Preterm Infants: Transition to Home and Follow-up

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Preterm Birth Statistics

- In the United States in 2006, 1 in 8 babies (12.8 percent of live births) was born prematurely. This is an increase of more than 15 percent since 1995 (Hamilton et al., 2007).

- The increase is accounted for by changes in the late-preterm birth rate, which has increased 25 percent since 1990 (Martin et al., 2007).
Survival of VLBW infants has significantly improved over the last 3 decades (Fanaroff et al., 2007):

- 94 percent to 96 percent of infants born weighing 1,000 g to 1,500 g survive.
- 88 percent of infants weighing 750 g to 1,000 g survive.
Transition to Home

- Transition to home is often a difficult time for parents and families.
- The transition may not end for several years as the infant and family recover, develop and await a long-term outcome.
The Role of the Neonatal Nurse

- Recognize and accept their role in discharge management
- Work collaboratively with families in facilitating the transition to home from admission onward
- Develop evidence-based practice guidelines consistent with current knowledge and research
Family-centered Care

• Supports development of parental competence.

• Focuses on:
  - Identifying and building on individual and family strengths
  - Partnering and collaborating with parents
  - Empowering families so they can care for their infant in the NICU and at home

(Griffin & Abraham, 2006; IFCC, 1998; Saunders et al., 2003)
Promoting Parenting in the NICU

• Provide support to parents.
• Help parents identify and use support systems.
• Collaborate with families in planning and providing care.
• Enhance the role of parents as advocates for their infant.
• Empower parents to care for their infant, participate in rounds, ask questions, meet with the care team, etc.
Family-centered Care as Described by Families

- Communicating openly and honestly with parents on medical and ethical issues
- Sharing information and the meaning of information with parents
- Involving parents in decision-making
- Partnering with parents in providing care
- Developing policies and programs to promote parenting skills and family involvement

(Cooper et al, 2007)
Family-centered Care in Nursing Practice

- The goal and focus of all NICUs should be implementation of family-centered care.
- However, family-centered care is not always fully or consistently implemented during hospitalization or the transition to home (Petersen, Cohen & Parsons, 2004).
- Nurses must reexamine their current processes and move from a traditional approach to a family-centered approach.
Continuum of Care

• Nurses link care across units, before admission and after discharge, in hospital systems and with external sites.
• Efforts focus on communication, information, policies and practices.
• Each transferring team should work with the next team or provider to facilitate consistency and continuity.
Readiness for Discharge: Infant Factors

• PMA
  - Most VLBW preterm infants by 35 to 37 weeks PMA (Bakewell-Sachs et al., 2009)
  - Most ELBW preterm infants by 37 to 44 weeks PMA (AAP Committee on Fetus and Newborn, 2008)

• Infant clinical status, including recovery from RDS, BPD, sepsis, hyperbilirubinemia, anemia and NEC

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Infant Factors (Continued)

- Full nipple feedings (although some infants are discharged to home on supplemental nasogastric tube feedings)
- Progressive weight gain of 15 g to 30 g per day over several days
- Successful weaning from a thermoregulated environment and maintenance of body temperature in an open crib

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Parent/Caregiver Factors

Factors that can increase parental stress and anxiety at discharge:

- Degree of prematurity
- Length of hospital stay
- Diagnosis of apnea
- Timing of the first scheduled visit to the primary care provider
- Feeding (Reyna, Pickler & Thompson, 2006)
  (McKim, 1993)
Key Components of NICU Parent Support Services

• Parents are respected and valued members of the health care team.
• Parents and health professionals form effective partnerships.
• The focus is on parental strengths; parents define their own needs and priorities.
Key Components of NICU Parent Support Services (Continued)

- All parents can give and receive; teach and learn; care and be cared for.
- Parents are viewed in the context of their families, neighborhoods or communities.
- Parent support services are accessible.
- Information shared by parents is confidential.

