



**“Taking it to the Streets”
NATIONAL PERINATAL
ASSOCIATION
October 2011**

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Charlotte Wool, PhD, RN**

OUR ROLES AS ETHICS RESEARCHERS



- **To study, consider, and assess what is done in clinical care**
- **To hear your concerns and moral dilemmas**
- **To support you in your work**
- **To conduct research that describes the ethical dilemmas that are faced**
- **To publish these studies**
- **To work nationally on the macro level to assist in problem solving**

PROGRAMS OF RESEARCH

Catlin

- Ethical Issues in End of Life for Newborns
- Funded by American Academy of Pediatrics, American Nurses Foundation, Sigma Theta Tau Lambda Gamma, National Perinatal Foundation

Wool

- Perinatal Ethics and Prenatal Decision Making
- Funded by Sigma Theta Tau, Hospice and Palliative Care Nurses



• 2011

• 2010

• 2009

• 2008

• 2007

• 2006

• 2005

• 2001

• 2000

• 1998

• 1994

• 1989

RESEARCH HISTORY

- 1988** • **Women Experiencing Pregnancy Loss**
- 1989** • **Ectopic Pregnancy**
- 1994** • **Mothers of Severely Impaired NICU Grads**
- 1998** • **Physician Opinion of Resuscitation Decisions**
- 1999** • **Model for Understanding Moral Distress in Perinatology**
- 2000** • **End of Life in the NICU**
- 2001** • **Creating A Neonatal End of Life Palliative Care Protocol**
- 2005** • **Children Unable to be Discharged**
- 2006** • **Prenatal Advance Directive**
- 2007** • **Home Care Needs of Child on Ventilator**
- 2008** • **Conscientious Objection to Futile Care**
- 2009** • **Defining Transition to Purely Palliative Care**
- 2010** • **Multiple Gestation Reduction-Disenfranchised Grief**
- 2011**

**INVITED TO NIH TO DISCUSS
NEONATAL PALLIATIVE CARE
at CONFERENCE ON VIABILITY**

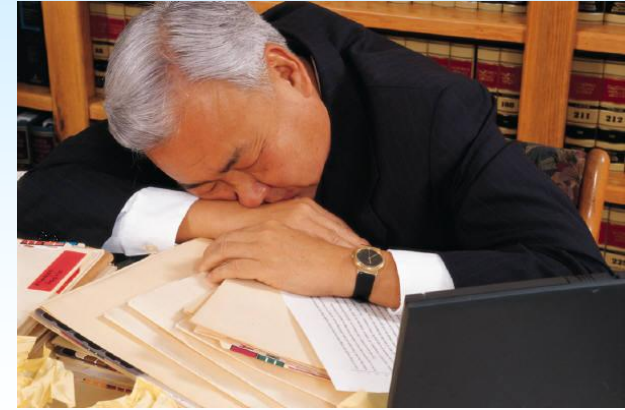


EXCITEMENT AND RESPONSIBILITY

- Palliative care finally to be accepted!



RESPONSE OF TOP SCIENTISTS



- **Interesting**
- **Ho, Hum**
- **Aware of Morbidity and Mortality of Prematurity**
- **“Let’s Get On with the Science”**



MY RESPONSES TO NIH MEETING

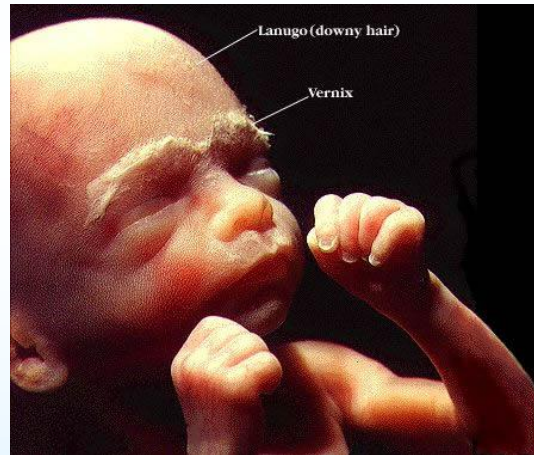
- Must continue to look at what will happen if we support sicker and sicker infants (“Good idea”)**
- Must turn the education over to pregnant women, and let them clearly understand fetal growth and gestational needs for viability and healthy development (“BAD idea!”)**

