NICU Follow-up & Outcomes: What happens in High Risk Infant Follow-up?

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Objectives

Participants will be able to:

1) Describe components of high risk infant follow-up assessments.
2) Explain short term outcomes to NICU parents.
3) Summarize long term outcomes of preterm infants:
   Cognitive
   Behavioral
   Emotional
NICU Nurses: perspectives from HRIF

- Key personnel with relationships with families
- Able to provide support and education over time
- Families keep in touch over time
Preterm birth <37 weeks gestation

California, 2012-2015 Average

US: 382,786
9.6% of births

California: 41,600
8.5% of births

Source: National Center for Health Statistics, final natality data.
Very preterm birth: <32 weeks

California and US, 2015

US: 63,145
California: 6,386

Very preterm is less than 32 weeks.
Source: National Center for Health Statistics, final natality data.
Prematurity: risks for adverse outcomes

- Developmental delays or disability
- Cerebral Palsy
- School problems
- Emotional Problems
- Behavioral problems
- Medical Problems in childhood
- Medical risks in adulthood
What is High Risk Infant Follow-up? (HRIF)

- Programs designed to follow infants and children with risks for problems in development and help families get services
- Named HRIF in California: “NICU follow-up” programs exist in many states and countries
California Children’s Services
High Risk Infant F/U Program

Mandates Diagnostic Services to eligible children birth to age three

- Comprehensive history, physical and neurologic assessment
- Developmental assessment
- Family psychosocial assessment
- Hearing assessment
- Ophthalmologic assessment
- Case management services
Quality Measures

california perinatal quality care collaborative

Data from birth certificates, NICU records, Transport forms, AND High Risk Infant Follow-up
High Risk Infant Follow-up

- Infants who meet CCS criteria
  Prematurity <32 weeks, <1500 g
  Specific medical eligibility criteria (low pH, hypotension...)
  Neurologic Insults
  Congenital Heart Disease requiring surgery or minimally invasive procedures during neonatal period

- Other criteria are HRIF program specific (some only accept CCS criteria, others take all comers)
CCS HRIF PROGRAM MEDICAL ELIGIBILITY CRITERIA

Data should be collected on infants/children under three years of age who meet California Children's Services (CCS) HRIF medical eligibility criteria and who met CCS medical eligibility criteria for Neonatal Intensive Care Unit (NICU) care OR had a CCS eligible medical condition at some time during their stay in a CCS-approved NICU, even if they were never a CCS client. Infants are medically eligible for the HRIF Program when the infant:

Met CCS medical eligible criteria for NICU care, in a CCS Program-approved NICU, regardless of length of stay, (as per Number Letter BS-0502, Medical Eligibility in a CCS Program-approved NICU or the most current N.I.). NOTE: Medical eligibility includes neonates who require direct admission to a CCS-approved NICU, who are never admitted to a CCS Program-approved NICU, but who otherwise meet all medical eligibility criteria for HRIF services.

OR

Had a CCS Program-eligible medical condition in a CCS Program-approved NICU, regardless of length of stay, even if they were never CCS Program Clients during their stay (as per California Code of Regulations, Title 22, Section 41515.1 through 41518.9, CCS Program Medical Eligibility Regulations).

AND MET ONE OF THE FOLLOWING:

Birth weight ≤ 1500 grams or the gestational age at birth < 32 weeks.

OR

Birth weight > 1500 grams and the gestational age at birth ≥ 32 weeks and one of the following criteria was met during the NICU stay:

1. pH less than 7.0 on an umbilical blood sample or a blood gas obtained within one hour of life or an Apgar score of less than or equal to three at five minutes or an Apgar score less than 5 at 10 minutes.

2. An unstable infant manifested by hypoxia, acidemia, hypoglycemia and/or hypotension requiring pressor support.

3. Persistent apnea which required caffeine or other stimulant medication for the treatment of apnea at discharge.

4. Required oxygen for more than 28 days of hospital stay and had radiographic finding consistent with chronic lung disease (CILD).

5. Infants placed on extracorporeal membrane oxygenation (ECMO).

6. Infants who received inhaled nitric oxide greater than four hours, and/or treatment during hospitalization with sildenafil or other pulmonary vasodilatory medications for pulmonary hypertension.

7. Congenital heart disease requiring surgery or minimally invasive intervention.

8. History of observed clinical or electroencephalographic (EEG) seizure activity or receiving antiepileptic medication(s) at time of discharge.

9. Evidence of intracranial pathology, including but not limited to, intracranial hemorrhage (grade II or worse), white matter injury including periventricular leukomalacia (PVL), cerebral hemorrhage, cerebral infarction or stroke, congenital structural central nervous system (CNS) abnormality or other CNS problems associated with adverse neurologic outcome.

10. Clinical history and/or physical exam consistent with neonatal encephalopathy.

11. Other documented problems that could result in neurologic abnormality, such as: history of CNS infection, documented sepsis, bilirubin at excessive levels concerning for brain injury as determined by NICU medical staff, history of cardiovascular in stability as determined by NICU medical staff due to sepsis, congenital heart disease, patent ductus arteriosus (PDA), neonatal necrotizing enterocolitis, other documented conditions.
Changes in brain volume and maturation with increasing gestational age.

