Primary Care Follow-Up of the Extremely Preterm Infant

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Follow-Up of the Preterm Infant

I. Discharge counseling for the preterm infant
II. Growth and nutrition after discharge
III. Immunizations: when and what?
IV. Chronic diseases associated with prematurity: bronchopulmonary dysplasia, anemia
V. Vision and hearing follow-up
VI. Developmental outcomes and follow-up
Definitions

- Low Birth weight (LBW) <2500 grams
- Very LBW <1500 grams
- Extremely LBW <1000 grams
- Chronological Age: age from date of birth
- Corrected Age: (aka adjusted age) age from estimated term birth

Preterm Birth %

- 36 weeks: 40%
- 35 weeks: 14%
- 34 weeks: 13%
- 33 weeks: 7%
- 32 weeks: 5%
- <32 weeks: 7%
NICU Discharge

- Important to recognize the prior illnesses and length of the hospital stay
  - Not just from a medical perspective and the relationship to disease processes, but also regarding parental anxiety
  - They might have watched for months as their baby did not sleep properly regarding SIDS
  - Can be very challenging for parents, and typically requires weeks/months of mental preparation

Parental Concerns

1) “My baby is so fragile! We are scared to go home on the monitor and medications. Is my baby ready to go home?”
2) “Am I capable of taking care of my baby on my own? I am terrified!”
3) “How do I get through the first night without you there to help?”
Parental Concerns

4) “What if I forget CPR?”
5) “What do I tell people about visiting?”
6) “What is our future going to be like?”
7) “Will my baby continue to sleep all the time?”

NICU Discharge

➢ What we do for an NICU discharge:
   ✓ NICU discharges take weeks-months to occur for complicated patients
   ✓ Parents are required to complete monitor training provided by company
   ✓ NICU provides CPR training
   ✓ Extensive parental education and training provided by NICU staff
   ✓ We routinely require parents to do “Care by Parents”
   ✓ We utilize medically fragile foster care if necessary
NICU Discharge

- During period of high anxiety
  - Discuss anxiety with the parents
    - Normal to be anxious
  - Encourage periods of full care
  - Encourage kangaroo, breastfeeding to empower parents
- Direct contact with primary MD

Sleep Patterns

- Changing Sleep and Feeding Patterns
  - Preterm infants are asleep 80% of the time
  - Short sleep/wake cycles
- Leads to frequent small feeds
- Few long periods of sleep for parents
- Interaction periods short
- Lengthens by 3-4 months corrected age
Sleep Positioning

➢ SIDS and sleep positioning
  • Back to sleep
  • Parents have seen bad “role modeling” by the NICU for months
  • Must reinforce the importance

➢ Education
  • Home infant monitoring does not decrease the chance of SIDS

Behavioral Changes

➢ Preterm Infants have delayed state control
  • Avoid over stimulation
    − One stimulus at a time
  • Recognize behavioral patterns
    − Time-out cues
Colic

- Onset by gestational age
- Lack of crying in premie leads to fear when crying starts
- Colic starts 2-4 weeks after discharge
- Management the same as term
- DON’T stop iron, change formulas

Growth

- Use corrected age (i.e. correct for prematurity)
- Chronic problems will slow growth
  - will see catch-up with resolution
- What is the order of “catch-up”?
  1) HC 8 mos CA
  2) Weight 12-18 mos CA
  3) Length 2+ years CA
**Rate of Growth**

<table>
<thead>
<tr>
<th>Corrected Age (mos)</th>
<th>0-3</th>
<th>3-6</th>
<th>6-9</th>
<th>9-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight (g/d)</td>
<td>≥20</td>
<td>≥15</td>
<td>12-14</td>
<td>10</td>
</tr>
<tr>
<td>Height (cm/wk)</td>
<td>0.8</td>
<td>0.5</td>
<td>0.4</td>
<td>0.3</td>
</tr>
<tr>
<td>HC (cm/wk)</td>
<td>0.5</td>
<td>0.25</td>
<td>0.25</td>
<td>0.25</td>
</tr>
</tbody>
</table>

**Growth**

- IUGR infants follow their own curves
- How long do you use corrected age?
  1. Weight until 24 months
  2. Height until 4 years
  3. HC until 18 months
Nutrition

- Extremely preterm infants have increased nutritional requirements
  - Truncated 3rd trimester accretion of Fe, Ca, and Vitamins
  - Increased protein needs to grow
    - 3.5-4 g/kg/d