(Hurst, 2006)
Assessing the Home Environment

• Who will care for the infant?
• Does the caregiver have child care experience?
• Does the family have others it can count on for support?
• What type of insurance does the family have?
• Which family members work outside the home?
• What are the daily schedules for family members?
• In what type of home does the family live?
Assessing the Home Environment

(Continued)

- How old is the home?
- Does the home have utilities (electricity, heat, water, phone)?
- Does the family have financial resources to care for the infant?
- Does any family member have a history of substance abuse or mental health disorders?
- Has social services ever intervened with the family?
Parent Education

• The nurse ensures that parents have the knowledge and skills they need for the infant’s transition to home.

• The nurse individualizes teaching content for each family based on the family’s needs and priorities, which the family and staff determine together (Griffin & Abraham, 2006).

• Each family needs at least two caregivers.

• As much teaching as possible should occur before discharge (Broedsgaard & Wagner, 2005; Griffin & Abraham, 2006).
Parent Education Topics

- Choosing a primary care provider
- Hand washing
- Behavioral cues
- Basic infant care
- Feeding
- Sleep and wake cycles
- Sleeping position
- Stool and urine patterns
- Signs of illness
- Medication and equipment
- Home and car safety
- Visitors and outings
Choosing a Primary Care Provider

• Helping families select a primary care provider can:
  - Reduce anxiety
  - Ensure that a provider is in place at the time of discharge
  - Allow provider involvement during the discharge process

• Nurses should encourage parents to meet with potential providers to help make their selection.
Readiness for Oral Feeding

Readiness includes:

• Transition from tube-feeding to breastfeeding or bottlefeeding
• Assessment of the infant before each feeding to be sure he’s ready to feed

(McGrath & Braescu, 2004; White-Traut et al., 2005)
Parameters for Assessing Readiness for Oral Feeding

- Postconceptional age
- Respiratory status
- Gag reflex
- Suck-swallow-breathe pattern
- Infant behavioral cues
Feeding Topics for Parent Education

- Hunger and satiation cues
- Positioning, rooting and sucking reflexes
- Breaking suction
- Burping
- Schedule vs. demand
- Duration and volume of feedings
- Latching on and letting down
- Formula type
- Correct preparation of formula
Breastfeeding

- In the first few weeks, regular and frequent pumping is important to establish milk supply (Isaacson, 2006; Spatz, 2004, 2006).

- Kangaroo care (Brodsky & Ouellette, 2008; Ludington-Hoe et al., 2008; Nye, 2008; Spatz, 2006):
  - Promotes earlier breastfeeding and maternal milk supply
  - Increases the number of mothers breastfeeding at NICU discharge
  - Increases the duration of breastfeeding
Bottlefeeding

• Nurses should teach formula preparation, including mixing instructions and type of water to use.
• The primary care provider needs to know water fluoride content to decide whether or not to supplement.
• Parents should clean utensils with hot, soapy water and a bottle and nipple brush; sterilization is not necessary.
Behavioral Cues

• Engagement cues (stability cues) indicate that the infant is coping well.
• Disengagement cues (stress or instability cues) signal that the infant is becoming stressed or overloaded.
• Parents, nurses and other care providers must be sensitive to infant cues and respond appropriately.
Engagement Cues

- Relaxed tone with smooth movements
- Extremities flexed
- Quiet, alert state
- Animated face with bright eyes
- Periodic eye contact with caregiver
- Hand-to-mouth movements
- Turning toward a voice
- Smiling
- Well-perfused, oxygenated appearance
Disengagement Cues

- Averted gaze
- Falling asleep
- Yawning
- Frowning or grimacing
- Arching
- Gagging, grunting or sneezing
- Hiccupping, spitting or gagging
- Splayed fingers
- Crying
- Becoming pale, mottled or red
Responses to Disengagement Cues

• Provide a rest or time-out with minimal or no sensory input.
• Swaddle or contain the infant.
• Position the infant with nesting or blanket rolls.
• Hold the infant quietly with no other input.
• Use the infant’s cues to determine when to engage again.
Sleep Position and Safety Guidelines for Sleeping

• To reduce the risk of SIDS, preterm infants should be placed to sleep on their backs (AAP Task Force on Infant Positioning and Sudden Infant Death Syndrome, 1996).

