite difficult when predicting the potential outcomes. Whether by poor prognostication or by overtreating neonates to acquiesce to parental demands, these actions carry with them the potential consequence of violating the neonate's rights to a range of opportunities. Neonates should have the right or opportunity to interact and to be in relationship with their parents, and these are opportunities that should be protected rather than violated by health-care. If their conditions are life-limiting or death is near, they should be allowed to die with dignity in a loving and symptom-free manner. Much like Baby V, many neonates are left neurologically impaired and developmentally delayed where it may never be possible to interact in a meaningful way. The story of Baby V is tragic, one that leaves the feeling that a great injustice has been done. Neonatology is an unpredictable process and one that is never intended to harm, but carries with it the potential of devastating consequences, thus creating a benevolent injustice.

References

1. Guyer RL. *Baby at Risk: The Uncertain Legacies of Medical Miracles for Babies, Families, and Society*. Sterling, VA: Capital Books; 2006:11.
2. Mariner WK. Rationing health care and the need for credible scarcity: why Americans can't say no. *Am J Public Health*. 1995;85(10):1439-1445.
3. Meadow W, Lee G, Lin K, Lantos J. Changes in mortality for the extremely low birth weight infant in the 1990s: implications for treatment decisions and resource use. *Pediatrics*. 2004;113:1223-1229.
4. American Academy of Pediatrics Committee on Fetus and the Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics*. 2007;119(2):401-403.
5. Catlin A. Extremely long hospitalization of newborns in the United States: data, descriptions, dilemmas. *J Perinatol*. 2006;26:742-748.
6. Lantos JD. Hooked on neonatology. *Health Aff*. 2001;20(5):233-240.
7. Beauchamp T, Childress J. *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press; 2001:166-173.
8. Daniels N. Justice, health, and health care. In: Rhodes R, Battin M, Silvers S, eds. *Medicine and Social Justice: Essays on the Distribution of Health Care*. New York: Oxford University Press; 2002:6-23.
9. Merriam-Webster Online Dictionary. Injustice. <http://www.merriam-webster.com/dictionary/injustice>. Accessed December 14, 2008.
10. Zupancic JAF. Dangerous economics: resource allocation in the NICU. *Can Med Assoc J*. 1992;146(6):1073-1076.
11. Catlin AJ. Physicians' neonatal resuscitation of extremely low-birth-weight preterm infants. *Image J Nurs Sch*. 1999;31:269-275.
12. Smith K, Uphoff ME. Charting uncharted terrain: problems born in the NICU grow up in the PICU. *J Clin Ethics*. 2001;12:231-238.

13. Meadow W, Reimshisel T, Lantos J. Birth weight specific mortality for extremely low birth weight infants vanishes by four days of life: epidemiology and ethics in the neonatal intensive care unit. *Pediatrics*. 1996;97:636-643.
14. Meadow W, Frain L, Ren Y, Lee G, Soneji S, Lantos J. Serial assessment of mortality in the neonatal intensive care unit by algorithm and intuition: certainty, uncertainty, and informed consent. *Pediatrics*. 2002;109:878-886.
15. Sliverman WA. Overtreatment of neonates? A personal retrospective. *Pediatrics*. 1992;90:971-976.
16. Fine RL, Whitfield J, Carr B, Mayo T. Medical futility in the neonatal intensive care unit: hope for a resolution. *Pediatrics*. 2005;116:1219-1222.
17. Peabody JL, Martin GI. From how small is too small to how much is too much: ethical issues at the limits of neonatal viability. *Clin Perinatol*. 1996;23:473-487.
18. Paris JJ, Singh J, Schreiber M, Reardon F. Unilateral do-not-resuscitate order in the neonatal intensive care unit. *J Perinatol*. 1999;19:383-387.