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CARE OF THE POST-NEONATAL INTENSIVE CARE UNIT GRADUATE

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I. Introduction and general background

Greater numbers of recuperating infants, shorter hospital stays, and complex health demands have increased the need for comprehensive post–neonatal intensive care unit (NICU) care. Survival to discharge has improved across all gestational ages, although many survivors have residual disabilities requiring specialized care, expertise by providers versed in the needs of the fragile infant, and a provider who can intervene early (Carley, 2008; Kelly, 2006b). The American Academy of Pediatrics (AAP) has identified four categories of post-NICU patients who are considered high risk at discharge: (1) premature infants, (2) those with special health needs or who are dependent on technology, (3) those at risk because of social or family issues, and (4) those for whom early death is anticipated. Essential elements at discharge include physiologic stability, active caretaker involvement and preparation to assume care, and an integrated plan for follow-up care and management (Committee on Fetus & Newborn, 2008).

A. Common issues for the post-NICU population include

1. The infant who is premature at discharge

   Premature infants constitute over 12% of births, and late preterm infants (of gestational age 34–36 weeks) account for most of the recent increase in numbers of preterm infants. An analysis of data from 2002 suggested that infants completing the 34th, 35th, and 36th gestational week accounted for 12.7%, 21.9%, and 40.1%, of the preterm population, respectively (Davidoff et al., 2006). With decreasing gestational age the incidence of neonatal complications increases; however, even late preterm infants are at risk for issues, such as impaired thermoregulation, poor feeding and nutrition, gastroesophageal reflux and other gastrointestine issues, late-onset sepsis, jaundice, or neurodevelopment impairment. Often managed as their term counterparts, these infants are at risk for rehospitalization after illness in the early postnatal period (Darcy, 2009; Doyle, Ford, & Davis, 2003).

2. Chronic lung disease (CLD)

   CLD is the leading cause of pediatric lung disease occurring secondary to pulmonary system immaturity or dysfunction and the additive effects of therapies, such as oxygen or mechanical ventilation support. Also referred to as "bronchopulmonary dysplasia," CLD commonly affects the premature infant, and despite overall improved survival and advances, such as exogenous surfactant therapy, it affects more than half of infants less than 1,000-g birth weight. Infants with CLD are at increased risk of pulmonary infections, long-term growth failure, and development delay (Verna, Sridhar, & Spitzer, 2003).

   a. Postdischarge therapies that may be used to optimize pulmonary function and growth include supplemental oxygen or ventilation, cardiorespiratory monitors, diuretics, and bronchodilators (Kelly, 2006b).
   b. Supplemental oxygen aims to optimize growth and stamina, and prevent development of cor pulmonale.
   c. Home mechanical ventilation, although rarely needed, may be used for those infants unable to wean from mechanical ventilation before hospital discharge (Committee on Fetus & Newborn, 2008).

3. Apnea

   Apnea is a serious condition for the neonate, and may result from pulmonary disorders; infection; brain injury; or metabolic derangements, such as hypoglycemia. Apnea is also a common complication in the preterm population, caused by immature central regulation of respiratory effort, and may be managed with oxygen or ventilator support, respiratory stimulants (e.g., methylxanthines), and cardiopulmonary monitoring. Although typically resolved by 42–44 weeks postconceptual age, apnea caused by immaturity in some infants (known as "apnea of prematurity") may persist until the time of discharge (Verna et al., 2003).

4. Gastroesophageal reflux disease (GERD)

   Infants born prematurely, those whose early course included structural or functional disorders of the gastrointestinal tract, those with pulmonary conditions requiring surgical intervention, and those with neurologic compromise are at risk for GERD. GERD may lead to erosive esophageal injury, and may be associated with serious conditions, such as apnea, bronchospasm, aspiration, or long-term growth failure (Verna et al., 2003).

   a. Physiologic reflux is common in infants; up to two-thirds of all infants less than 4 months of age exhibit regurgitation.
   b. Pathologic reflux, also known as GERD, is associated with complications including apnea, bronchospasm, esophagitis, esophageal strictures, and failure to thrive. It may be managed conservatively with small, frequent feedings; upright positioning; medications to optimize gastric emptying; or may necessitate surgical management for intractable cases (Verna et al., 2003). Some providers advocate use of thickened feedings; success of this strategy has shown variable results, although a recent meta-analysis of randomized clinical trials supported a moderate effect in healthy infants (Horvath, Dziechciarz, & Szajewska, 2008).