Nutrition

- Modify breast milk to increase protein, Ca, Phos, vitamins
- Breast milk has many advantages early and late
  - Immunoprotectant
  - Maternal attachment
MBM supplements

- Alternate with premie formula
- Enhance with premie formula
  - Neosure
    - 1 tsp/90 cc = 24 cal/oz (loose)
  - Enfagrow
    - 1 tsp/90cc = 24 cal/oz (packed)
- Fe for 6 months corrected age
  - Can stop when preterm discharge formula reaches a volume of 720 ml (24 oz)

Premie Formulas

- Fairly low in iron
- Ad lib plus 4 mg/kg/d of iron
- MVI until taking at least 450 ml of premie formula per day
- Change to whole milk at 1 year corrected age
  - Preterm formula companies suggest for at least 9 mos CA
Soy Formula

- Never use soy
- Frequently given due to colic
- Phytate in soy binds calcium
  - Leads to rickets
  - Prevents healing of osteopenia of prematurity

Solids

- Introduce on corrected age schedule
  - Typically not until 6 mos CA
- Most initial solids are carbohydrates
- Babies need prolonged period of protein from formula (9-12 mos CA)
Immunizations

- Give on chronological basis
- Give standard doses
- Hepatitis B
  - 1st dose is given at 1 mos regardless of the weight
- Influenza is > 6 months
- If < 6 months, immunize the herd
- Rotavirus is not given until after discharge

RSV Prophylaxis

- Reduces risk of being hospitalized for infants with Congenital Heart Disease, Chronic Lung Disease (BPD), and birth <35 weeks
  - Decreased hospitalizations by 55%
- Seasonality varies depending on region
RSV Prophylaxis Indications

1. Chronic lung disease requiring medical management in the last 6 months and < 2 years
2. Premature infants < 28 weeks and less than 1 year at the start of RSV season
3. Premature infants 29-32 weeks and < 6 months at the start of RSV season
4. Premature infants between 32-35 weeks who are < 6 months at the start of RSV season
5. Congenital heart disease in infants <2 years (CHF, pulmonary hypertension, and cyanotic heart disease)

RSV Prophylaxis

- 5 doses for infants with Congenital Heart Disease, Chronic Lung Disease (BPD), and birth <32 weeks
- 3 doses for infants 32 0/7-34 6/7 weeks who are born within 3 mos of the flu season or during the flu season
  - Risk factors:
    - Infant attends child care
    - 1 or more siblings or other children younger than 5 years live permanently in the child’s household
**Chronic Lung Disease**

- **Definition:** Neonate discharged on supplemental oxygen
- **BPD definition:** Preterm infant discharged on supplemental oxygen
  - Post-hospital discharge there should be liberal use with BPD
  - Infants lack hypoxic drive
    - Acutely → apnea
    - Chronically → cor pulmonale
- **Try to maintain at 95% or better**

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**Oxygen Management in BPD**

- Reinforce importance of parents not weaning
- Steady growth indicates resolving disease
- Avoid rapid weans, move sequentially 1-2 times/month
  - Sleep, feeding, car seat last to go
- Wean completely off when well saturated during “work periods”
- Signs of hypoxia include A/Bs, poor feeding and weight gain, pallor, sleepiness
- Consider an echocardiogram to assess for pulmonary hypertension with a cardiology consult if the infant fails to wean off by 3 months after discharge
BPD: Other Aspects

- **Diuretics**
  - Try letting outgrow dose
  - Most will be off by 3-4 months post discharge without any ill effects

- **Infection**
  - 30-50% will be readmitted for pulmonary complications, usually infections
  - RSV prophylaxis

**Anemia**

- Occurs in all ELBW neonates
- Anemia peaks at 2-3 mos after last transfusion
- More profound than in term due to loss of iron stores
  - hemodilution with rapid catch-up growth
- Iron replacement until 6 mos corrected age and up to 1 year in ELBW neonates
Vision and Hearing

- Reinforce to parents the facts at the time of discharge:
  - ROP is the leading cause of blindness in kids in America
  - Infants admitted to the NICU are 10x more likely to have hearing loss than term infants

Vision and Hearing

- Monitor follow-up
- Parents often frustrated with multiple appointments
- Ophthalmology, audiology first to be omitted by the parents
Vision and Prematurity

- **GLAUCOMA**
  - Infants with severe ROP can develop closed angle glaucoma in as many as 30% of cases.

- **LATE-ONSET RETINAL DETACHMENT**
  - Retinal detachments may occur in the mid-teens or early adulthood due to ROP scar.
  - Any person with a history of ROP should have yearly retinal examinations during adolescence and early adulthood.

