Transitioning the NICU Baby to Primary Care & Primary Care of the NICU Graduate

Lindsay A. Thompson, MD, MS
Clinical Assistant Professor of Pediatrics and Health Outcomes Policy
University of Florida, Gainesville, FL

The speaker has signed a disclosure form and indicated she has no significant financial interest or relationship with the companies or the manufacturer(s) of any commercial product and/or service that will be discussed as part of this presentation.

Session Summary

The presenter will discuss the many issues of transition of care for infants from the NICU to the primary care setting. A pilot study at the University of Florida will be described, with time available to discuss how to implement this at the participant’s home institution. Also addressed will be the primary care issues that pediatricians face when caring for the NICU graduate over the first years of life. Medical management and growth will be highlighted, paying special attention to areas such as nutrition management, most often perceived as complex for the PCP.

Session Objectives

Upon completion of this presentation, the participant will be able to:

- review discharge planning vs. transition of care from the NICU to the primary care setting;
- describe common problems and barriers to transition services;
- implement ways to improve transition at your home institution to the primary care setting;
- identify discharge needs for the primary care provider;
- discuss the primary care issues of NICU graduates.

References


**Session Outline**

See presentation handout on the following pages.
TRANSITION OF THE NICU BABY TO PRIMARY CARE

Lindsay A. Thompson, MD
Mississippi State University
lathompson@peds.ufl.edu
With help from Amber Loyson, MD
October 18th, 2013

LECTURE AND WORKSHOP GOALS

- Review discharge planning vs. transition of care from the NICU to primary care setting
- Understand common problems and barriers to transition services
- Plan improved transition at your home institution
- Review discharge needs for the primary care provider
- Discuss the primary care issues of NICU graduates

DISCHARGE PLANNING

NPN/Doctor concerns

Infant stability

Parental concerns

Social concerns

Staff concerns

NICU DISCHARGE CRITERIA

- Clinical Stability ("Infant Readiness")
  - Ingest sufficient oral feeding to support appropriate growth
  - Coordinate oral feeding and breathing
  - Maintain normal body temp
  - Stable cardio-respiratory function
  - Complex decision-making: not based on weight (2kg) or technology
  - Want to ensure that cost is not primary driver of discharge
  - 6 components: ("Family Readiness" and "Health System Readiness")
    - Parental education, family and home readiness
    - Hospital-based primary care
    - Management plan for unresolved medical issues
    - Comprehensive home plan
    - Identification and management of support services
    - Determination and designation of follow-up care

TYPICAL DAY IN PRIMARY CARE:

- 4:30pm pt: listed as “Establish care, NICU d/c yesterday”
  - Ex 23 weeker, on Oxygen, d/c summary 15 pages printed
  - HIE, IVH, multiple transfusions, stressed parent....
    All in the next 30 minutes
- How do can a PCP prepare?

TRANSFER TO PRIMARY CARE

- Pressure to reduce LOS and readmission
- Need strategies that bridge providers
- Adult and pediatric literature cite transitions as major barrier to quality care
  - 49% adults have 1+ error due to d/c communication
  - 19-23% adults have 1+ adverse event
  - 28% pediatric discharges did not receive timely f/u
- Neonate:
  - Many discharged without meeting PCP
  - Increasingly complex infants

IN OTHER WORDS....

Successful discharge ≠ Transition of care

TRANSITION SERVICES

- NNP/ Doctor communication
- Infant and parental needs
- Staff recommendations and training
- Social situation: home, transportation, day care, PCP
TRANSITION SERVICES

NPN/Doctor communication

- Infant and parental needs

Social situation: home, transportation, day care, PCP

Staff recommendations and training

CRITERIA FOR QUALITY PRIMARY CARE

- PCP needs “expertise with caring for patients who have had NICU care”
- Medical Home Model:
  - Patient-centered
  - Comprehensive care
  - Coordinated care
  - Access to care
  - Systems-based approach to quality and safety

PRIMARY CARE NICU DISCHARGE CRITERIA

- Early ID of PCP
  - Get involved early!
- Discharge checklist complete: parental and pediatrician
  - Examples next page
- Discharge summary

