Pediatric Primary Care and The NICU Graduate: A Unique Perspective

The Role of Developmental Follow-up Clinics and the NICU Graduate

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Role of Neonatal Follow-up Programs

“Medical Home Model”
- Provide a continuum of specialized medical management for NICU graduates
- Identify deviations in growth, behavior and neurodevelopmental outcomes
- Audit outcomes of perinatal interventions
- Ensure that NICU graduates and their families receive necessary medical and therapeutic intervention services (care coordination)
- Education, clinical research and quality improvement.
Advances in neonatal and perinatal care have resulted in significantly improved survival for premature infants

- Survival advances have not resulted in proportional reductions in disability rates

- Universal acceptance that neurodevelopmental outcome after preterm birth is the most important measure of neonatal ICU “success”
Long-term Neurodevelopmental Outcomes of Premature Infants

- Survival rates (insert survival graph over time)
# Outcomes of Premature Infants: Comparison of European and US Cohorts

<table>
<thead>
<tr>
<th></th>
<th>European Cohort 1998-2002</th>
<th>ELBW</th>
<th>34%</th>
<th>10.2%</th>
<th>18.6%</th>
<th>71.2%</th>
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<tbody>
<tr>
<td></td>
<td>ELBW</td>
<td>33%</td>
<td>14%</td>
<td>25%</td>
<td>64%</td>
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Overall Disability at 30 Months for 22-25 week ELBW Infants

- No Disability: 49%
- Severe disability: 23%
- Other Disability: 25%
- Died: 2%
- No data: 1%

Wood NS, et al. NEJM 2000
Neonatal Antecedent Risk Factors Associated with CP and Neurodevelopmental Impairment

**ELBW outcomes: Have they improved?**

<table>
<thead>
<tr>
<th>Table 4: Neurodevelopmental Outcomes at 20 Months’ CA</th>
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<tr>
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<tr>
<td>Neurosensory abnormality, n (%)(^a)</td>
</tr>
<tr>
<td>Cerebral palsy(^b)</td>
</tr>
<tr>
<td>Hypotonia</td>
</tr>
<tr>
<td>Hypertonia</td>
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<tr>
<td>Shunt–dependent hydrocephalus</td>
</tr>
<tr>
<td>Blindness(^c)</td>
</tr>
<tr>
<td>Deafness(^c)</td>
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<td><strong>n</strong></td>
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<td>MDI(^d)</td>
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<td>Mean ± SD</td>
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<td>&lt;70, n (%)</td>
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<td>≥85, n (%)</td>
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<tr>
<td>Neurodevelopmental impairment(^e)</td>
</tr>
</tbody>
</table>

*Wilson-Costello Pediatrics 2007
Neonatal Research Network*
Impact of early Nutrition and growth on brain development

- Premature infants are at risk for postnatal growth restriction
- Postnatal growth does not often match intrauterine growth
- Early malnutrition exerts an adverse affect on long-term developmental outcomes
- Malnutrition during vulnerable periods of brain development impacts outcomes
Neonatal Research Network: Growth Observational Study

Growth in the Neonatal Intensive Care Unit Influences Neurodevelopmental and Growth Outcomes of Extremely Low Birth Weight Infants

Richard A. Ehrenkranz, MD*, Anna M. Dusick, MD*, Betty R. Vohr, MD*, Linda L. Wright, MD*, Lisa A. Wragge, MPH*, W. Kenneth Poole, PhD*, for the National Institutes of Child Health and Human Development Neonatal Research Network

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Cohort
495 ELBW infants born at centers participating in The NICHD Neonatal Research network

Measurements
- Growth velocity in NICU
- Anthropometric measurements and outcome at 18-22 months corrected age
Conclusion: Growth velocity during the ELBW infant’s NICU hospitalization exerts a significant, and independent effect on neurodevelopmental outcomes long-term.

LONG-TERM developmental FOLLOW-UP programs: Purpose and goals

- To provide a continuum of specialized medical management for NICU graduates
- Identify deviations in growth, behavior, neurodevelopment, and facilitate medical management, support, and referral for intervention to ensure the best possible outcomes (e.g. ECI, rehab services (PT/OT/Speech therapy, feeding disorders clinic)).
- Clinical outcomes research and quality improvement
- Teaching and education
AAP Committee on the Fetus and Newborn 2008: recommends that premature NICU graduates should be enrolled in a follow-up program providing standardized neurodevelopmental assessment, and multidisciplinary care after discharge.

NICHD recommends that all ELBW infants <1000 grams at birth be followed up after discharge to assess growth, development, neurological status, behavior, and language outcomes.

State of Texas Levels of NICU Care Designation (HB15):
- “Ensure provisions for follow-up care at discharge for infants at high risk for neurodevelopmental, medical or psychosocial complications”
The State of NICU Follow-up in the USA

**Figure 1.** Services available in neonatal intensive care unit (NICU) follow-up clinics. ROP, retinopathy of prematurity.

**Figure 3.** How neonatal intensive care unit (NICU) follow-up clinics improve outcomes of NICU graduates.

**Figure 4.** Allocation of additional resources. NICU, neonatal intensive care unit.

COOK CHILDREN’S HOSPITAL N.E.S.T FOLLOW-UP Center

NICU graduate
Early
Support and care
Transition
developmental
follow-up Center
Nest Clinic Mission Statement

- Our goal is to provide comprehensive, multi-disciplinary, and family-centered care program designed to support the developmental, medical and psychosocial progress of each child and their family through five years of life.

- To ensure that every NICU graduate has the opportunity to reach their fullest individual developmental potential.
To support patients and their families as they transition from the NICU to home and the community.

