

Ethical Issues in Newborn Care

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Prenatal Education Regarding Gestational Development, Viability, and Survivorship

Looking to Our Obstetric Colleagues for Change

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This article describes the creation of an educational program for pregnant women and who desire to be pregnant. The intent, if used, is to decrease the number of families asking for resuscitation and technological support of premature infants at or below the level of viability.

Premature birth rates in the United States have steadily risen since the 1980s; currently, 1 in 8 deliveries occur earlier than 37 weeks' gestation.¹ As stated in the recent publication, *Preterm Birth: Causes, Consequences, and Prevention*,

The increasing prevalence of preterm birth in the United States is a complex public health problem that requires multifaceted solutions. Preterm birth is a cluster of problems with a set of overlapping factors of influence. Its causes may include individual-level behavioral and psychosocial factors, socio-demographic and neighborhood characteristics, environmental exposure, medical conditions, infertility treatments, and biological factors. Many of these factors co-occur, particularly in those who are socio-economically disadvantaged or who are members of racial and ethnic minority groups.^{1(p2)}

Complications of premature birth are well known to neonatal intensive care unit (NICU) care providers, including minor to major morbidities and mortalities, that increase in frequency as the gestational age at birth decreases. Educating pregnant women about this potential condition has not been as great a priority

in the obstetric community as neonatal providers would like.

A NEW PARADIGM

A comprehensive search of current literature reveals the absence of any component within prenatal care describing gestational development, viability, or survivorship.² Therefore, I am proposing a paradigm shift: Including in the standard prenatal education package, in language suitable for the lay population, a clear description of fetal development, the time necessary for healthy viability and survivorship, and related medical terminology for the expectant parent. Premature birth is a serious and costly problem for millions of families in the United States each year and all potential parents deserve the right to accurate, evidence-based, and understandable information regarding premature birth and the predictable outcomes.

A review of current guidelines regarding prenatal care includes education regarding the recognition of the symptoms of premature labor and comprehensive screening for rare and unusual complications of the newborn, yet the incidences of these complications remain much less prevalent than the actual incidence of premature birth, which is now at 12.8% of all deliveries.¹ Many families, in preparation for their roles as parents, search and disseminate information regarding pregnancy, yet the majority of new parents are uneducated regarding the incidence of premature delivery and the risks involved. Current neonatal medical treatments are often portrayed by the media as "miraculous," and may mislead parents in their understanding of viability and survivorship; factual information is missing from mainstream presentation to the public.

In her article "Thinking Outside the Box," Catlin² asks that the prenatal education model be reframed and gives evidence-based argument to the need to educate women on fetal development, viability, and survivorship. Catlin includes a study conducted by Shivas that evaluated the content of 89 articles

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regarding prematurity in which no article mentioned the terms “viability” or “disability.”² It was Shivas’ conclusion that the articles available gave no clear indications of the risks involved in premature delivery or the resulting outcomes of technological interventions. As a currently practicing neonatal nurse, I encounter the moral dilemma of “saving” and caring for the results of extremely premature deliveries each day that I work; it is this dilemma and my personal response to each ethically challenged situation that has drawn me to the area of prenatal education on viability.

This is not an entirely new concept. In 1991, author and the former NICU parent Helen Harrison assembled a group of other former NICU parents and physicians and formulated the document called “Ten Principles for Family-Centered Care.” Included in the verbiage of principle no. 1 is “communication about ethical issues and treatment choices is crucial . . . some families may wish to do so through the use of family treatment plans to be filled out during the prenatal period, in which parents put in writing their requests regarding resuscitation and treatment of their child should he or she be born extremely premature or critically ill.”^{3(p3)} Nurse educator Andrea Robertson, in her article about antenatal education, also suggests that discussion about premature delivery begins during pregnancy, “as part of the session on fetal growth and development, premature labor, visiting the hospital, and complications during pregnancy and birth.”⁴

The American College of Obstetricians and Gynecologists guidelines regarding *Perinatal Care at the Threshold of Viability* offers a discussion about providing families with an overview of the potential complications of extreme prematurity and prolonged intensive care,⁵ but the report fails to address the method of education to provide such an overview. The report considers education at the time of imminent delivery, but does not suggest a time, such as during the prenatal period, when the family is more able to read and discuss the material and make informed choices. In their article, “DNR in the DR?” Yellin and Fleischman acknowledge, “These communications should begin as early in the prenatal period as possible.”^{6(p235)}

