PEDIATRIC PRIMARY CARE and THE NICU GRADUATE: A Unique Perspective

Jennifer Aguilar, MD
Adjunct Assistant Professor
Department of Pediatrics
• Policies and standards of the Texas Medical Association, the Accreditation Council for Continuing Medical Education, and the American Medical Association require that speakers and planners for continuing medical education activities disclose any relevant financial relationships they may have with any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients whose products, devices or services may be discussed in the content of the CME activity.

The planners and speakers have no relevant relationships to disclose.

• I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.
Objectives:

• To identify challenges and barriers pediatricians encounter in caring for the NICU Graduate.

• To identify strategies that will optimize care of the NICU Graduate.

• To develop a NICU Graduate transitional care plan to a medical home model that will improve quality and safety.
The Stats

• According to the “2015 Healthy Texas Babies: Data Book,” the preterm birth rate in Texas has consistently been higher than the national average over the past ten years. ¹

• There are an estimated 380,000 premature infant births in the U.S. each year. In 2013, there were 47,611 preterm births in Texas. ²

  • ~ 920 pre-term births/week in Texas

  • 1 in every 11 Texas births is preterm

• 12.3% of live births in Texas are preterm (2020 US objective is 11.4%). ¹
Increasing number of premature births

Decreasing number of premature infant deaths

GROWING population of ex-premature infants
Pediatric Primary Care

- Evaluation of Growth and Nutrition
- Vision and Hearing Screening
- Developmental Progress
- Close monitoring of common medical problems of the preterm infant
- Ongoing Preventative Care
  - Immunization status
  - Synagis
Outpatient Management for Medically Fragile Infants

- Hypoxic ischemic encephalopathy
- Congenital heart disease requiring surgery
- Oxygen requirement at discharge
- Gastrostomy tube placement
- History of necrotizing enterocolitis
- Metabolic disorders
- Genetic disorders
- Hematology/oncology patients
CHALLENGES

• Patient/family obstacles

• Physician/practice obstacles

• Facility obstacles

• Community obstacles
RESOURCES

• Patient/family: Engage and Empower

• Physician/practice: Process Improvement

• Facility: NICU Graduate Transitional Care Plan

• Community: Identifying Resources
RESOURCES

• Patient/family: Engage and Empower
  • Advocating for child

• Physician/practice: Process Improvement
  • Scheduling/Coordinating

• Facility: NICU Graduate Transitional Care Plan
  • Communicating with NICU team

• Community: Identifying Resources
Follow-Up: Growth and Nutrition

• Preterm infants have increased requirements for protein, calcium, and iron. Appropriate growth requires increased caloric intake (>110 kcal/kg/day).

• NICU Graduate Feeding Issues
  • Feeding difficulty
  • Poor weight gain
  • Failure to thrive
  • Weight loss
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
Follow-Up: 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
Development - Therapy Services

- Early Childhood Intervention and Speech/Occupational/Physical Therapy
- Evaluations for corrected gestational age
- Early detection of developmental delays
- Close monitoring for deformity
- Provides instruction on home therapy exercises
Follow-Up: Psychosocial

- Financial concerns
- Emotional trauma, unresolved issues of anger and/or guilt
- Fear/uncertainty concerning the infant's susceptibility to a life-threatening illness

Social Concerns

- Teen mother
- Infants of drug dependent mothers
- Maternal history of significant medical illness or mental health concerns
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)
STRATEGIES

• TRANSITION

• CONNECT PATIENTS TO CARE

• PLUGGED IN
Transitioning the High-Risk Infant Home

- Weekly discharge planning meetings

- Discharge Criteria
  - Infant Readiness
  - Family and Home Environmental Readiness
  - Community and Healthcare System Readiness
Transitioning the High-Risk Infant Home

- Discharge planning able to assist with transition from inpatient setting
- Discharge summary arrives to clinic prior to initial visit
- Maintain connection with inpatient team on infant, family, and home readiness for discharge
TRANSITIONAL CARE PLAN

- Patient/family: Involved and Prepared

- Physician/practice: Systems In Place

- Facility: Improved Communication

- Community: Involved
1. Mandell, D.J., & Kormondy, M. 2015 Healthy Texas Babies: Data Book. Austin, TX: Division for Family and Community Health Services, Texas Department of State Health Services, 2015.