PCP NICU DISCHARGE CHECKLIST

- PKU
- Eye Exam
- Car seat test
- Apgar
- Circumcision
- Pediatrician Name
- Pediatrician Appointment
- Eye Follow Up Appointment
- Other Follow Up Appointment
- PT/OT
- Formula Preparation
- WIC
- Hepatitis B
- Synagis
- Prescriptions
- Discharge prescriptions filled
- Medication teaching
- Health insurance paper work completed
- Rooming in completed

---

**LECTURE AND WORKSHOP GOALS**

- Review discharge planning vs. transition of care from the NICU to primary care setting
- Understand common problems and barriers to transition services
- Plan improved transition at your home institution
  - Review discharge needs for the primary care provider
  - Discuss the primary care issues of NICU graduates

**NICU GRADUATE TRANSITION PROGRAM**

- NNP/Neonatology communication with PCP
  - Phone call
  - Discharge summary
  - Develop a management plan
  - Provide additional education to parents
- Parental visit from the patient’s PCP PRIOR to discharge
  - Coordinate the transfer of care
  - Orient family to primary care clinic
  - Plan follow up visits
  - Develop a management plan
  - Provide additional education to parents
- Barriers:
  - Early ID of PCP
  - Variation in clinical stability
  - Reimbursement
  - Culture shift

**NICU GRADUATE TRANSITION PROGRAM**

- Pilot program
  - Implemented Winter 2013
  - Variable phone calls
  - Email communication
  - A few planned visits
    - Prior to discharge
  - After discharge

- Outcomes:
  - High PCP satisfaction
  - Minimal Neonatology change in patient flow
  - Reimbursed
  - Clear SW/ nursing satisfaction (relief)
  - Too early for meaningful parental measures of satisfaction

**PLANNING YOUR OWN TRANSITION SERVICES:**

- When should a PCP be determined?
- Who should communicate with the PCP, and when should they be notified?
- What information needs to be given to the PCP?
- What are the planning needs for the PCP to come to the NICU to perform such a visit?
- How to ensure continuity time for residents?
- What documents should we create to advertise and inform both staff and families of this service?

**PRIMARY CARE ACCEPTANCE CRITERIA**

- PCP needs “expertise with caring for patients who have had NICU care”
- Medical Home Model:
  - Patient-centered
  - Comprehensive care
  - Coordinated care
  - Access to care
  - Systems-based approach to quality and safety
Lecture and Workshop Goals

- Review discharge planning vs. transition of care from the NICU to primary care setting
  - Understand common problems and barriers to transition services
- Plan improved transition at your home institution
  - Review discharge needs for the primary care provider
  - Discuss the primary care issues of NICU graduates

Primary Care Issues of Prematurity

Immediate Health Issues
- Oral intake
- Growth
- Coordinate oral feeding and breathing
- Maintain body temp
- Stable cardio-respiratory function
- Issues specific to additional diseases (genetic, cardiac, HIE, NEC, inborn errors, etc)

TALK EARLY, TALK FREQUENTLY

- Office procedure in case of emergencies
- Immunization schedules
- The concept of adjusted age
- Catch-up growth
- Developmental monitoring
- Possible need for physical/occupational/speech therapy and Early Steps/Early Intervention referral

Parent-Child Interactions & Attachment

Successful Interactions
- Relaxed muscle tone
- Flexion of extremities
- Quiet alert State
- Periodic eye contact
- Hand to Mouth activity
- Smiling

Avoidance Techniques
- Averting face or eyes
- Yawning or hiccups
- Movement to shield face
- Back arching
- Color changes and mottling
- Excessive fussiness or drowsiness

Primary Care Issues of Prematurity

Immediate Health Issues
- Oral intake
- Growth
- Coordinate oral feeding and breathing
- Maintain body temp
- Stable cardio-respiratory function
- Issues specific to additional diseases (genetic, cardiac, HIE, NEC, inborn errors, etc)

Chronic Health Issues
- Growth
- Development
- Chronic lung disease
- Poor hearing
- ROP/poor vision
- Immunizations
- Obesity
- Issues specific to additional diseases (genetic, cardiac, HIE, NEC, inborn errors, etc)
GROWTH PATTERNS

- USE:
  - Fetal-infant growth curves
    - Up to 50 weeks post-conceptional age
  - Adjusted-age
    - Up to 2 years of life
  - 'Weight for length' charts
    - WIC uses too