RESPONSE

- **Extremely long hospitalizations in newborns --Journal of Perinatology**
- **Thinking Outside of the Box: Need for prenatal advance directive --Journal Neonatal And Perinatal Nursing**
- **Conscientious objection to care for neonates that causes suffering at the end of life --Neonatal Network**
- **Revision NANN Policy 3015 on Care of Critically Ill Newborns—Advances in Neonatal Care**
- **Transition Study on defining ‘Dying—’—Advances in Neonatal Care**
- **Taking this to the Streets**



A New Paradigm For Prenatal Education: Fetal Development, Viability, And Healthy Survivorship



Anita Catlin, DNSc, FNP, FAAN

Thank you to colleague Christine Armigo, RN, MSN

DILEMMA AT BIRTH

Lack of Knowledge

- “Please save my baby”
- Unaware of meaning
- Unable to imagine later life
- Staff comes to a realization before parents
- Dream is held on to
- Suffering for infant
- Suffering for parents
- Moral distress for staff
- Rare resources of perinatal hospice



Can The Answer To Change Be Contained In Prenatal Care?

- Research on newborn decision making says teach critical issues early in pregnancy
- Gilligan discussed that women's decisions are made in context of who depends on them (feminist ethics)
- Extensive study conducted of what is contained in prenatal care/education

LITERATURE SEARCH

- Medline
- CINAHL
- National Guidelines
www.guidelines.gov
- Cochrane data base

Only one article re fetal growth

- Robertson from Ireland stated that
“fetal growth, premature labor, baby’s
death must be part of childbirth
education”

STUDY ON CONTENT OF PRENATAL CARE REVEALED NO MENTION OF VIABILITY

- **Search in CINAHL, Medline, Cochrane**
- **AAP Guidelines- No mention of viability**
- **Renkert and Nutbeam focus groups- No mention of viability**
- **7 international guidelines- No mention of viability**
- **Standing meta-analysis states fetal growth and development on a chart but does not discuss**
- **Agency for Healthcare Research and Quality-
"Discuss fetal physiology at first visit"**

SEVEN INTERNATIONAL PRENATAL GUIDELINES

- **69 topics**
- **Screenings and education**
 - **Education about seat belt placement**
- **Only 3 topics in common to all 7 guidelines**
 - **related to Rh antibodies**
- **No mention of education about fetal development or viability**

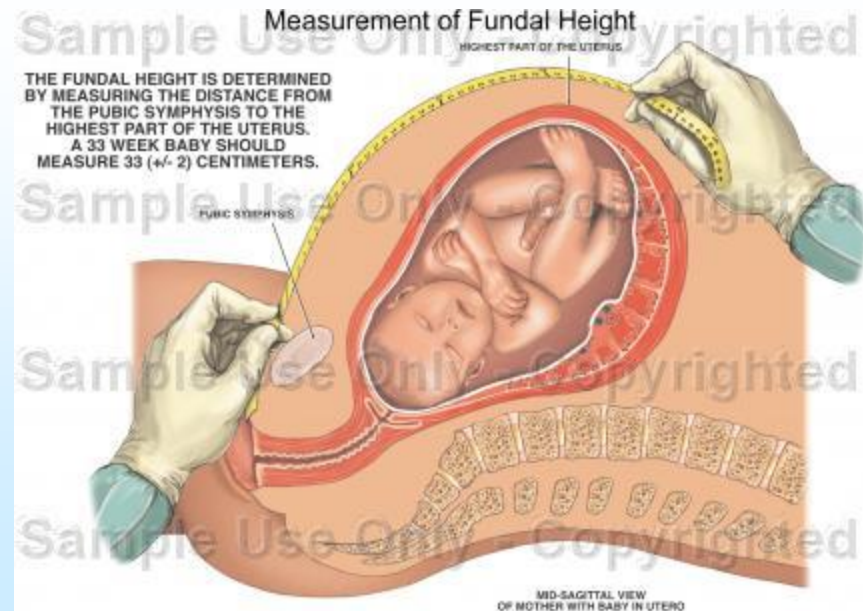
CURRENT PRENATAL CARE

- Assessment of Maternal Health
 - Hypertension, anemia, thyroid, diabetes, urinary tract infections, cervical cancer, sexual transmitted infections
 - Emotional health, social assessment, domestic violence



