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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

Identified Biological/Medical Risk Factors for Developmental Delays

- Prematurity
- Low Birth Weight
- Intraventricular hemorrhage-IVH
- Periventricular leukomalacia-PVL
- Hypoxic ischemic encephalopathy-HIE
- Bronchopulmonary dysplasia-BPD
- Necrotizing enterocolitis-NEC
- Retinopathy of prematurity
- Congenital anomalies
- Poor NICU growth and nutrition
- Neonatal seizures
- Severe hyperbilirubinemia w/exchange transfusion
- IVF and Multiparity
- Hearing or Vision Impairment
- Medical procedures (e.g. postnatal steroids, total parenteral nutrition)

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/
  - KidsHealth from Nemours - https://kidshealth.org/en/parents/preemies.html
  - 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)
  - http://www.easterseals.com/florida/our-programs/childrens-services/treasure-coast-early-steps/treasure-coast-early-steps.html
  - 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

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