GROWTH PATTERNS, CONT

- Catch-up growth:
  - Maximum by 36-40 weeks post-conceptional age
  - Early growth is crucial
  - Abnormal growth:
    - <2/3 this rate
    - No gain 2 weeks
    - Weight for length <5th percentile
  - Monitor younger infants frequently
  - Ensure adequate intake:
    - Calories: 110 – 120 Cal/kg/day
    - Protein: 3 - 3.5g/kg/day

GROWTH PATTERNS - HEAD GROWTH

- VLBW infants:
  - Catch-up growth occurs in spurts
  - May continue up to the 3rd year.
- SGA infants:
  - Catch-up growth generally in 1st year of life.
  - Concern if infant has not entered the 5th percentile by the end of the 1st year of life.
  - Outcome: AGA > asymmetrical SGA > symmetrical SGA
- Final mean size of preterm infants is below term infants

GROWTH & NUTRITION ISSUES

- PCP must
  - Ask about duration and difficulty of feeds
  - Assess GER
  - Assess pulmonary and cardiac health
  - Consider tube feeds, especially if infant has high caloric need
  - Witness a feeding – look for:
    - Poor-suck swallow coordination
    - Excessive tongue thrusting or back arching
    - Excessive gag or no gag reflex
  - Refer early to Speech therapy

NUTRITION

- Caloric needs
  - Healthy preemies: 110-120 kcal/kg
  - BPD/IUGR/other: 160-180 kcal/kg
- Protein: 3 to 3.5mg/kg
- Use standard (24 cal) preterm formulas until 1800 - 2000 g weight
- Use transitional formulas (22 cal) until 12m chronological age for ELBW infants
- Often able to switch by 6 months
- Breastmilk: supplement with fortifier if being tube-fed
NEUROLOGICAL & DEVELOPMENTAL SCREENING

Objectives
Find impairment early
Prevent disability
Optimize abilities

- 12-22% of US children have developmental/behavioral disorders
- Options exist to tailor screening to what works in specific practice setting
- Services available to children with developmental delays from birth through childhood

Better outcomes for participants:
- Higher graduation rates
- Delayed pregnancy
- Employment opportunities
- Decreased criminality

HOW TO ASSESS DEVELOPMENT?

- Surveillance
- Screening
- Evaluation

DEVELOPMENTAL DISORDERS

- Surveillance:
  - “a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care…”
  - Age-appropriate checklists
  - Recording of milestones
  - Problems might lead to screening....

DEVELOPMENTAL DISORDERS

- Screening:
  - “a brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment”
  - Possible outcomes:
    - Definitive diagnosis
    - Development of an interdisciplinary plan of remediation
    - No significant problem
    - Additional observation
  - AAP recommends formal screening at 9, 15 and 30 months

DEVELOPMENTAL DISORDERS

- Diagnosis:
  - Referral to a specialist
  - NUMEROUS modalities for testing

DENVER SCREEN

- Practitioner-lead
- Relies on child participation
- Time consuming
- Sensitivity ~50-60%
DEVELOPMENTAL SCREENING: ASQ

- Parental Report: Ages & Stages Questionnaires
  - 19 age-based surveys
  - Asks parents about developmental skills common in daily life
  - Literacy level ~ 5th grade
  - Length (15 minutes) may be daunting
  - Provider scoring = easy
  - Cutoff scores in 5 domains prompt referrals
  - Sensitivity 70%-90% (10% - 30% are being under-referred)
  - Specificity 76%-91% (9%- 24% are being over-referred)
  - Cost = $ 4.60

