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THE MORAL STATUS OF THE NEWBORN AND ITS IMPLICATIONS FOR MEDICAL DECISION MAKING

INTRODUCTION

The decision to edit a journal issue on newborns and to ask the question, “Are newborns morally different than other children?” came from two personal experiences. My colleague and friend, Bill Meadow, a neonatologist, claims that he has done hundreds of straw polls around the world that shows that we treat newborns differently than older children. His question is a modification of Sophie’s Choice.¹ You have 2 children; one is 6 hours old and one is 6 years old. One has to die. Which child do you choose? Now the first answer that most people give is that they do not want to choose. But when forced (cajoled?), the vast majority of the audience allows the six hour infant to die. Why? Bill thinks it is because we think of neonates differently than we think of all other children. I can only hypothesize that people respond in this way because the 6 year old has a lived biography that is intertwined with its parents, and parents cannot envision (or refuse to imagine) life without their child. The newborn has had a shorter relationship with them. This is not to say that the newborn can be replaced by another, nor that the child will not be mourned.

Annie Janvier, a neonatologist from McGill University in Montreal tried to capture this in a more systematic way. She presented two papers at a bioethics panel at the Society of Pediatric Research in May 2006 at which Bill Meadow and I were the moderators.² She and colleagues compared the attitudes of students in medicine, law, and anthropology regarding active treatment of eight hypothetical patients needing intubation and intensive care at the same time. She found that the students would prioritize a healthy two month old infant with bacterial meningitis over all the others, but the premature infant was placed seventh, only before the hypothetical demented 80 year old with a stroke even though the expected outcomes for the

premature infant was as good if not better than many of the other hypothetical patients. There are other studies in the literature that confirm this de-valuation of the very young (as well as the elderly).³ This special issue of *Theoretical Medicine and Bioethics* includes seven articles from colleagues from the U.S. and Canada who were asked to consider whether there are morally relevant features of newborns, particularly premature newborns, that distinguish them from other children; and if so, whether these features permit or require a unique ethical analysis. All were then invited to write a manuscript on a current issue in neonatal ethics. The focus of these manuscripts can be divided into three topics: 1) Best Interest standard, 2) parental decision-making, and 3) care at the end of life.

The first topic focuses on the Best Interest standard. Although informed consent is often viewed as the cornerstone of medical ethics whereby a competent adult must be informed of his or her options and then make a decision that best reflects his own values and needs, the neonate has neither decision making capacity nor has the neonate expressed any interests. For neonates, like others who lack decision making, surrogate decision-making is required. While surrogates for adults are often instructed to use the principle of “substituted judgment”—that is, to act as the patient would have acted if he were still competent”—neonates have never been competent and have no prior expressed interest. For neonates and for adults who have never been competent, then, the best interest standard is the traditional guidance principle.

The first article is by Micah Hester, a philosopher at the University of Arkansas for Medical Sciences. He examines what it means to employ a Best Interest determination for newborns. Since the patient is not able to express interests, “these Best Interests must be imported from sources other than the individual patient.” He notes that the scope of interest-sources has focused on two sources of interests: avoiding harm and parents. He argues for a more robust consideration of the many interests at play.

Loretta Kopelman has written numerous articles on the best interest standard.⁴ In this issue, she and Arthur Kopelman describe a case of a 26 week premature infant born to parents who are graduate students from India who argue for treatment withdrawal after 1 week despite a 70% chance of survival with a 2/3 chance of at most mild to moderate problems. Their request is based on their understanding of what is in their child’s best interest. The parents explained that he would not be able to receive many of the treatments necessary to

maximize his outcome and that any obvious disability would leave him a subject of scorn and ridicule and would bring shame upon the parents and relatives as disabilities are viewed as punishment for the family's sins. Thus, they stated that "maximal treatment was not in their son's best interest, not in the family's best interest, and that it was unfair to use the host country's outcome data and traditions to decide what treatment was appropriate." The Kopelmans analyze this case with the Best Interest standard as a practical guide using three necessary and jointly sufficient features: 1) decision makers should assess the newborn's immediate and long term interests; 2) decision makers must make choices that meet a minimum threshold of acceptable care; and 3) decision makers should make choices compatible with moral and legal duties to other incompetent individuals. Although the Kopelmans are willing to hold the first condition as ambiguous in this case, they argue that the second and third condition decisively show that treatment is in this child's best interest. Treatment, therefore, is continued over parental objections. While clinicians should seek to accommodate other cultural values and preferences, accommodation must be balanced by our policies and practices that support the rights and welfare of children and other incompetent persons.