CURRENT PRENATAL CARE

- Health and Well-being of Fetus
 - Growth, heart rate, movement
 - Morphology
- Assessment for safest delivery



CURRENT PRENATAL EDUCATION

- Addresses health of mother as a gestator
- Nutritional and emotional health
- Childbirth preparation classes- generally begin at 30-32 weeks
- Identification of symptoms of preterm labor (NANN, MOD)
- Fails to answer the question of “what happens if I deliver before 30 weeks?”

CURRENT PRENATAL CARE DOES NOT ASSESS:

- Response to complicated outcome
- Where family will have to obtain care, possibly live
- Effect of child on family
- Trajectory of child's life
- Trajectory of motherhood/parenthood



PRENATAL CARE AND EDUCATION

Blood Tests

- Syphilis 1 per 10,000 live births
- Neural Tube Defects 1 per 10,000 (2500 per year)

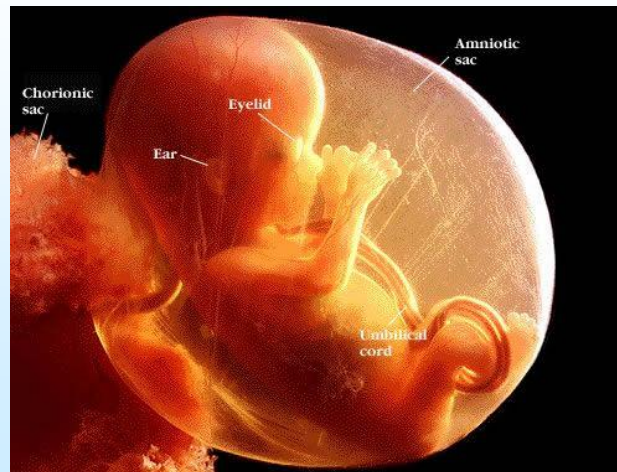


Ultrasound

- Hypoplastic Heart 1 per 5000 (1000 per year)
- Lack of Kidneys 1 per 4000

NEWBORN SCREENING PROGRAM

- PKU 1 per 15,000 live births
- Hypothyroidism 1 per 3500 live births
- Hearing disorder 2 per 1000 live births
- New multiphasic screenings for up to 133 enzyme and genetic deficiencies that very rarely occur



PREMATURITY FACTS

- **About 4,500,000 births per year in the U.S.**
- **12% of all births are premature**
- **12 per 100**
- **1 in every 8 births**
- **503,200 preterm babies per year the U.S.**
- **57,000 under 1500 grams**
- **4,100 under 500 grams**

CURRENTLY: EDUCATION ONLY AT THE TIME OF IMMINENT DELIVERY

- Campbell and Ross conducted 13 postpartum focus groups to see if women remembered education done **at time of birth**
- 9 of 13 groups, no one remembered, the other 4 groups only 1 person remembered
- Participants said, ‘The time for education about decisions for our babies is in the prenatal period.’



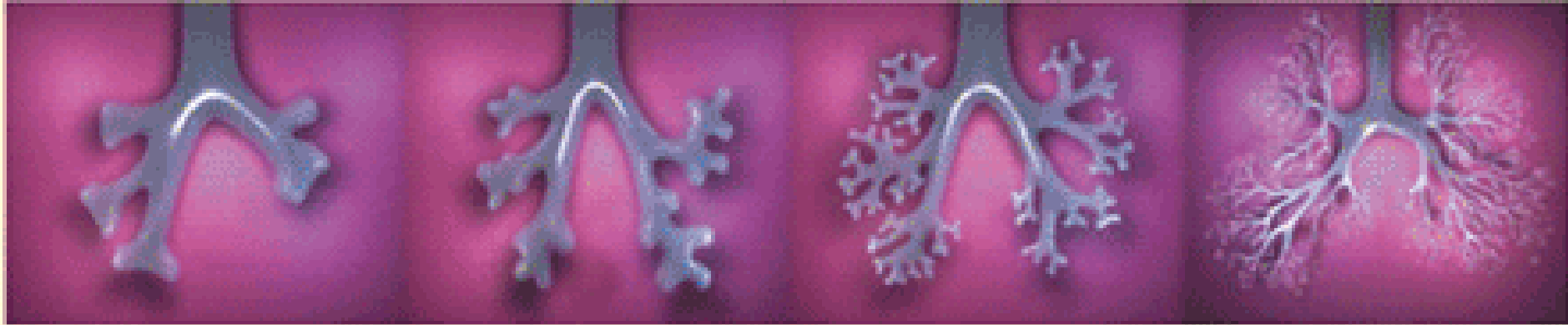
LACK OF KNOWLEDGE BECOMES A CRISIS AT DELIVERY

