Pediatric Primary Care and the NICU Graduate: A Unique Perspective

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Objectives:

1. Identify challenges and barriers pediatricians encounter in caring for the NICU Graduate

2. Identify strategies that will optimize care of the NICU graduate

3. Develop a NICU graduate transitional care plan to a medical home model that will improve quality and safety
Surviving the NICU

• Advances in both obstetrics and neonatal care has led to the survival of more premature and critically ill newborns surviving to NICU discharge and transitioning into community medicine.

• Of NICU graduates, 20% to 40% have complex medical problems and need specialty outpatient services and frequent primary care visits.
• Hobbs surveyed 200 community pediatricians who reported outpatient care of the NICU graduates as challenging and they identified multiple barriers to optimal care for the NICU graduates.
### Distribution Of Gestational Age

**Texas & United States, 2013**

<table>
<thead>
<tr>
<th></th>
<th>US (Count)</th>
<th>US (%)</th>
<th>Texas (Count)</th>
<th>Texas (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Term</strong></td>
<td>3,999,386</td>
<td>88.0</td>
<td>386,118</td>
<td>86.9</td>
</tr>
<tr>
<td><strong>Total Preterm</strong></td>
<td>478,790</td>
<td>11.4</td>
<td>50,582</td>
<td>12.3</td>
</tr>
</tbody>
</table>

National Center for Health Statistics, final natality data.
2014 Texas and United States data are preliminary
Source: 2005-2014 Texas Birth Files, National Center for Health Statistics
Prepared by: Department of State Health Services (DSHS), Office of Program Decision Support, Sept 2015
2014 Texas data are preliminary
Source: 2005-2014 Birth Files
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
Maternal Age Distribution in 2005 and 2013

Source: 2005 & 2013 Birth Files
Prepared by: DSHS, Office of Program Decision Support Sept 2015
Infant Mortality Rate in Texas and The United States, 2005-2014

Deaths per 1,000 Live Births

2014 Texas data are preliminary
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
Infant Mortality Rate in Texas by Race/Ethnicity, 2005-2013

Deaths per 1,000 Live Births

Source: 2005-2013 Birth and Death Files, National Center for Health Statistics
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
Error bars represent 95% confidence intervals
Source: 2011 Linked Birth-Death Files
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
Leading Causes of Infant Death, 2007 - 2013

Deaths per 10,000 Live Births

2007 2008 2009 2010 2011 2012 2013

- Congenital Malformation
- Short Gestation & Low Birth Weight NOC
- Sudden Infant Death Syndrome
- Maternal Complications of Pregnancy
- Unintentional Injuries
- Maternal Complications of Placenta
- Infections in the Perinatal Period

NOC: Not otherwise classified
Source: 2007-2013 Death & Birth Files
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
2014 Texas and United States data are preliminary
Source: 2005-2014 Texas Birth Files, National Center for Health Statistics
Prepared by: Department of State Health Services (DSHS), Office of Program Decision Support, Sept 2015
2014 Texas data are preliminary
Source: 2005-2014 Texas Birth Files
Prepared by: DSHS, Office of Program Decision Support, Sept 2015
The March of Dimes Prematurity Campaign aims to reduce preterm birth rates across the United States. Premature Birth Report Card grades are assigned by comparing the 2014 preterm birth rate in a state or locality to the March of Dimes goal of 8.1 percent by 2020. The Report Card also provides city or county and race/ethnicity data to highlight areas of increased burden and elevated risks of prematurity.
Preterm Birth Rates

2014 Data based on obstetric estimate (OE) of gestational age; all previous years based on last menstrual period (LMP). Preterm is less than 37 weeks gestation.
Rising Rate of Prematurity

- The preterm birth rate has increased by 36% since the 1980s*
  - > 540,000 each year at present
  - 21% increase since 1990 (10.6% to 12.8%)
- Primarily 34 to 36 weeks gestation
  - Increase of 25% since 1990

*NCHS 2006 final natality data; March of Dimes, 2009
Rise in Late Preterm Births
(34-36 wks)

Source: National Center for Health Statistics
Prepared by March of Dimes, Periantal Data Center, 2009
Very preterm = <32 weeks’ gestation
U.S. Trends in Neonatal Mortality: Advances in Intensive Care

*NMR=neonatal mortality rate: # deaths to infants <28 days/1,000 live births
Number of Self-Reported NICU and NICU Intermediate Care Beds (Texas, 1998-2010)

Purpose

• Develop and recommend criteria for designating levels of neonatal and maternal care, including:
  • Specify the minimum requirements to qualify for each level designation
  • Establish a process for the assignment of levels of care to a hospital,
  • Provide recommendations for dividing the state into neonatal and maternal care regions,
  • Examine utilization trends in neonatal and maternal care, and
  • Recommend ways to improve neonatal and maternal outcomes.
Specialty Care Nursery Admissions (By Gestational Age)

