**Pediatric Primary Care and the NICU Survivor: A Unique Perspective**

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**Objectives**

1. Identify challenges and barriers pediatricians encounter in caring for the NICU survivor
2. Identify strategies that will optimize care of the NICU survivor
3. Develop a NICU survivor transitional care plan to a medical home model that will improve quality and safety

**Comprehensive Care for NICU survivors**

- Understanding who are the babies that reside in the NICU
- How many babies are we talking about?
- Is this number increasing or decreasing?
- What is the impact to families? Both emotionally or financially?

**Surviving the NICU**

- Advances in obstetrics and neonatal care has led to more premature and critically ill newborns surviving to NICU discharge and transitioning into community medicine.
  - 2013, US survival rate for preterm infants > 96%
- Of NICU survivors, 20% to 40% have complex medical problems and need specialty outpatient services and frequent primary care visits.
  - 110,000 for US annually

**Surviving the NICU**

- Within the first four months of NICU discharge for VLBW infants (BW<1500 grams):
  - Have 6 pediatric primary care visits
  - One ED visit
  - 24% readmitted
  - Highest medical complexity (vent-dependent, G-tube) may need 26 outpatient visits

Kuo et al, Matern Child Health J, 2015
Surviving the NICU

- AAP members surveyed: 259 community pediatricians reported outpatient care of the NICU survivors as challenging
- Identified multiple barriers to optimal care for the NICU graduates.
- 14% associated with "certified medical home" – Accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective care.
- Represented wide range of practice in years, equal numbers across decades from 1980’s to present.

Common NICU Morbidity

- Less than ½ reported being comfortable caring for infants with:
  - 28% CHD
  - 37% BW <1000 grams
  - 14% Short gut syndrome
  - 35% BPD
  - 27% HIE
- 61% comfortable caring for Trisomy 21.

Case Management

- 50-60% comfortable writing letters of medical necessity, determining need for OT, PT, ST, and coordinating care among subspecialists.
- 26-37% were comfortable in ordering adaptive equipment, home healthcare supplies, assisting families accessing community-based resources.

Bridging the Care Gap

- 50% Satisfied with obtaining sub-specialty consultation
- 50% Subspecialty communication
- 47% Uncomfortable with developmental screening and getting early intervention services
- 93% Comfortable with referrals to ECI
- 62% Comfortable with helping families navigate the system

Postpartum Depression

- 60% no evaluation
  - Those that do, use Edinburgh

End-of-Life/Palliative Care

- 11% Comfortable providing palliative care services
- 13% Comfortable in finding respite care

Other Significant Barriers

- 75% Time constraints
- 62% Reimbursement rate
- 45% Insufficient office help
- 37% Inadequate residency training
- 13% Absence of local NICU follow-up clinic
- 28% Medical legal concerns
- 10% Lack of interests
### Distribution of Gestational Age

<table>
<thead>
<tr>
<th></th>
<th>US (count)</th>
<th>US (%)</th>
<th>Texas (count)</th>
<th>Texas (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Term</td>
<td>3,605,221</td>
<td>90.4</td>
<td>358,590</td>
<td>89.7</td>
</tr>
<tr>
<td>Total Preterm</td>
<td>382,855</td>
<td>9.6</td>
<td>41,176</td>
<td>10.3</td>
</tr>
</tbody>
</table>


### US and Texas Birth Rate, 2005-2014

![Graph showing birth rates](source)

Source: 2005-2014 Texas Birth Files, National Center for Health Statistics

### Distribution of Race/Ethnic Groups Among All Live Births, 2005-2014

![Graph showing distribution](source)

Source: 2005-2014 Birth Files

### Maternal Age Distribution in 2005 and 2013

![Graph showing maternal age distribution](source)

Source: 2005 & 2013 Birth Files

### Infant Mortality Rate in Texas and The United States, 2005-2014

![Graph showing infant mortality rates](source)


### Infant Mortality Rate in Texas by Race/Ethnicity, 2005-2013

![Graph showing infant mortality by race/ethnicity](source)

Source: 2005-2013 Birth and Death Files, National Center for Health Statistics
Pediatric Grand Rounds - UT Health San Antonio 6/16/2017

Source: 2011 Linked Birth-Death Files

Source: 2007-2013 Death & Birth Files

Source: 2005-2014 Texas Birth Files, National Center for Health Statistics

Source: 2005-2014 Texas Birth Files

2016 MOD Premature Birth Report Card

United States 9.6%

C

US preterm birth rates

Preterm Birth Rate 9.6%
Rise in Late Preterm Births (34-36 weeks) - >70%

![Graph showing rise in late preterm births](image)

Source: National Center for Health Statistics, Prepared by March of Dimes, Perinatal Data Center, 2009