As the continued increase in preterm birth has been recognized, it has also become the focus of financial studies regarding healthcare spending. The healthcare system in the United States is the costliest in the world⁷ and NICUs share of this cost is enormous: “annual expenditures are probably even higher than \$12 billion today since growth within neonatal intensive care has been greater than growth in other areas of medicine.”⁸ In their article, “Maternal Education During the Perinatal Period,” Standing, El-Sabagh & Brooten state, “Education of pregnant women is especially important because deliveries comprise the largest number of hospital admissions each year in the United States; pregnancy

outcomes resulting in birth of low-birth weight infants produce a group with one of the highest healthcare costs of any patient group.”⁹ Additionally, it is acknowledged by Lantos, “The NICU has become the economic engine that keeps children’s hospitals running.”¹⁰ In a sense, the survival of hospital-based pediatrics, as we know it, is increasingly dependent upon the commitment to the technologies and the personnel that enable the survival of extremely premature babies.”^{8(p115)} In light of these financial considerations, it would seem sensible to educate the public regarding the significant healthcare expenditures such as preterm birth and care of the premature infant.

The most recent Institute of Medicine publication, *Preterm Birth*, devotes an entire section to the societal costs of preterm birth, including both medical care services at the time of delivery and those expenditures associated with long-term intervention services.¹ Naming 4 major disabling conditions associated with prematurity—cerebral palsy, mental retardation, hearing loss, and vision impairment—the report reveals a societal economic burden of at least \$26.2 billion in 2005, acknowledging that this figure is a floor, or minimum.¹ Efforts to understand the increased incidence of premature birth, and implement preventive measures, are the focus of this report. Certainly, increased educational methods for the family of the pregnant woman must also be a part of this plan, yet they are only alluded to. Inclusion of prenatal education explaining gestational development, viability, and survivorship, within the healthcare delivery system will contribute to increased understanding among the public utilizing healthcare during pregnancy.

PROPOSED PACKAGE OF EDUCATION FOR INCLUSION IN PRENATAL CARE

Many prospective parents are highly educated and pursue literature entailing gestational development during pregnancy, yet most parents I have encountered lack understanding regarding gestational development, viability, and survivorship. I have developed a brochure, with input from parents of premature infants and nursing staff, with the intention of widespread regional distribution to prenatal healthcare providers. Content for this brochure has been written in lay terms, suitable for reading at the eighth-grade level, referenced from current medical literature (see Appendix). Discussion among colleagues, and identification in the literature, points to the need for this teaching tool to be definitive and informative to the lay reader in a nonthreatening manner. The teaching tool developed for this project was compiled utilizing facts from scientific text, Web-based medical information, and personal practice. The content includes simple definitions of common, prenatal terminology, and bullet-type facts, with each trimester section focused on the areas of gestational

development occurring during that trimester. Viability and survivorship are discussed at each stage. Color photographs depicting the fetus at each particular stage of development are also included.

Catlin has suggested 3 ethical dilemmas regarding nursing care of the extremely premature infants whose parents did not receive prenatal information on fetal development, viability, and survivorship. She looks at infants unable to be discharged from the hospital,¹¹ the lack of skilled home care for those who are discharged with intense medical need,¹² and the possibility of nurses' conscientious objection to providing futile care in the NICU.¹³ These ethical topics have been presented throughout the United States in the past year. The attached educational package on fetal development is a fourth component offered in response to the ethical dilemmas resulting from the care of the extremely premature infant. Networking and discussion among nursing colleagues in areas all around the country has produced interest in a component of prenatal education regarding gestational development, viability, and survivorship, and these colleagues welcome the ability to provide this education to families both before and during the course of NICU care. Initial discussion among medical colleagues has also lent support to this endeavor, with trial distribution of this brochure included in prenatal packages (G. Neubert, MD, personal written communication, 2008).