- Women uneducated at 20-27 week period
- 1 in 8 women will face a preterm delivery
- Learn about preemies on Lifetime and in the media, internet
- Never taught how long it takes for lung development
- Never taught how long it takes for vessel integrity

Normal lung development

Premature

Term

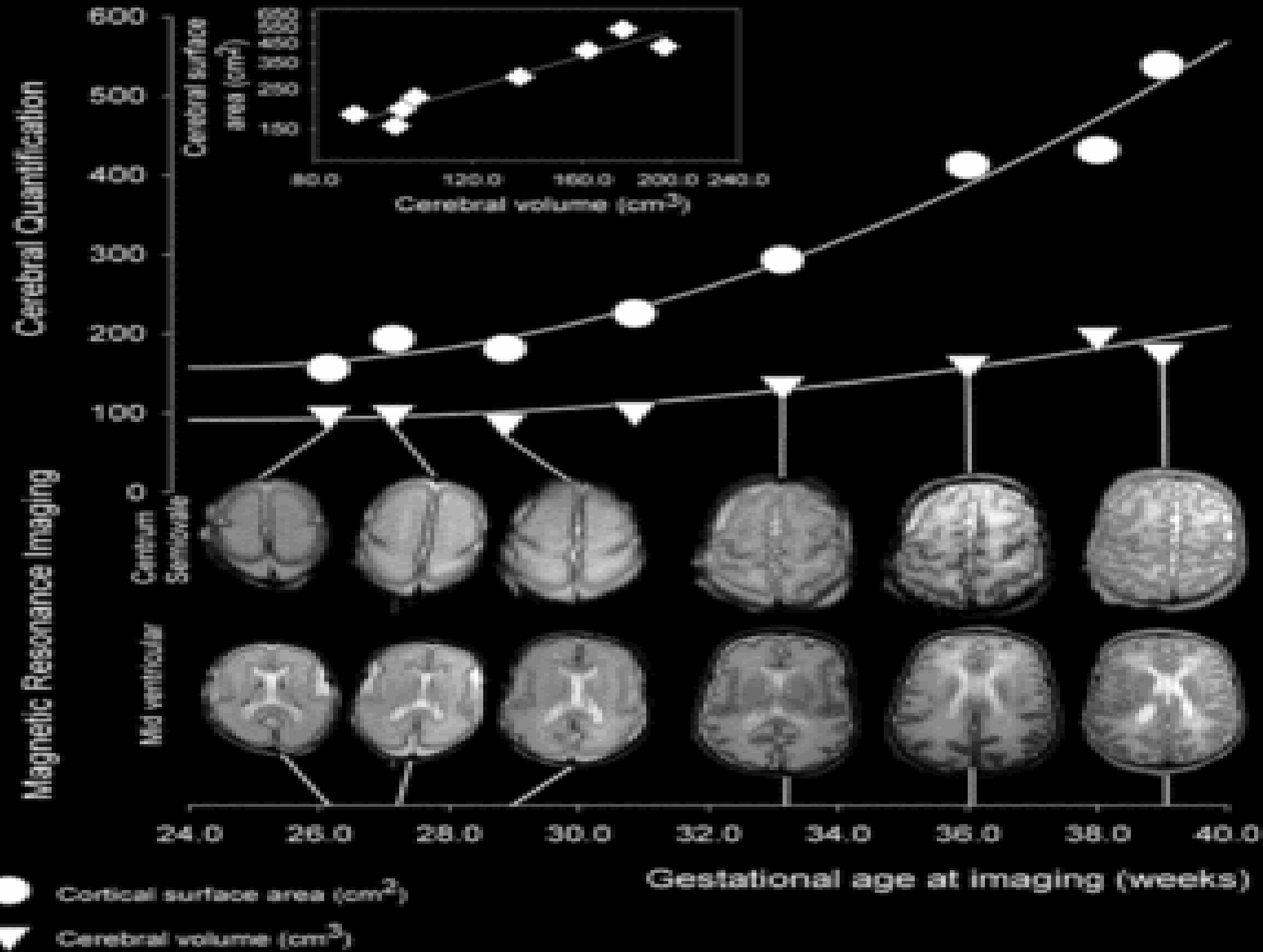


Pseudoglandular Period
(7 to 16 weeks)

Canalicular Period
(16 to 26 weeks)

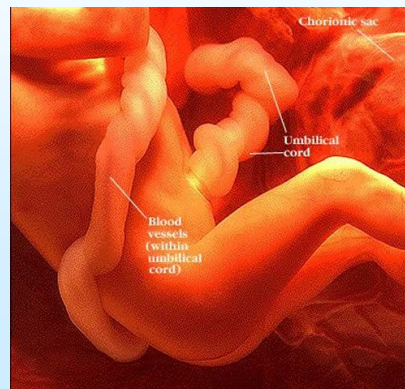
Saccular Period
(26 to 36 weeks)

Alveolar Period
(36 to 41 weeks)



INVESTIGATION OF MEDIA REGARDING PREMATURE BIRTH

- Conducted by Tricia Shivas, PhD, Media Expert
- Six month Lexis-Nevis database in the four regions for US News
- Search terms were “premature” and “baby” or “preemie.” N=146 (47 not applicable)



LAY PRESS INVESTIGATION



- 89 articles analyzed
- New methods for treatments of premature infants, March of Dimes events, requests to Congress
- Majority personal stories of individual families who had premature infants
- 23 weeks to 37 weeks
- Articles mentioned disabilities in passing, but this was not the focus of the articles

RESULTS : 89 NEWSPAPER REPORTS

18/89= lung problems

11/89= heart problems

9/89=blindness

7/89=cerebral palsy

20/89= Risk of brain damage

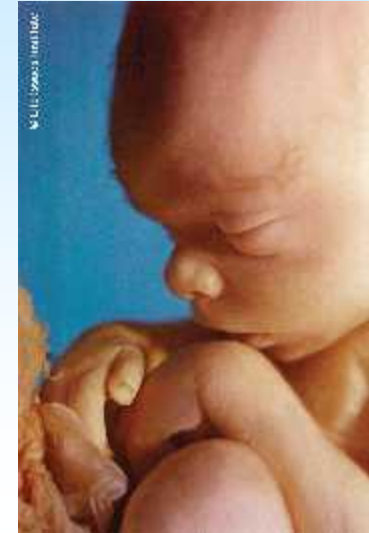
5/89 =difficulties sucking and swallowing

2/89= high white blood cell count

1/89=problems with motor skills

50/89 of articles mentioned no disability

1/89 =possibility of long term disability



CONCLUSION BY SHIVAS

- “A reader encountering these articles would have a difficult time evaluating the risks of disability and death to a baby born prematurely...”
- “Without clear data on ... the relationship between the number of weeks of fetal development to newborn disability or death, the articles in the media provide only limited information on prematurity.”

PROPOSED PRENATAL CARE EDUCATION

- Discussion of fetal growth and development at each visit
- Literature given at each visit providing images of the developing fetus
- Tell the timeline for “approaching viability”
- Discussion of a Birth Plan
- Discussion of a Premature Delivery Plan

INCLUSION IN PRENATAL CARE

- Time with care provider to discuss information
 - Length of gestation required to establish healthy viability
 - Survivorship, with and without major impairment
 - Consideration and desires for future life trajectory

Thinking Outside the Box: Published in Journal of Perinatal & Neonatal Nursing

PREMATURE DELIVERY

WHAT IF:

- **Idea of Prenatal Advance Directive-**

What does it mean?

Will my wishes be respected?

Can I make a plan for the birth of a child who is not expected to live?