Very Preterm: USA 2001-2011

![Graph showing very preterm births](image)

US Trends in Neonatal Mortality: Advances in Intensive Care

![Graph showing US trends in neonatal mortality](image)

Texas Self-reported NICU beds, 1998-2010

![Graph showing NICU beds in Texas](image)

Perinatal Advisory Council

**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.

NICU Admissions by Gestational Age

![Graph showing NICU admissions by gestational age](image)

High Human Cost of Prematurity

- Low birth weight
- Underdeveloped organs or organ systems
- Increased morbidity
  - Breathing problems
  - Life-threatening infections
  - Gastrointestinal problems
- Increased disability
  - Cerebral palsy, mental retardation, blindness, and deafness
  - Short Gut syndrome
- Learning and developmental disabilities
- Increased mortality
  - Premature birth is the 2nd leading cause of newborn deaths
  - Increased early childhood and late childhood mortality
- Significant impact on family

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: (O2 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>Death</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

Improved Survival

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

Impact of Prematurity

- Low birth weight
- Underdeveloped organs or organ systems
- Increased morbidity
  - Breathing problems
  - Life-threatening infections
  - Gastrointestinal problems
- Increased disability
  - Cerebral palsy, mental retardation, blindness, and deafness
  - Short Gut syndrome
- Learning and developmental disabilities
- Increased mortality
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Impact on Babies

- Increased risk of serious and life-long health consequences, including breathing problems, feeding problems, cerebral palsy, developmental delay, vision problems, hearing problems, behavior problems, learning disability.
- 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.
Impact on Families

- 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. Fear for the baby’s life.
- 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.

Costs to Society

- ~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

TX Medicaid Birth Expenditure, 1999-2010

Costs after the NICU

- Post-discharge resource utilization is inversely related with gestational age.
  - Late preterms – costs 3 times higher than term infants post discharge
- Costs for re-hospitalization are higher than outpatient costs.
- Common medical issues require additional subspecialty care
- More discharged with assistive devices
- High risk for later behavior disorders
- Effects of prematurity persist into adolescence and adulthood
- Population that is at risk for excessive health care use.

Priority Population for Health System Redesign

- Population Health Management
  - Little research on costs/utilization prevention with optimal management of NICU survivors post discharge
- Optimal health/development achievement:
  - Appropriate growth
  - Timely management of acute/chronic conditions
  - Prevention of medical complications
  - Timely developmental assessments/interventions
  - Proactive recognition/management behavior disorders
  - Family support

Systems Based Practice

- Improved health, growth, and development
- Lower costs and preventable utilization

Raju et al., Acta Paediatrica, 2017

Kuo DZ, et al. Pediatrics, 2017
Transitioning the High-Risk Infant Home

- Discharge Criteria
  - Infant Readiness
  - Family and Home Environmental Readiness
  - Community and Healthcare System Readiness

AAP Fetus Newborn, Pediatrics, 2008.

Goals

- Successful transition to home care
- Provide an interdisciplinary medical home
- Optimize growth and development
- Prompt identification of specialty needs
- Limit ED visits and urgent care use
- Prevent hospitalizations
- Timely well child checks, vaccinations and RSV prophylaxis
- Use of patient data for process and outcomes of improvement

Care Team for NICU Survivor Medical Home

- Pediatrician
- Pediatric Nurse Practitioner
- Care Coordinator
- Medical assistants
- Registered Dietitian
- Social Worker
- Physical Therapist
- Speech Therapist
- Lactation Consultant

UHS NICU Graduate Clinic

A model primary care-based medical home for complex infants discharged from NICU up to the first 2 corrected years of life.
RN Care Coordinator

Transitioning the High-Risk Infant Home

- Connected with inpatient team on infant, family, and home readiness for discharge
- Attends discharge planning meetings
- Creates an Individual Family Care Plan
  - Meets family while still in NICU
  - Risk stratification based on medical and social complexity
  - Schedule initial visit within 3-5 days of NICU discharge
- Assists with specialty referral coordination

Pediatric Primary Care

Outpatient Management Specialized for Medically Fragile Infants

- Vision and Hearing Screening
- Ongoing Preventative Care/Immunizations
- Close monitoring of common medical problems of the preterm infant
- Evaluation of Growth and Nutrition
- Social Services
- Developmental Progress

Vision

- Retinopathy of Prematurity (ROP)
  - Can lead to retinal detachment and blindness
  - Intravitreal injections associated with late onset ROP
  - Yearly follow-up

Hearing

- Follow-up Neonatal Hearing Screen
  - At risk for hearing loss
    - NICU stay of greater than 5 days
    - Prematurity
    - Very low birthweight
    - ECMO (treatment for cardiorespiratory failure)
    - Assisted ventilation
    - Postnatal infections
  - Consider delayed onset or acquired hearing loss
  - Audiology assessment by 24-30 months