SUMMARY

I have been a neonatal nurse for more than 7 years and have aided in the healthy outcomes for hundreds of babies and their families. I have also participated in the care of infants who may never achieve the most simple of accomplishments, such as rolling over or

sitting up; I feel it is unfair to present educational information to families only after their infants are born and already committed to efforts to extend life. As an ethical professional and clinician, I feel it is my duty to reach a greater number of families before they become parents, when they initially become pregnant, and to provide them with the knowledge and understanding of gestational development, viability, and survivorship. Families with clear understanding of when lungs develop, when vessels have integrity, when the heart can pump properly, etc may be less likely to insist upon resuscitation at ages that lead to severe morbidity and mortality. Please share this educational information with your obstetric colleagues.

References

1. Institute of Medicine. Committee on Understanding Premature Birth and Assuring Quality Outcomes, Board on Health Sciences Policy. *Preterm Birth: Causes, Consequences, and Prevention*. Washington, DC: National Academies Press; 2007.
2. Catlin A. Thinking outside the box: prenatal care and the call for a prenatal advance directive. *J Perinat Neonatal Nurs*. 2005;19:169-176.
3. Harrison H. The principles for family-centered neonatal care. *Pediatrics*. 1993;92:643-650.
4. Robertson A. Mentioning the unmentionable. *Practical Midwife*. 1999; 2(6):32-33.
5. American Colleges of Obstetricians and Gynecologists. *Perinatal Care at the Threshold of Viability*. Washington, DC: American Colleges of Obstetricians and Gynecologists; 2002.
6. Yellin P, Fleischman A. DNR in the DR? *J Perinatol*. 1995;15:232-236.
7. Lamm R. *The Brave New World of Health Care*. Golden, CO: Fulcrum Publishing; 2005.
8. Lantos J. *The Lazarus Case*. Baltimore: The Johns Hopkins University Press; 2001.
9. Standing T, El-Sabagh N, Brooten D. Maternal education during the perinatal period. *Clin Perinatol*. 1998;25:389-402.
10. Lantos J, Meadow J. *Neonatal Bioethics*. Baltimore: John Hopkins Press; 2006.
11. Catlin AJ. Extremely long hospitalization of newborns in the United States: data, description, dilemmas. *J Perinatol*. 2006;26:742-748.
12. Catlin AJ. Home health for at risk neonates: availability of funding and nurses is essential. *Home Healthcare Nurse*. 2007;25:131-132, 134-135.
13. Catlin A, Armigo C, Volat D, Hadley MA, Valle E, Bassir R, Anderson K, Gong W. Conscientious objection: a possible neonatal nursing response to end of life care which is harmful or causes suffering. *Neonatal Netw*. 2008;27: 101-108.

APPENDIX. Facts About Pregnancy and Fetal Development

Pregnancy is a time of great anticipation and concern. The development of this brochure was intended to educate the pregnant family, enabling them to make informed choices about their prenatal care and subsequent delivery, easing those concerns.

Definitions

Gestation: Period of pregnancy

Preterm, or premature: Less than 37 completed weeks of gestation

Term: 37 to 41 completed weeks of gestation

Postterm: More than 41 completed weeks of gestation

Low birth-weight (LBW): less than 2500 g (5.5 lb)

Very low birth-weight (VLBW): less than 1500 g (3.3 lb)

Extremely low birth-weight (ELBW): less than 1000 g (2.2 lb)

NICU: Neonatal intensive care unit; a highly specialized hospital unit for the care of critically ill neonates

Neonate: The infant in the first 28 days of life outside the womb

Viability: The ability of a fetus to survive life outside the womb

Surfactant: Special fluid in the lungs required to breathe outside the womb

Resuscitation: The act of rescuing from potential death



FIRST TRIMESTER FETAL DEVELOPMENT: CONCEPTION TO 12 WEEKS OF GESTATION

- A period of rapid growth and development, the embryo is undergoing many physical changes including formation of brain, spinal cord, and organ formation.
- At 5 weeks of gestation, blood vessels will complete a circuit and a heartbeat is detectable by ultrasound.
- At 6 weeks, the neural (nervous system) tube containing the spinal cord closes, basic facial features begin to appear, and the buds that will form arms and legs have begun to develop.
- The umbilical cord is now visible.
- This is a period when the many developmental changes occurring in the fetus can be negatively affected by poor health practices of the mother.
- Continued prenatal care is essential.
- At 11 weeks, the embryo is now termed a *fetus*.
- Genitalia may be visible.
- A fetus born at this stage of development cannot sustain life outside the womb; it is not *viable*.



