

# Ethical Issues in Newborn Care

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## Two New Neonatal Ethics Books

### *One Examines the Past; One Questions the Future*

*Neonatal Bioethics: The Moral Challenges of Medical Innovation* by John Lantos, MD, and William Meadow, MD (John Hopkins University Press, 2006, ISBN-080188344)

*Baby at Risk: The Uncertain Legacies of Medical Miracles for Babies, Families, and Society* by Ruth Levy Guyer (Capital Books, 2006, ISBN-1933102268)

These two books, both published in 2006, frame the debate on advances in technological medicine for sick newborns. Although the text by renowned pediatrician John Lantos and neonatal colleague William Meadow competently tells the story of the development of neonatal medicine, it stops short of questioning today's realities. It is therefore very helpful that scientist-bioethicist Dr. Ruth Guyer steps in where Lantos and Meadow leave off. Lantos and Meadow spell out the story of the development of neonatal technology, neonatal innovation, and neonatal medicine as a subspecialty of pediatrics. Guyer asks: Now that we have this innovative field of medicine, should we be using it with more considerations about long-term outcomes? The books are so very different, it is as if the two authors drew a line in the sand and one said "we will talk about everything except ethics" and the other "I will question only ethics."

Lantos and Meadow provide the historical context for this new field. They present the development of mechanical ventilation for newborns, the use of extracorporeal membrane oxygenation, and the debates over oxygen levels and subsequent eye damage. The most fascinating part of the book is the story of the actual creation of the modern neonatal intensive care unit (NICU). They describe why intensive care for newborns came into being, how it was supported by the federal funding plans, and why it is now such a money maker for hospitals. The focus on finance is the closest that Lantos and Meadow come to questioning ethical dilemmas in neonatal medicine. NICUs are seen as a source of revenue; small hospitals shy away from embracing regionalization, and every hospital puts in some level of neonatal beds. Lantos and Meadow report studies showing that between 1980 and 1995, the number of neonatal beds grew by 138% and the number of neonatologists by 268%. As there were more beds and more trained physicians, more early gestational and low birth-weight infants starting being treated. The authors write proudly that "neonatology saves lives." They con-

tinue "Access to neonatal care is a right in the United States . . . This reflects the uncontroversial medical success of neonatal care" (p 135).

It is not until one reads Ruth Guyer's book that the hard questions are asked. It is she who discusses parent Helen Harrison and her group of parents who are raising the children saved but not "fixed" by neonatal medicine. Author and mother, Helen Harrison is the founder of Neonatology and the Rights of Families, a parent organization which questions the medical field which sent them home with devastated children. It is Dr. Guyer who discusses long-term outcomes, children with impairments, and the ethics of offering or not offering palliative care as an option for marginally viable infants. While Lantos and Meadow philosophically debate the long-term outcomes from afar, citing the American Disabilities Act as their guide to treating fetal infants, Guyer gets up close and personal, showing pictures of Sydney Miller, a child living with spastic quadriplegia and severe cognitive impairment, interviewing parents such as Mark Miller and Helen Harrison, and discussing the incorporation of palliative care in the NICU. Lantos and Meadow discard as a "moral myth" the many survivors of the NICU who have neurological deficits and rebut those who feel neonatal medicine needs to be held in check. Guyer interviews key players who are asking moral questions about neonatal medicine that Lantos and Meadow do not acknowledge. Guyer, a scientist by background and not a physician, appears to have more feel for the heart-felt dilemmas experienced by parents, nurses, and physicians.

It is unfortunate that Lantos and Meadow, scholars, ethicists, and leaders in the field, do not take a stronger position on parents and colleagues who insist that "everything be done." The closest they come to this is stating we should be "attentive and cautious." Instead, their arguments are based on the facts that neonatal medicine really doesn't cost that much. "The direct cost of neonatal care in U.S. hospitals is \$21 billion . . . The indirect costs after discharge are roughly the same. . . . Thus the overall costs is only 1% of the national health

care expenditures” (p 125). Guyer, however, cites philosopher Andrew Jameton, who has written about the lack of justice that the NICU represents. “The NICU represents an ‘island mentality,’ ” Jameton states, “suggesting that the economic development that improves the lives of a few people, while neglecting a vast peripheral population, is . . . an extravagant and unbalanced way to invest social resources” (p 149).

For many infants, in fact, most infants, neonatal medicine has been a blessing, and the work of neonatal nurses and physicians a personal calling. For those interested in the debate on its rightness or wrongness, its ability to accept and apply life-extending treatment without more discernment, these two texts will earmark the year of 2006 as an important year in print.