- <32: 88.5%
- 32-33: 95.3%
- 34-36: 47.8%
- 37-38: 10.5%
- 39-41: 7.2%
- 42+: 13.6%
- All gestational ages: 14.4%
Table 1. Length of Stay and Hospital Charges Among Special Care Nursery Admissions

<table>
<thead>
<tr>
<th>Gestational Age</th>
<th>Average Length of Stay (Days)</th>
<th>Average Hospital Charges (Dollars)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Admissions</td>
<td>13.2</td>
<td>$76,164</td>
</tr>
<tr>
<td>&lt;32 weeks</td>
<td>46.2</td>
<td>$280,811</td>
</tr>
<tr>
<td>32-33 weeks</td>
<td>20.3</td>
<td>$102,182</td>
</tr>
<tr>
<td>34-36 weeks</td>
<td>9.8</td>
<td>$51,083</td>
</tr>
<tr>
<td>37-38 weeks</td>
<td>5.9</td>
<td>$37,137</td>
</tr>
<tr>
<td>39-41 weeks</td>
<td>4.9</td>
<td>$29,771</td>
</tr>
<tr>
<td>42+ weeks</td>
<td>6.5</td>
<td>$47,282</td>
</tr>
</tbody>
</table>
• Survival of extremely low-birth-weight infants (birth weight < 1000 g) increased 35% between the 1980s and the 1990s
  • 85% of infants with very low birth weight (between 500 and 1500 grams) survive

Improved Survival

• Mortality: 1980s vs. 1990s
  • 32 weeks’ gestation: 30% to 11%
  • <27 weeks’ gestation: 76% to 33%

### Increased Morbidity

Disabilities have also increased between 1980s & 1990s

Primarily chronic lung disease and neuro-developmental impairment

<table>
<thead>
<tr>
<th>Condition</th>
<th>1980s (%)</th>
<th>1990s (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sepsis</td>
<td>37</td>
<td>51</td>
</tr>
<tr>
<td>Periventricular leukomalacia</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>CLD: (O&lt;sub&gt;2&lt;/sub&gt; at 36 wks PMA)</td>
<td>32</td>
<td>43</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Deafness</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Neurodevelopment impairment*</td>
<td>26</td>
<td>36</td>
</tr>
</tbody>
</table>

(*major neurosensory abnormality and/or Bayley Mental Developmental Index score.

Canadian Data: 1996-97

Definitions:

• Early: < 28 weeks gestational age
• Moderate: 28–32 weeks
• Late: 33–36 weeks

BMC Pediatr. 2014; 14: 93
Canadian Data: 1996-97

Late Preterm: Age 10
Late Preterm: Age 2
Moderately Preterm: Age 10
Moderately Preterm: Age 2
Early Preterm: Age 10
Early Preterm: Age 2

Expected Survival

BMC Pediatr. 2014; 14: 93
Impact of Prematurity
A High Human Cost of Prematurity

- **Low birth weight**
- **Underdeveloped organs or organ systems**
- **Increased morbidity**
  - Breathing problems, including respiratory distress syndrome
  - Life-threatening infections
- **Increased disability**
  - Cerebral palsy, blindness, and deafness
  - Chronic lung disease
- **Learning and developmental disabilities**
- **Increased mortality**
  - Premature birth is the number one killer of newborns
  - Increased early childhood and late childhood mortality
- **Significant impact on family**
• Increased risk of serious and life-long health consequences, including cerebral palsy and other disabilities, as well as hearing, vision and breathing problems.
• Some babies are hospitalized for months, often miles from home.
• The baby’s health can change very quickly. Families often refer to it as a roller-coaster experience.
• Parents often see the baby only for a moment before he or she is whisked away to the NICU.

• Families face a stressful new world. Day-to-day life is completely disrupted.

• Parents often spend hours in the NICU, away from their jobs, other children, and normal responsibilities.

• Families face financial stress to pay the high NICU costs while spending time away from work.

• Emotional toll as they worry about their baby. Marriages can become strained.
Medicaid Costs

- ~54% of all Texas births (204,000) paid by Medicaid
- $2.2 billion per year in birth and delivery-related services for moms and infants through first year
  - >67% of Medicaid costs for hospitalized newborns tied to billing codes for prematurity
- **Newborn costs (1st year)**
  - Extreme Preterm infant: $54,400
  - Term infant: $480
Texas Medicaid Birth Expenditures (1999 – 2010)

Source: AHQP Claims Universe, TMHP. DSP Delivery records, HHSC
Economic Burden

• Do not include costs of the caregivers for individuals with disabilities such as out-of-pocket payments for education or loss of earnings during childhood
Costs after the Neonatal Period

- Post-discharge resource utilization is inversely related with gestational age.
- The majority of costs accrue in the first year of life.
- Costs for re-hospitalization are higher than outpatient costs.
Gilbert et al. estimated total per-patient neonatal hospital costs of $202,700 USD for a surviving baby born during the 25th week.

- $46,400 USD @ 30th week
- $1,100 USD @ 38-week

• Adjusted CPI for September 2014
  – Overall cost now 31.75 billion
  – 25 week infant now $304,245