• Hospitalized preterm infants should be kept in a predominantly supine position from the PMA of 32 weeks onward (AAP Committee on Fetus and Newborn, 2008).
Sleeping Guidelines for the Preterm Infant at Home

- Position the infant supine.
- Use a firm, tight-fitting mattress in a crib covered only by a fitted sheet.
- Put the infant in a sleeper or other sleep clothing.
- Don’t cover the baby with sheets, blankets or other covers.
Sleeping Guidelines for the Preterm Infant at Home (Continued)

- Don’t overheat the infant during sleep.
- Don’t put soft or gas-trapping objects under the infant.
- Keep the infant’s head uncovered.

(AAP Task Force on Sudden Infant Death Syndrome, 2005)
Stool and Urine Patterns

• Although parents often expect a daily bowel movement after discharge, daily stooling is not necessary.
• Urine frequency and color indicate hydration status.
• Generally, the infant has a wet diaper with each feeding.
Signs and Symptoms of Infection

- Cyanosis
- Pallor
- Refusal to eat
- Increased irritability
- Lethargy
- Vomiting (distinguished from reflux)
- Abnormal respirations or respiratory pattern
- Diarrhea
- Fever
- Hypothermia
Infection Prevention

• Anyone who holds, feeds or cares for the infant should first wash his hands.

• Families can reduce exposure to infection by limiting the infant’s contact with visitors.

• Day care may be limited for preterm infants during the first 6 to 12 months after discharge (Brodsky & Ouellette, 2008; Simoes, 2008).
Transportation Safety for Preterm Infants

- Before discharge, observe the infant in the car seat for at least 90 minutes to monitor for apnea, bradycardia or oxygen desaturation.
- Minimize travel for infants at risk of respiratory compromise.
- If desaturation, apnea or bradycardia in a semi-upright position has been documented, place the baby supine in an appropriate car carrier.
Transportation Safety for Preterm Infants (Continued)

- Maintain home cardiorespiratory monitors during travel.
- Secure oxygen tanks, monitors and other equipment.

(AAP Committee on Injury, Violence and Poison Prevention and Committee on Fetus and Newborn, 2009)
Emergency Plan

- Nurses should help caregivers develop a plan for emergencies and encourage them to get training in CPR and first aid for choking.
- Emergency plan components:
  - Emergency phone list
  - Child care arrangements for other children
  - Backup telephone service
  - Prenotification to the local rescue squad and utility companies
  - Identification of the nearest 24-hour pharmacy
Medications and Equipment

- Care providers must learn and demonstrate knowledge of the infant’s medications, including indications, proper measuring, side effects and administration techniques.

- When possible, the nurse should round dosages off to whole mLs or to one digit to the right of the decimal point.
The Predischarge Home Visit

- During this visit, the nurse (Bakewell-Sachs et al., 2000):
  - Assesses the infant’s planned physical environment
  - Helps the family prepare for the homecoming
  - Reviews discharge teaching

- If a community health nurse makes this visit, the neonatal nurse most familiar with the family should tell the family what is expected of infant care at home.
Discharge Summary Form

- Highlights of the infant’s perinatal history
- Immunizations
- Physical exam findings
- Medical problems for follow-up
- Family issues for follow-up
- Nursing follow-up
- Appointments with medical specialists
- Discharge instructions given to parents