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Vision and Prematurity

- **MYOPIA, STRABISMUS AND AMBLYOPIA**
  - Myopia is much more common in premature infants (6%) than in full-term infants (2%).
    - It is also more common in infants with ROP (24%) than in premature infants without ROP, especially in patients with threshold ROP (70-80%).
  - Strabismus and amblyopia are also more common in premature infants than in full-term infants, and are even more likely in premature children who had ROP.
  - Amblyopia can be especially severe in infants with more severe ROP.
  - Because of the increased risk of these two potentially treatable problems, premature infants need to be seen more frequently during their first few years of life than term infants.
Hearing and Prematurity

- Risk factors for neonates
  - VLBW
  - ECMO
  - Mechanical ventilation
  - Ototoxic medications or loop diuretics
  - Exchange transfusion for hyperbilirubinemia
  - In utero infections such as CMV, herpes, rubella, syphilis, and toxoplasmosis
  - Postnatal infections associated with hearing loss, including bacterial and viral meningitis
  - Craniofacial anomalies

Developmental

- Evaluate on corrected age
- Denver is inadequate
- First year
  - Detect major disabilities
- Second year
  - Less severe disabilities
  - Speech and language, fine motor
- Third year
  - Speech and language, visual/perceptual, visual motor
Defining the Major Neurologic Sequela

- Cerebral Palsy
- Hydrocephalus
- Blindness
- Seizures
- Deafness

Cerebral Palsy

- Cerebral Palsy: Chronic disorder of movement or posture
  - Fixed motor deficit
  - Most common type is spastic (hemiplegia, diplegia, quadraplegia), but other types include choreo-athetoid, and mixed.
  - 25-50% will have mental retardation
  - 50% with seizures
Patterns of Development

3-4 mos CA
- Transient dystonia
  - Increased extensor tone
  - Prefers standing
  - "strong baby"
- Should begin developing object permanence
- Begin reaching for objects
- Begins hand to hand
- Always be concerned about ↑ "strength" and/or asymmetry of tone

8 months CA
- Transient dystonia should be cleared
- Primitive reflexes should be gone
- Tone should normalize and have good trunk, head control
- Always concerning when there is persistent high extensor tone, poor head trunk control, asymmetries, persistent reflexes
Outcome by Birth Weight

Percentage of 6- to 7-year-old children born from 1982 to 1986 by birthweight (< 750g, 750 to 1499g, and term born) with subnormal functioning. Subnormal functioning was defined as a standard score < 70 for cognitive function, academic skills, visuomotor function, and adaptive function and a score < 30 in gross motor function. (Data from Hack M et al: School-age outcomes in children birth weights under 750 g. N Engl J Med 331:753, 1994.)

Outcome by Birth Weight

Percentage of 6- to 7-year-old children born from 1982 to 1986 by birthweight group (< 750g, 750 to 1499g, and term born), with each of four major impairments. Cerebral palsy was defined to include hemiplegia, diplegia, or quadriplegia. Visual impairment includes unilateral or bilateral blindness or visual acuity < 20/200 without glasses in at least one eye. Subnormal head size and height are < 2 standard deviations below the mean for the child’s age. (Data from Hack M et al: School-age outcomes in children birth weights under 750 g. N Engl J Med 331:753, 1994.)
Psychiatric outcomes in adolescent children who had very low birthweights. ADHD, attention deficit hyperactivity disorder; VLBW, very low birthweight. (Data from Botting N et al: Attention deficit hyperactivity disorders and other psychiatric outcomes in very low birthweight children at 12 years. J Child Psychol Psychiatry 38:531, 1997.)

The effects of perinatal white matter injury on subsequent cortical gray matter development at term, with a significantly lower cortical gray matter volume determined by three-dimensional magnetic resonance imaging with postacquisition image analysis in a group of preterm infants with perinatal white matter injury compared with control preterm and full-term infants. (From Inder TE et al: The postmigrational development of polymicrogyria documented by magnetic resonance imaging from 31 weeks' postconceptional age. Ann Neurol 45:798, 1999.)
### Developmental Patterns

- **12-15 mos CA**
  - Walking

- **Speech and Language**
  - Expressive lags behind receptive
  - 1/3 to 1/2 need speech therapy

### Anticipatory Guidance

- Maintain tucked and flexed, avoid standing
- Discourage high extensor tone
  - No walkers, doorway jumpers
- Tailor play activities to promote normal tone and movement
- Read to the baby