Immunizations

- Standard immunization schedule based on chronologic age
- Consider timing of blood products given and live virus vaccinations
- Palivizumab (Synagis®)
  - Humanized monoclonal antibody
  - Amelioration of Respiratory Syncytial Virus

Subspecialty Support

- All are needed
  - Pediatrics and Surgical
- Common care plan
- Bidirectional communication
  - Documentation, phone, SHM, email, face-to-face
- Triage medical problem for timely follow-up

Kuo DZ, et al. Pediatrics, 2017
Growth and Nutrition

- Extrauterine growth retardation
- Often discharged at a weight less than the 10th percentile for age
- Weight, length and HC must be plotted for CGA and nutritional assessments must be performed on a continuum, requiring long term surveillance.

Post NICU Discharge Nutrition Fact

The National Institute of Child and Human Development and Neonatal Research Network report that...

- By 36 weeks corrected age: 89% of low birth weight infants have growth failure
- By 18-22 months corrected age: 40% still have weight, length, and head circumference less than the 10th percentile
- By 7-8 years of age: 20% still remain below the 10th percentile for weight

Dusick et al, Sem Perinat, 2003

Difficulty with Feeds

- Disorganized Swallow
- Aspiration Risk
- Slow Feeding
- Decreased Feeding Endurance
- Reflux
- Gagging
- Oral Aversion

Nutritional Requirements

- Premature infants require increased protein, calcium, phosphorus, and iron intake
- Continue preterm/enriched formula 22 kcal/oz until 9-12 months CGA
  - Provide adequate energy/protein needs
- Most infants:
  - 108 kcal/kg/day
- Premature infants:
  - 110-130 kcal/kg/day

Average Growth Rates by CGA

- Weight:
  - First 4 months: 20-30 g/day
  - 12-18 months: 5-15 g/day
- Length
  - Initial growth: 0.8-1.1 cm/week
  - 12-18 months: 0.75-1.5 cm/month
- Head Circumference
  - Initial growth: 0.7-1 cm/week
  - 12-18 months: 0.1-0.4 cm/month
Breast Milk
- Optimal infant nutrition
  - Deficient in calcium, phosphorous, and vitamin D.
- Iron supplementation for exclusively breast-fed premature infants until 12 months CGA
  - Dose: 2-4 mg/kg/day
- Vitamin D supplementation
  - Minimum intake of 400 IU of vitamin D per day

Screening Labs
- Ca, Phos, Vit D 25-OH, Alk Phos
- H/H
- BMP

Psychosocial
- Financial/Emotional trauma
- Fear/uncertainty concerning the infant’s susceptibility to a life-threatening illness
- PTSD
- Social Concerns
  - Teen mother
  - Maternal history of significant medical illness or mental health concerns
  - Infants of drug dependent mothers

Social Services
- Provide emotional support for families as they navigate the medical needs of their child
- Address non-medical issues to avoid any delay in care
- Connect families to community resources for financial assistance and mental health needs
- Assist families in navigating government systems/resources (i.e. SSI, Medicaid and Medicaid Waiver Programs)
Therapy Services

Physical Development
- PT evaluations for CGA at well checks
- Early detection of physical developmental delays
- Close monitoring for cranial deformity
- Provides instruction on home therapy exercises
- Assists with referrals for ECI and ST/PT/OT

Neurodevelopment
- For high risk infants, formal screening should be done by specialized, multidisciplinary clinics.
- Neurodevelopment occurs on a continuum and requires long term surveillance.
  - Gross motor deficits manifest by 2 years of age
  - Language deficits manifest in the pre-school years
  - Behavioral and/or learning problems may not become apparent until school age

PREMIEre Clinic

Celebrating 38 years following University Health Systems’ Premature/High Risk Infants since 1979!
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Adult-Age Outcomes of the NICU Survivor

- Psycho-Social Difficulty
- Learning Disabilities
- Anxiety/depression
- HTN
- Metabolic Syndrome

Raju et al, Acta Paediatrica, 2017

Challenges…

- Patient/family obstacles
- Physician/practice obstacles
- Facility obstacles
- Community obstacles

Effective Care Delivery

- Patient/family: Engage and Empower
  - Self-management support
- Physician/practice: Interdisciplinary Team
- Facility: Process Improvement
- Community: Identifying Resources

Kuo DZ, et al, Pediatrics, 2017
Improving the Care of the NICU Survivor

- Clinical Practice Guidelines
- Specific to Preterm Infants
- Post-Discharge Nutrition
- Home Visitation
- Clinical Data-tracking

References