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Late Preterm Infants

- Born between 34 0/7 and 36 6/7 weeks gestation (Raju et al., 2006)
- Morbidity areas of concern (Engle et al., 2007; Wang et al., 2004):
  - Respiratory status
  - Apnea
  - Temperature instability
  - Hypoglycemia
  - Severe hyperbilirubinemia
  - Feeding
Discharge Criteria for Technology-dependent Infants

- Stable cardiovascular status
- Thermal stability
- Stable enteral and/or parenteral feeding
- Stable weight gain
- Capable care providers
- Appropriate home environment
- Ongoing support and respite for care providers

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Discharge Criteria for Technology-dependent Infants (Continued)

- Community and home follow-up plans
- Safe transport to appointments
- Access to emergency medical response, home nursing and medical equipment vendors

(AAP Committee on Fetus and Newborn, 2008; Gracey et al., 2002; Hummel & Cronin, 2004; Scherf & Reid, 2006)
Family Transitions

• The immediate postdischarge period is an exciting, but potentially stressful, time for parents.

• Mothers with infants in the NICU are at increased risk of postpartum depression, both during the infant’s hospitalization and in the postdischarge period, with its stress, anxiety, isolation and separation from NICU support (Beck, 2003).
Postdischarge Issues for Parents

- The ability to care for the infant
- The impact of the infant on the family
- The infant’s vulnerability
- Role expectations
- Feeding and crying
- Informational needs
- Physical and emotional tolls
- Long-term outcomes

(Kenner & Ellerbee, 2007; McKim, 1993; Reyna et al., 2006)
Factors that Affect Sibling Response

- Age of the sibling
- Preparation of the sibling for the baby and the baby’s homecoming
- Length of time the sibling has been separated from the mother
- Maternal health status
- Sibling’s response to the baby’s birth and hospitalization
- Opportunities for the sibling to visit the baby in the hospital and participate in care
Health Care

• Within the first week after discharge, the primary care provider should see the infant to review the baby’s hospital course, current status and risk factors for follow-up.

• The primary care provider, a public health nurse or a community-based nurse should follow the infant every 1 to 2 weeks until the baby is medically stable, consistent growth is established and the family and infant have adapted to the home environment (Brodsky & Ouellette, 2008; LaHood & Bryant, 2007).
Recommendations for Transition to Home

• Provide care consistently.
• Provide structure to the infant’s day.
• Pace caregiving using infant cues.
• Assist the infant during transition periods.
• Use an individualized feeding plan.
• Provide a quiet, soothing environment.
• Avoid overstimulation.
• Provide support for developmental issues.

(Berger et al., 1998)
Sleep and Wake Patterns

• Development of a preterm infant’s sleep pattern at home is unpredictable.
• Mature sleep patterns emerge around 34 to 36 weeks PMA, about the time many preterm infants are discharged.
• Preterm infants may have irregular sleep patterns for several months after discharge.
Crying, Colic and Shaken Baby Syndrome

- Right after discharge, preterm infants don’t cry as much as term infants, but they may become fussier and more irritable with increased crying around 40 weeks PMA.
- Preterm infants tend to get over colic at about 3 months corrected age.
- Preterm infants, medically fragile infants and infants who are difficult to console are at increased risk of shaken baby syndrome.
- Parent support and education are the most important interventions.

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Nutrition and Feeding

Areas of maternal concern in the early weeks at home:

• Interpreting infant feeding behaviors
• Managing the infant’s evolving feeding process
• Realizing the gaps in knowledge and learning how to cope

(Reyna et al., 2006)
Solid Foods

- Solid foods can be introduced at 4 to 6 months corrected age, beginning with rice cereal (LaHood & Bryant, 2007).
- Infants may have a sensitive period for taste and texture acceptance, with an increased risk of behavioral feeding problems if weaning is delayed.
Developmental Indicators for Introducing Solid Food

The infant:
- Sits with support and maintains head and neck control
- Takes food without choking or gagging
- Indicates the desire for food and satiety
- Sucks non-liquid foods
- Transfers food to the back of the tongue
- Demonstrates chewing movements
Gastrointestinal Problems