Why do we have Follow-up?
White matter maturation in the neonatal brain is predictive of school age cognitive capacities in children born very preterm.
Known or Potential Neurologic Injury

- Hypoxic Ischemic Encephalopathy (HIE)
- Seizures
- Significant hypoglycemia
- Significant hyperbilirubinemia
- Hypotension
- Brain Bleeds:
  - Strokes
  - IVH
HRIF: What happens?

- Review of medical and psychosocial history.
- Interim history, parental concerns
- Developmental evaluation (including age appropriate Autism Screening)
- Neuromuscular examination
- Assessment of growth
- Physical exam
- Development of plan, anticipatory guidance, recommendations, case management referrals
Psychosocial Assessment

Social worker or provider performs:

• SES issues? Money, insurance, housing, transportation...
• Stress
• Depression, anxiety, & PTSD
• Domestic violence
Bioecological Model

Development is influenced by multiple factors all interacting with each other.
Developmental Assessment

- Use a standardized test
- Administration takes time and expertise
- Criterion referenced = performance of the infant/child compared with a criteria and scored
- Norm referenced = a population was used to determine what is normal for a certain age
Early Developmental Outcomes

- Lower test scores on standardized assessments
- Higher rates of Autism Spectrum Disorder
- Depending on type of test and age of administration may or may not predict ability when older.

HRIF Role:
Based on **risks** and/or results of assessment, referred for early intervention services
Often: in home, early intervention specialist works with child and teaches/supports parent.
Later Outcomes

• Children are assessed by psychologists
• Not part of the “HRIF” program after age 3
• Requires different types of testing
Why measure cognitive and academic skills?

The preterm infants mean cognitive scores were 87.69 compared with 103.91 for term.

At kindergarten the preterm infants (<1000 g or <28 weeks) had lower cognitive scores than term controls BUT the mean was still in the “average” range, just more with lower scores.

Table 3

<table>
<thead>
<tr>
<th>Domain/Measure</th>
<th>EPT/ELBW Group n Adj M (SE)</th>
<th>NBW Group n Adj M (SE)</th>
<th>F (df) from ANCOVA</th>
<th>ES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global Cognitive Ability</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>WJ-III COG Brief Intellectual Ability (BIA)</td>
<td>142 87.69 (1.57)</td>
<td>110 103.91 (1.81)</td>
<td>40.58 *bc</td>
<td>0.87</td>
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</table>

Cognitive outcomes for extremely preterm/extremely low birth weight children in kindergarten.
Orchinik L, Taylor HG, Espy KA, Minich N, Klein N, Sheffield T, & Hack M.
Kindergarten readiness

Preterm infants more likely to be found “not ready” on testing

Long term Behavioral and Emotional Issues

ADHD and attention problems in preterm infants

Problems with social functioning

“Subtle differences” in social behavior
(Jones, Champion, & Woodward, Early Human Development; 2013; 89: 795-802)

Anxiety, depression and social problems in adolescence
Neuromuscular examination

- Quality of movement
- Flexibility: passive tone
- Strength: active tone
- Symmetry
- Reflexes
Motor Impairment

Preemies *may* have difficulty with:

- Fine motor tasks
- Gross motor tasks
- Visual motor tasks
- Visual spatial tasks
Strength

Conditions associated with decreased strength:

- Chronic Lung Disease
- Congenital Heart Disease
- Poor Growth
- Hypotonia
  - Hypotonic CP
  - Syndromes
Later Outcomes: Minor Motor Dysfunction

Saigal et al Pediatrics 2007;119:562-573
Cerebral Palsy

Overall incidence 1-3 per 1000 (0.1-0.3%)

Risks include: multiple gestation (even if not premature), maternal chorio, stroke, or birth hypoxia (small percentage of all cases of spastic cerebral palsy).

50% of cases unknown risk.

Prematurity: Statistics vary by country and how the diagnosis was made.

- < 1500 gm  5-10%
- < 1000 gm  10-30%
Spastic CP more common in The HRIF population. Some children have Hypotonic (or atonic), ataxic, mixed, or dyskinetic CP.
Motor tracks pass near the Ventricles. IVH or periventricular Leukomalacia may damage them.

Picture courtesy of Dr. Yvonne Vaucher
Higher prevalence of CP in Black children

Functional Classification of CP

From: “walks without limits”
To “no voluntary control of muscles Unable to maintain head in upright Position.”

Classification can be used for research AND to identify the level of support needed
HRIF Role

- Careful neuromuscular exams
- Refer those with concerning findings to the CCS Medical Therapy Program (MTP) serves children with qualifying diagnoses until age 21
- Recommend referral if findings suspicious but do not meet CCS MTP criteria
- Education and family support
Case Management

Primary care provider
Specialists
Early Intervention
Social Workers
Referrals
Therapists
Social Service Agencies
Parent Education
From NICU to HRIFF

• Teach parents
• Support families
  – Involve HRIF prior to discharge if a high risk situation
• Share information at case management/discharge planning rounds
• Assist with referrals
• Remind families about HRIF
• When they call with concerns reach out to HRIF
Questions?

- Thanks for your care for families and babies in the NICU
- HRIF programs welcome you to visit and see what we do