SECOND TRIMESTER FETAL DEVELOPMENT: 13–27 WEEKS OF GESTATION

- Although not yet detectable by you, at 20 weeks the fetus can now flex and kick.
- Eyelids are fused, skin is just beginning to develop.
- Bones that make up the skeletal system are developing.
- At 20 weeks, you are about halfway into your pregnancy.
- Your baby is covered with fine hair called *lanugo*.
- Skin is developing under a thick, waxy substance called *vernix*.
- At 20 weeks, a baby born at this stage is not *viable*.
- At about 22–23 weeks, the fetus' lungs are beginning to produce *surfactant*, and practice breathing occurs, moving amniotic fluid in and out of the lungs.
- A baby born at this stage of development, 22–23 weeks, is termed "at the edge of viability" or marginally *viable*.

(continued)

APPENDIX. Facts About Pregnancy and Fetal Development (continued)

- Some institutions practice *resuscitation* at this stage, but complications are numerous and survival is questionable.
- At 24 weeks, your baby now weighs about 1½ lb (500–680 g).
- Eyes may still be fused shut; skin is thin, red, and gelatinous; blood vessels are visible.
- A baby born at this stage of development will need vigorous, intensive support to survive (neonatal resuscitation and NICU support).
- A baby born at this stage of development has a 50% chance of survival.
- Complications at this stage of development are frequent and serious and the infant may face a lifetime of health problems such as cerebral palsy (brain damaged), hydrocephalus (fluid accumulation in the brain), seizures, neurological (nervous system) problems, developmental delays, or blindness.
- Survival in the NICU may include treatment of such conditions as intracranial hemorrhage (bleeding in the brain), intestinal problems such as necrotizing enterocolitis (digestive system damage), and retinal (vision) problems.
- At the end of the second trimester, your baby has completed 27 weeks of development and weighs about 1½ to 2 lb (800–1000 g)
- If born at this stage of development, your baby's chance of survival is almost 85%, but chances of serious complications are still possible.

THIRD TRIMESTER FETAL DEVELOPMENT: 28–40 WEEKS OF GESTATION

- At 28 weeks of gestation, your baby's eyes begin to open and it weighs about 2–3 lb (1000–1500 g).
- Getting stronger and storing calcium, bones are developed and baby has periods of wakefulness, and movements are vigorous.
- Severe complications associated with prematurity are reduced after 30 weeks of gestation.
- By 31 weeks, your baby's lungs are more fully developed but would require mechanical respiratory support (help breathing with a machine), if born at this time.
- Your baby would need nutritional support and intravenous fluids; it could not eat on its own.
- At 32 weeks, the fine hair called lanugo is beginning to disappear and your baby is rapidly gaining weight, weighing about 4 to 4½ lb (1800–2000 g) now.
- If born at this time, chances for survival are very good.
- At 33–34 weeks, your baby continues to gain weight and is beginning to store brown fat under the skin; this fat is used to maintain body temperature and sustain him or her until your breast milk "comes in."
- If a woman delivers prematurely, breast milk production must be stimulated by pumping as soon as possible, within hours after birth.
- If born at this time, your baby would need help learning how to eat.
- The final weeks of pregnancy, 36–40 weeks, are a period of rapid growth and development; lungs continue to mature, skin thickens, vision and hearing are developed, and neural (brain) development is occurring.
- At 37–41 weeks of gestation, your baby is well developed for adaptation to life outside your womb and is ready to be born.



Suggested Reading

1. Lissauer T, Fanaroff A. *Neonatology at a Glance*. Malden, MA: Blackwell Publishing; 2006.
2. Mayo Clinic. Prematurity. <http://www.cnn.com/HEALTH/library/DS/00137.html>. Accessed June 12, 2007.
3. Pregnancy.Org. Fetal development. <http://www.pregnancy.org/pregnancy/fetaldevelopment1.php>. Accessed June 12, 2007. Embryoscopy and fetoscopy photos appearing on this Web site are reproduced under "fair use" terms for the purpose of public education.
4. *Stedman's Concise Medical Dictionary*. 3rd ed. Baltimore: Williams & Wilkins.