But that is not the end of the case study. We then learn that the outcome is not what was statistically expected. Despite maximal treatment, the child's condition worsened. At that point, the health care team agreed that comfort care was morally appropriate and respected the parents' request to discontinue aggressive treatment. Palliative care was provided, the child died, and his parents returned to India. The denouement affirms that what is best for a child is complex, evolving, and situationally-dependent. Clinicians and families must work together and regularly reassess the benefit burden calculation.

Three authors have written manuscripts that address the second topic, parental decision making. Ken Kipnis, a professor of philosophy from the University of Hawaii, defends parental authority to permit or forgo life-saving treatment. Kipnis argues that there are three types of uncertainties in neonatal medicine that undercut the claim that "neonatologists are ethically obligated to act to override parental nontreatment decisions for imperiled premature newborns when there is a reasonable chance of good outcome." These three uncertainties are: 1) the vagueness of the boundary at which an infant's deficits become so intolerable that death could be reasonably

preferred; 2) the uncertainty about whether aggressive treatment will lead to a reasonably healthy child or a child with intolerable deficits; and 3) the inability to determine an acceptable ratio between the likelihoods of those two outcomes. When these uncertainties exist, as they often do in the care of extremely premature infants, Kipnis believes that neonatologists should defer to parental decisions, including nontreatment decisions.

In contrast, Janvier, Bauer, and Lantos question why the uncertainty in the neonatal intensive care unit should allow for such wide parental discretion when older individuals with similar prognoses are routinely treated. For example, they point out that the 1983 President's Commission Report, "Deciding to Forego Life Sustaining Treatment" devoted a special section to dilemmas surrounding the treatment of newborns, thus distinguishing these dilemmas from the more general dilemmas addressed in its discussion of withholding and withdrawing life-sustaining treatment in adults.⁵ They also note how the value of a newborn's life may depend on maternal attributes. They make the claim that "neonatologists are generally willing to intervene more aggressively and for a longer time when a mother is older or when she conceived by in vitro fertilization after many years of infertility". They argue that this overvaluation for the woman who may not be able to conceive a "replacement child" may unconsciously work to denigrate the value of other babies. They seek to make these medical biases transparent in order to reverse the trend of treating neonates differently.

Paris, Schreiber, and Moreland concur that the 1983 President's Commission Report gave wide discretion to parents of newborns. However, they express misgivings that the current legal environment has moved away from this position of wide discretion and now promotes the position that "all conscious viable premature newborns must be treated, even if they are likely to have severe physical and mental disabilities."⁶ They argue that such a change is neither good policy nor good medicine. This is not to support absolute parental discretion, because "treatment options should be guided by the prospects for the individual infant." Rather, their position holds when uncertain prognoses exist. They support a recent policy statement by the American Academy of Pediatrics on non-intervention or withdrawal of intensive care for high-risk newborns which they interpret to support parental discretion at the extreme margin of viability.⁷

The third topic in this special issue is end-of-life care for neonates. Porta and Frader, pediatricians at Northwestern University, Chicago, note that decisions to withhold or withdraw life-supporting measures commonly precede death in the neonatal intensive care unit. The most common means is withdrawing a ventilator, but they argue that “forgoing fluids and food represents a morally acceptable option as part of a carefully developed palliative care plan considering the infant’s prognosis and the burdens of continued treatment.” They realize that caregivers often feel greater turmoil with regard to stopping hydration and nutrition than they do about discontinuation of mechanical ventilation or circulatory support. They defend the position that “decisions to stop any form of life support should focus on the clinical circumstances, not the means used to sustain life.”