• Regurgitation and reflux are common problems in preterm infants <1 year of age.
• Regurgitation peaks at 3 months; usually is resolved by 6 to 12 months (Brodsky & Ouellette, 2008).
• GER peaks at 4 to 5 months; usually is resolved by 18 to 24 months (Brodsky & Ouellette, 2008).
Rehospitalization Rates

- Healthy preterm infants = 22 percent to 27 percent
- VLBW infants = up to 40 percent
- Infants who weigh >2,500 g = 8 percent
- Infants born <25 weeks have highest rates and longest stays.

(Erdeve et al., 2008; Smith et al., 2004; Underwood et al., 2007)
Immunizations

- Preterm infants are immunized with full doses based on chronologic age, not PMA (Klein et al., 2008; Saari, 2003).
- Immunizations should begin when infants reach 2 months chronologic age, regardless of whether they’re hospitalized or discharged.
- Preterm infants are at increased risk of apnea in the 48 hours after immunization, especially for infants in the NICU with a history of apnea in the 24 hours before immunization (Klein et al., 2008; Lee et al., 2006).
Growth

- Many preterm infants are growth-restricted by the time they are discharged (Carroll et al., 2005; Sherman et al., 2007).
- VLBW infants many not achieve weight and length comparable to term infants until well into childhood or adolescence (Hack et al., 2003).
- Premature infants often have growth spurts between 36 and 50 weeks PMA and again at 6 to 9 months of age.
- Preterm infant growth can be graphed on standard U.S. growth charts by adjusted age for the first 2 years.
Factors that Influence Growth and Growth Potential

- Gestational age
- Birthweight
- Severity of neonatal illness
- Caloric intake
- Chronic illness
- Environmental factors in the home
- Heredity

(Bernbaum, 2005; Sherman et al., 2007)
Anemia

- All infants experience physiologic anemia of infancy in the first 2 to 4 months after birth.
- Term infants reach their lowest hemoglobin level (11.4 g/dl +/- 0.09) at 8 to 12 weeks; preterm infants reach their lowest levels (7 to 10 g/dl) at 4 to 8 weeks (Blackburn, 2007).
Infections

Compared to term infants, preterm infants are at greater risk for infections, including:

- Upper- and lower-respiratory tract infections (RSV, pneumonia, bronchitis)
- Gastrointestinal infection
- Acute and chronic (serous) otitis media
SIDS

- Among preterm and LBW infants, the risk of SIDS is at least 3 to 4 times higher than for term infants; the risk increases as gestational age decreases.
- When preterm infants are positioned prone, the SIDS risk can be 85 percent greater than for full-term infants.

(Blair et al., 2006)
Hearing, Speech and Language

- Preterm infants are at risk for conductive and sensorineural hearing loss and for expressive and receptive language delays.
- Two percent to 4 percent of LBW infants have hearing impairment severe enough to require hearing aids (Bennett, 2005; Brodsky & Ouellette, 2008).
- About 95 percent of all newborns in the United States receiving hearing screening in the first month of life (JCIH, 2007).
Vision

Premature infants are at risk for two types of vision problems:

1. Structural, including retinopathy of prematurity (ROP), strabismus, amblyopia and refractive errors
2. Functional, including vision processing alterations
Neurobehavioral and Developmental Concerns

Preterm infants are at risk for:

- Transient dystonia
- Cerebral palsy
- Progressive hydrocephalus
- Chronic seizures
- Developmental and cognitive delays
- School and learning problems

(Bennett, 2005)
Summary

• From the moment a preterm infant is born, skilled nursing care is essential for survival and for optimizing outcomes.

• Neonatal nurses are:
  - Vital members of the NICU team, often leading discharge management efforts
  - Advocates for family-centered care and parental involvement as members of the health care team
  - Essential providers across all sites for preterm infants and their families