PRIMITIVE REFLEXES

<table>
<thead>
<tr>
<th>Reflex</th>
<th>Stimulus → Response</th>
<th>Age disappears</th>
</tr>
</thead>
<tbody>
<tr>
<td>Galant</td>
<td>Stoking along paravertebral area → lateral flexion of the trunk to stimulated side</td>
<td>3 months</td>
</tr>
<tr>
<td>Rooting</td>
<td>Stroking perineal area → head turns toward source and mouth opens</td>
<td>4 months</td>
</tr>
<tr>
<td>Placing</td>
<td>Dorsum of foot touches the underside of the table → infant places the foot on the table top</td>
<td>varies</td>
</tr>
<tr>
<td>Palmar grasp</td>
<td>Pressing against palm → flexion of the fingers</td>
<td>2-4 months</td>
</tr>
<tr>
<td>Plantar grasp</td>
<td>Pressing against sole of foot → flexion of the toes</td>
<td>4-6 months</td>
</tr>
<tr>
<td>Moro</td>
<td>Sudden movement of the head causes symmetric abduction and extension of the arms followed by adduction and flexion</td>
<td>4-6 months</td>
</tr>
<tr>
<td>Asymmetric tonic neck (ATNR)</td>
<td>Turning the head to one side causes extension of arm on same side, and flexion on opposite side</td>
<td>4-6 months</td>
</tr>
<tr>
<td>Babinski</td>
<td>Stroke sole of foot from toe toward heel → toes fan out and curl as foot twitches in</td>
<td>8-12 months</td>
</tr>
</tbody>
</table>

ABNORMAL NEUROLOGICAL SIGNS AT 40WK POSTMENSTRUAL AGE

- Increased tremors plus startles
- Head control abnormal: poor, differential
- Arm flexor tone greater than leg flexor tone
- Persistently adducted thumb
- Absence of palmar or plantar grasp
- Absence of placing
- Abnormal Moro reflex (extension only present)
- Poor orientation (in state 4) (visual or auditory)
- Irritability

Dubowitz LMS: Neurological Assessment in Ballard RA ed: Pediatric Care of the IHN Graduate.1988, WB Saunders Co.

CHRONIC LUNG DISEASE

- Adequate growth
- Supplemental Oxygen (SaO2 - 94% to 96%)
- Diuretics - watch for electrolyte imbalance & nephrocalcinosis
- Bronchodilators - PRN
- Screen for Hypertension and Cor Pulmonale
- Reduce environmental factors
- Palivizumab
VISUAL MONITORING

- Myopia and Strabismus in 30 to 50% of preemies with ROP
  (vs. 20 –15% in preemies without ROP)
- Glaucoma and late retinal detachment rare sequelae of ROP.
- Optic atrophy or visual processing disturbances may result from IVH or cerebral insult.
- Look for
  - ability to fix and follow by 6 weeks of age
  - evidence of fixed strabismus at any age
  - alternating strabismus beyond 6 months of age
  - excessive tearing and photophobia with a large cornea
  - or repeated poking at or waving in front of the eyes.

HEARING EVALUATION

- Risk of poor hearing 20x higher than term
- Formal and repetitive testing now the standard
- Screen high risk children every 6 months until 3y of age
- History of congenital infections or postnatal meningitis
- Persistent pulmonary hypertention or ECMO
- Down’s Syndrome, craniofacial anomalies, other syndromes
- Hyperbilirubinemia
- F/H of permanent childhood hearing loss
- ...All premature infants
- Early signs: failure to respond to loud noises, lack of response to vocal play and pleasant sounds, cooing limited to one or two sounds.

IMMUNIZATION

- Chronologic age
- Except Hepatitis B - start at 1mo or at d/c
- Influenza - @ 6 mo; immunize close contacts
- Synagis
  - Reduces hospitalization - not acquisition or mortality
  - Depends on insurance as to what will be covered

“PRIMARY CARE” ISSUES WITH SYNAGIS

- Efficacy of synagis is well-documented
  - Studies included infants now excluded (IMpact study, 1998)³
- On-going debates (and insurance coverage) as to:
  - Who should receive?
  - Gestational age
  - Social situation
  - Medical co-morbidities
  - Second season
  - When should each infant start?
    - 48-72 hours PRIOR to NICU discharge
    - Are time to first dose if not received in NICU: 26 days²
  - How many doses?
  - Compliance: only 29% Medicaid
  - Infants received >5 doses³

```
```

PRIMARY CARE ISSUES OF PREMATURITY

- Adult Outcomes of ELBW Preterm Infants
  - MUST HAVE NO ONGOING HEALTH ISSUES:
    - Growth
    - Hypertension
    - Decreased pulmonary function
    - Neurologic
      - CP
      - Blindness, deafness
      - Lower educational achievement
      - Psychiatric
- Obesity
- ADHD

```
``