The final essay, by Alex Kon of the University of California at Davis, examines neonatal euthanasia as presented by “the Groningen protocol.”⁸ Kon argues that the justification for permitting euthanasia focuses on arguments of autonomy and beneficence. Whether or not one accepts these arguments to support a protocol for adult euthanasia, Kon shows that these arguments do not work for newborns. First, newborns cannot make autonomous decisions. Second, arguments from beneficence also fail because they assume that the physician “could be certain that the infant was suffering unbearably and that the burdens of living outweighed the benefits of life.” He suggests that both parents and physicians may be poor judges of the subjective experiences of infants and therefore “can never judge with certainty whether death is in the infant’s best interest.” Therefore, given that the primary duty of a physician is not to harm his patients, he argues that it is better to err on the side that the benefits of life outweigh the harms. That is, Kon argues that it is better to allow some children to suffer unbearably in order to avoid the error of euthanizing some children whose suffering is less than unbearable: “Euthanizing a child for whom the benefits are greater than the burdens of living constitutes the greatest harm a physician can inflict on his patient.”

Are newborns morally different from other children? Does neonatology need a separate ethics from other pediatric specialties? The ethicists in this issue hold mixed views. For some, the answer is that all children are children and there should be no differentiation. Different treatment, then, is problematic. For other ethicists, the answer is that newborns are different and these differences justify different treatment.

In their book entitled *Neonatal Bioethics*, Lantos and Meadow examine whether our attitudes towards newborns and their medical care are a result of technological developments in neonatal practice or the stimulus to develop new neonatal technologies and legal policies.⁹ They conclude that our answer may influence our moral understanding of infants and neonatal practice that in turn may influence our moral understanding of ourselves and our relationship to each other:

Scientific discoveries challenge us to change the way we think about the potential for particular projects. These projects may, in turn, change the way we think about what it means to be human and what it means to live in community. Things that once seemed good may, over time, seem problematic.¹⁰

Perhaps this issue of *Theoretical Medicine and Bioethics* will motivate us to examine the practices and policies that guide our treatment of newborns, both to ensure that our treatment of infants is ethical and just and to better understand who we are and our moral relationships and obligations to each other.

NOTES

¹ *Sophie's Choice* was directed by Alan Pakula and was based on the book by William Styron. New York: Random House, 1979.

² Annie Janvier, Isabelle LeBlanc, Keith J. Barrington, "No Justice for Premies," Pediatric Academic Societies Annual Meeting, May 2, 2006, San Francisco CA. Abstract #5152.5; Annie Janvier, Isabelle Leblanc, and Keith J. Barrington, "The Child's Best Interest," Pediatric Academic Societies Annual Meeting, May 2, 2006, San Francisco CA; 5121.4.

³ P.A. Lewis and M. Charny, "Which of Two Individuals Do You Treat When Only Their Ages Are Different and You Can't Treat Both?" *Journal of Medical Ethics* 15 (1989):28–34; and Jennifer Jelsma et al., "Preferences of Urban Zimbabweans for Health and Life Lived at Different Ages," *Bulletin of the World Health Organization*, 80 (2002): 204–209. Nine studies published between 1989 and 1997 are summarized in Aki Tsuchiya, "Age-related Preferences and Age Weighting Health Benefits." *Social Science and Medicine* 48 (1999): 267–276.

⁴ Loretta M. Kopelman, "Children and Bioethics: Uses and Abuses of the Best-Interests Standard," *Journal of Medicine & Philosophy* 22 (1997): 213–7; Loretta M. Kopelman, "The Best-interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22 (1997): 271–89; Loretta M. Kopelman, "Rejecting the Baby Doe Rules and Defending a 'Negative' Analysis of the Best Interests Standard," *Journal of Medicine and Philosophy* 30 (2005): 331–52; and Loretta M. Kopelman, "The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages," *Journal of Law, Medicine & Ethics* 35 (2007):187–96.

⁵ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment*. Washington DC: U.S Government printing Office, 1983.

⁶ John J. Paris, Michael Schreiber, and Michael Moreland, citing John Robertson, "Extreme Prematurity and Parental rights after Baby Doe," *Hastings Center Report*, 34, no. 4 (2004): 32–39.

⁷ Committee on Fetus and Newborn, American Academy of Pediatrics, "Noninitiation on Withdrawal of Intensive Care for High-Risk Newborns," *Pediatrics*, 119 (2007): 401–403.

⁸ Eduard Verhagen and Pieter J.J. Sauer, "The Groningen Protocol—Euthanasia in Severely Ill Newborns," *New England Journal of Medicine* 352 (2005): 959–962.

⁹ John Lantos and William Meadow, *Neonatal Bioethics: The Moral Challenges of Medical Innovation*, Baltimore MD: The Johns Hopkins University Press, 2006.

¹⁰ *Ibid.*, p. 155.

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