- Function as an extension of the NICU ("Outpatient NICU")
- Early identification of developmental delay and motor difficulties
- Identify mothers at significant risk of postpartum depression/PTSD and impaired maternal-infant interactions
- Provide care coordination and community referrals
- Build collaborative relationships with the primary care provider serving as a vital resource in the care of these high-risk infants and families.
NEST IS NOW 36 MONTHS OLD!!!

- **DOB**: 11/12/2013
- **GA**: 28 weeks’
- **BW**: Infinity
- **CGA**: N/A
Who do we see?

Referral is based on diagnosis and physician recommendation.

- <1500 grams
- <32 weeks’ gestation
- NEC (> stage II)
- Twin-to-twin transfusion
- Bronchopulmonary dysplasia
- Seizures
- ECMO
- Physician referral
- Double volume or partial exchange transfusion
- ICH (Gr III-IV)
- Congenital Heart Disease (critical)
- Diaphragmatic Hernia
- iNO therapy
- ROP (severe)
- PPHN (severe)
- Congenital Anomalies
- HIE
- Research Study Patients
- Maternal substance abuse
Timing of follow-up?

- 4-6 wks
- 6 mo
- 12 mo
- 18 mo
- 24 mo
- 3-5 yrs.
How long will they followed in the clinic?

The patients will be followed by the center through age 5 years.
Assessments

- Monitoring Growth trends and nutrition
- Standard comprehensive neurological exam
  - Amiel-Tison neurological assessment
  - Gross Motor Function Scale
- Developmental assessments:
  - Infant: Ireton Infant and Child Developmental Review
  - Bayley Scales of Infant Development III
- Sensorimotor
  - Assess oral-motor skills
  - OT/PT/Speech/Audiology
- Behavioral
  - Child Behavior Checklist
  - MCHAT, ADOS, Connors
Assessments

- Maternal post partum depression/PTSD screening
- School readiness evaluation
- Food security questionnaire
Interventions

- Family and sibling support
  - NICU Helping Hands: Parent support and mentoring program
  - Parenting education
- On-site clinical Therapist (NICU-NEST)
- Care coordination with medical specialists and community services
- Partner with primary care physician/medical home
- Referrals to other subspecialists and community programs
Goals and Objectives:
✓ Monitor growth trends using WHO or CDC growth charts
✓ Dietary history and nutrition assessment
✓ Assess feeding behavior and oral-motor skills
✓ Recommendations for dietary modifications, coordinate with NEST team

Challenges/QI opportunities:
✓ Compliance with feeding recommendations to ensure appropriate postnatal growth
✓ Awareness of post-discharge nutrition recommendations:
  ✓ Use of preterm enriched formulas after NICU discharge
  ✓ Timing of transition to term formulas for VLBW graduates
Nutrition at 1st NEST Visit among vlbw infants: 4-6 weeks after discharge

- Patients Discharged from NICU on Transitional Formula
  - 19.4% (12/62)
  - 80.6% (48/62)

- Type of Formula Reported at 1st NEST Visit
  - 3.2% (2/62) Transitional Formula
  - 33.9% (21/62) Term Formula
  - 62.9% (39/62) Exclusive EBM
Goals and Objectives:
✓ Provide consultation and support for breastfeeding mothers after NICU discharge.
✓ Evaluate compliance with post-discharge breastfeeding rates according to national targets
✓ Challenges:
  ✓ Breastfeeding discontinued before D/C to “get the baby home faster”
  ✓ Increased demands at home and increased stress lead to early discontinuation.

✓ QI opportunity: Evaluate barriers to continued BF in NICU and post-D/C, implement a QI initiative to sustain higher rates of BF after NICU D/C.
**Goals and Objectives:**

- Provide on-going evaluation and surveillance for early detection of infants at high risk for motor (gross & Fine), and neurosensory delays after NICU discharge.

- Make recommendations for early intervention and intensive rehab. therapy services

- Identify infants at high-risk for impaired oral-motor skills, oral aversion, and sensory integration abnormalities.

- Early identification of infants with speech and language delays

- Early referral for evaluation and treatment.
Goals and Objectives:

- Follow-up OAE hearing screen for at risk population post-NICU discharge

- Based on AAP recommendations:
  - Identify infants at highest risk for sensorineural hearing impairment (OAE/ABR screening)
  - Referral to ENT
  - Amplification (as indicated)
Social Worker, Family & Sibling Support, Clinical Therapist

Goals and Objectives:

- Evaluate family functioning, coping, and utilization of community support services.
- Identify factors involved in family dysfunction and barriers to sustained follow-up compliance.
- Assist families to gain access to community resources and financial services (SSI, Medicaid waivers, WIC, ECI, parenting services, drug rehabilitation, and crisis counseling).
- Assist families with transportation services, and emergency food resources.
- Implement strategies to track high-risk families, and minimize lost to follow-up.
- Family and peer-to-peer support
- Family evening educational sessions
- Facilitate transition to school
Goals of NEON:

- To establish best practices for follow-up care and assessment of the NICU graduate
- Conduct quality improvement and outcomes research
- Develop clinical care guidelines
- The collaborative was established February 20, 2015, at which time key stakeholders in neonatal follow-up convened at University of Texas, San Antonio for our 1st annual summit.
  - Initiated dialogue about NICU follow-up best practices
  - Discussed the differences and common features of each follow-up program
  - Shared common challenges of establishing and maintaining a NICU follow-up program in both academic and non-academic institutions
  - Discussed the feasibility of creating working groups and common clinical guidelines focused on long-term follow-up of high-risk NICU survivors
- Second annual summit was held February 19, 2016 at Cook Children’s Hospital in Fort Worth
  - Presentations by Keynote speakers
  - Expanded participation of key stakeholders
  - Established active working groups for best practices
- Third Annual Summit will be held February 10, 2017 at University of Texas, Houston
Thank you!!!