Developmental Care and Concerns of the NICU Graduate

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Objectives

1. Identify biological, medical, and psychosocial risk factors for developmental delay among NICU graduates
2. Examine developmental outcomes among high-risk NICU graduates
3. Make appropriate recommendations for developmental follow-up and early intervention services for high-risk NICU graduates
<table>
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<th>Identified Biological/Medical Risk Factors for Developmental Delays</th>
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<tr>
<td>• Prematurity</td>
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<td>• Low Birth Weight</td>
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<td>• Intraventricular hemorrhage-IVH</td>
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<td>• Periventricular leukomalacia-PVL</td>
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<td>• Hypoxic ischemic encephalopathy-HIE</td>
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<td>• Bronchopulmonary dysplasia-BPD</td>
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<td>• Necrotizing enterocolitis-NEC</td>
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<td>• Retinopathy of prematurity</td>
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Psychosocial Risk Factors for Developmental Delay

• Low maternal education
• Low income
• Single parenthood
• Minority status

• No/late prenatal care
• Substance abuse
• No insurance
• Environmental stress
Protective Factors – Predictors of Resiliency

• Caregiver characteristics
  • Responsive
  • Accepting
  • Stimulating
  • Organized

• Physical environment characteristics
  • Safe play area for the child
  • Non-crowded home
Incidence of Major Disabilities for NICU Graduates

• Major Disabilities
  • Moderate to Severe Intellectual Disability
  • Sensorineural deficits – hearing loss, blindness
  • Cerebral Palsy
  • Epilepsy

• Incidence Rates
  • Full Term – 5%
  • Low Birth Weight (<2500g) – 6-8%
  • Very Low Birth Weight (<1500g) – 14-17%
  • Extremely Low Birth Weight (<1000g) – 20-34%

• Similar pattern found based on gestational age
Other Neurodevelopmental Difficulties for NICU Graduates

- Learning disabilities (e.g. math, writing)
- Borderline to low-average IQs (Each week <33 weeks ↓ 1.7-2.5 IQ points)
- Attention-deficit hyperactivity disorder (ADHD)
- Coordination difficulties
- Language difficulties (e.g. understanding syntax, shorter sentences)
Other Neurodevelopmental Difficulties for NICU Graduates Continued

- Visual-motor problems
- Impaired executive functioning (e.g. planning, problem solving flexibility)
- Specific Neuropsychological Deficits (e.g. verbal working memory, processing speed)
- Autism Spectrum Disorders
- Behavior and psychological problems (e.g. internalizing problems, social difficulties)
Incidence of Other Neurodevelopmental Difficulties for NICU Graduates

• 50-70% of VLBW/VPT have neurodevelopmental difficulties
  • Often multiple, compounding difficulties that influence academic performance

• Incidence of Special Education Service Needs
  • Full Term – 2.3-8%
  • Late Preterm (34-36 weeks) – 17%
  • VLBW/VPT – 25-40%
  • ELBW/EPT – 60-70%
Cognitive Recovery

• Some evidence of IQ and verbal ability scores improvement from ages 3 to 8 years

• Predictors of higher scores
  • Older child age
  • Two parent household
  • Higher maternal education

• Declining scores were seen for children with early IVH and subsequent CNS injury

• Improvements through preschool age seen with early intervention services
Transition to Adulthood - Outcomes for Prematurity

• Strongly influenced by environmental factors for those without major disabilities
• More self and parent reported functional difficulties than full term peers
• Self and parent reported quality of life is high and similar to full term peers

• Identified challenges compared to full term peers
  • Lower high school graduation rates
  • Lower college enrollment rates for men
  • Mildly lower IQ scores
  • Slower processing speeds
  • Higher rates of mental health difficulties
  • Higher rates of receiving disability income
Outcomes of Late Preterm Delivery

• Late Preterm - 34-36 weeks: 75% of preterm births
  • Time of significant brain development (e.g. brain size, white matter volume, neural connections)

• Outcomes generally between those of full term and earlier preterm births

• Significant neurodevelopmental impairment rare - but greater risk than term infants
  • cerebral palsy (0.43 versus 0.14%) and intellectual disability (0.81 versus 0.49 %)

• Higher rates of elementary school special education and kindergarten retention

• Varied findings on risk for mental health outcomes
Why is Developmental Follow-up Necessary?

• Assess how NICU practices affect functional outcomes

• Improve compliance with NICU discharge recommendations

• Identify developmental concerns early to initiate interventions
  • Risk factors not sufficient to predict outcomes for an individual child

• Identify continued need for academic or psychosocial supports
  • Milder difficulties may not be identified until later ages
Recommended Ages of Assessment

• 4-6 months adjusted age – identify severe disability, connect with family, begin services
  • Results may be influenced by medical recovery

• 12 months adjusted age – emerging skills across domains, cognitive-motor interaction
  • Greater medical stability

• 18-24 months adjusted age – influence of environment, domain-specific skills
  • Minimum standard of care

• 3-4 years – begin to predict IQ, academic readiness

• 6 years – identify academic and attention difficulties

• 8 years – stable IQ, neuropsychological functioning, behavior, learning
Parent Education and Support

• Structured teaching for specialized care needs at home – two caregivers
• Discussing risks and follow-up needs
• Involving parents in decision making
• Counseling to address family overprotection and anxiety - Vulnerable child syndrome

Resources:

• Parent support groups

• Preemie Primer: A Complete Guide for Parents of Premature Babies--from Birth through the Toddler Years and Beyond, Jennifer Gunter, MD, 2010.

• Online resources – English and Spanish
  • HealthyChildren.org from the AAP - https://www.healthychildren.org/English/ages-stages/baby/preemie
  • March of Dimes - http://www.marchofdimes.org/
  • Support 4 NICU Parents - http://support4nicuparents.org
Assessment/Interventions for High-Risk Infants and Toddlers

• NICU follow-up clinics

• Early Steps
  ◦ IDEA Part C Early Intervention services for families of children 0-3
  ◦ Focus on coaching parents/caregivers to enhance developmental stimulation

• Healthy Start
  ◦ Pregnant women and infants
  ◦ Care coordination to assure access to services
  ◦ Parent education, psychosocial counseling

• Preschool programs
  ◦ Early Head Start, Early Learning Coalition

• Direct therapies
  ◦ PT, OT, ST
Early Steps - Determining Eligibility

CURRENT CRITERIA

• Developmental delay – at least 2.0 SD below the mean in one developmental domain (DQ ≤ 70) or 1.5 SD below the mean in two or more developmental domains (DQ ≤ 78)

OR

• Documented, established condition that places a child at risk for developmental delay
Established Conditions

• Birth weight below 1200 grams
• Genetic and metabolic disorders
• Neurological disorder
• Significant sensory impairment (vision/hearing)
• Autism spectrum disorder
• Severe Attachment Disorders
Early Steps Contact Information

• Treasure Coast (Palm Beach, Martin, St. Lucie, Okeechobee, Indian River Counties)
  • For referrals in Palm Beach County: 561-882-6426, Toll Free: 866-790-6963, Fax: 561-881-0972
  • For referrals in Martin, St. Lucie, Okeechobee & Indian River: 772-380-9972, Toll Free: 866-986-9486, Fax: 772-380-9976

• Gold Coast (Broward County) - Phone: (954) 321-7200, Fax: (954) 779-2316

• Miami-Dade North (Dade North of Flagler) - Phone: 305-243-6660, Fax: 305-243-3501

• Southernmost Coast (Dade South of Flagler, Monroe) - Phone: 786-268-2611, Fax: 786-268-1748
Key References