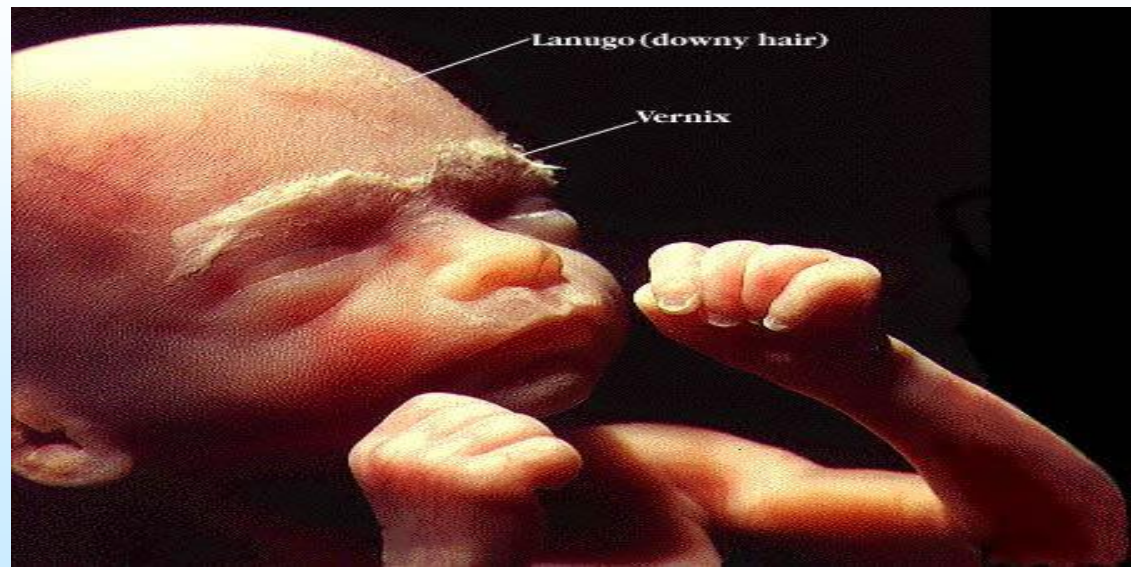


EDUCATION TRANSFER = POWER TRANSFER = KNOWLEDGEABLE DECISIONS

“The physicians and nurses have explained to me what is happening to the baby developing inside of me and how long it takes to develop into a child with a good chance of living without major medical problems. I understand that there are many serious medical problems that can occur if the child is born too early. I would like to write down some of my opinions about the care and treatment I would want for my baby if he or she is born very early.”

CREATION OF EDUCATIONAL FLYER BY CHRISTINE ARMIGO, MSN

- Armigo, C. (2008). Prenatal education regarding gestational development, viability, and survivorship: looking to our obstetric colleagues for change. *Advances in neonatal care*, 8 (3)185 -189



AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

- Recent patient education pamphlet **Early Preterm Birth (AP173)** explains concepts of viability and intact survivability to patients who are at risk of early preterm birth
 - “However, the pamphlet should be revised in light of ethical considerations regarding decision-making”
- 6th edition **Guidelines for Prenatal Care (2007)**
Prenatal Section- “explain expected course of pregnancy
 - Has small section pp 181-182 for physicians on morbidity and mortality of prematurity

Harrison H. 1993 The principles for family-centered neonatal care. *Pediatrics*. 92:643-650

Harrison H. Making lemonade: a parent's view of "quality of life" studies. *J Clin Ethics*. 2001;12:239-250.

Harrison H The offer they can't refuse: parents and perinatal treatment decisions. *Semin. Fetal Neonatal Med* 2008 13(5) 329-334.

Multiple continuous responses



EXPECTING PARENTS TO 'CHOOSE' IN THE NICU CAN BE HEARTBREAKING

Work of Kristina Orfali, PhD

- Comparison of end of life care in France with the United States
- Year long ethnographic emergence
- French children too premature to live; physician says this is so. Says care will turn to palliative
- American children dying. Parents given “choice.”

Later findings

- Parents in US have much higher levels of grief, guilt and anguish having had to “choose” child’s death.
- French parents content with the direction and support given by a connected physician

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