5. Postnatal growth restriction

   Premature infants are at increased risk for poor feeding and growth failure, and at discharge typically are below their healthy term counterparts in weight. Growth risks are compounded by the effects of chronic illness and genetic potential. Premature infants frequently need higher calories and nutrients than their healthy term counterparts. Diligently applied nutritional support plays a key role in supporting adequate long-term growth.

   a. Human milk is the ideal food for all infants regardless of gestational age; if human milk is not available, premature formula and postdischarge formula may be indicated to optimize catch-up growth (Greer, 2007).
   b. Premature infants may require additional supplementation to support nutrient requirements for protein; calcium; phosphorus; sodium; vitamins, such as B_{12}, B_6, D, E, and K; and trace minerals, such as zinc, copper, magnesium, selenium, and carnitine (Greer, 2007; Shah & Shah, 2009; Verna et al., 2003).
   c. Recuperating infants, especially preterm infants attempting to achieve adequate catch-up growth, may require up to 165 kcal/kg/d. Chronic health issues creating increased nutritional demands, such as CLD or growth failure, may warrant increased caloric goals (Verna et al., 2003).
   d. Structural or functional comorbidities, such as orofacial anomalies or altered tone, may complicate the nutritional plan (Kelly, 2006b).

6. Neurobehavioral and sensory deficits

   Infants recovering from the effects of initial illness or prematurity, and the NICU environment, may have residual neurobehavioral challenges including developmental delays, learning disabilities, hyperactivity, and cerebral palsy. Additionally, sensory deficits may include hearing or vision loss, auditory processing disorders, or language delay. Up to 50% of infants less than 1,000-g birth weight have some learning disability at school age (Verna et al., 2003).

   a. Hearing screening is recommended universally for all infants, and indicated for the NICU infant before discharge. Up to 50% of abnormal hearing screens occur in NICU graduates (Kelly, 2006b), and up to 10% of preterm infants may have severe sensorineural hearing loss (Verna et al., 2003). Exposure to ototoxic medications enhances this risk. Early intervention (i.e., at age < 6 months) enhances language development (Kelly, 2006a).
   b. Vision screening is recommended for preterm infants less than 1,500-g birth weight (or < 28 weeks gestation); those with a complicated medical course; and those exposed to supplemental oxygen. The first examination typically occurs at 31–33 weeks postconceptual age, with regular follow-up until vascular maturity is ensured at 3–6 months (Kelly, 2006b).
   c. Formal developmental assessment is indicated for all at-risk infants including those born preterm or with a complicated clinical course.
   d. Goals of developmental follow-up include optimizing growth and development to maximize long-term potential; integrating the infant into family and community; and providing early intervention to reduce medical, social, and emotional burden (Allen, 2005).

7. Dependence on technology

   Infants with unresolved cardiopulmonary issues, such as apnea, chronic hypoxia, or growth failure, may require technologic support in the home after discharge.

   a. Pulmonary support may be achieved with supplemental oxygen, cardiopulmonary monitoring, or the use of mechanical ventilation.

b. Weaning from ventilatory support is dictated by the infant demonstrating normal oxygen saturation, resolution of apnea or bradycardia, and showing appropriate growth.
c. Use of in-home technology requires vigilant attention to safety and hygiene, consistent education, and support of caretakers. Mechanical ventilation requires dedicated personnel and ongoing caretaker support including respite.
d. Nutritional support may be achieved with complementary enteral feedings or parenteral nutrition. In-home use of intermittent orogastric gavage or gastrostomy feedings requires vigilant attention to safety and hygiene, and education and support of caretakers. Efforts should concentrate on encouraging oral feeding skills.
e. Weaning from supplemental nutritional support can be considered when the infant demonstrates consistent appropriate growth, under the supervision of a nutrition specialist (Kelly, 2006b; Verna et al., 2003).
f. A plan for emergency management in the case of equipment malfunction must be in place (Committee on Fetus & Newborn, 2008).

8. Postnatal infection

Convalescing post-NICU patients, especially preterm infants, are at risk for complications related to infections, including respiratory syncytial virus (RSV) and influenza virus. Their increased vulnerability to infections may result in acute decompensation and the need for rehospitalization (Allen, 2005). At-risk infants discharged during peak RSV transmission seasons (i.e., October through March in the United States) should receive RSV prophylaxis in addition to routine immunizations given at recommended intervals (Department of Health & Human Services, Centers for Disease Control & Prevention, 2008; Kelly, 2006).

B. Additional issues for the post-NICU population may include

1. Social and environmental risks

The AAP identifies premature birth, need for hospitalization, presence of birth defects, and infant disability as risks for family dysfunction and child abuse. These risks are compounded by family and environmental risks, such as low socioeconomic status, lack of social supports, substance exposure, and lack of family involvement during the infant's hospitalization. Identifying strategies to enhance infant safety and family functioning before discharge is encouraged (Committee on Fetus & Newborn, 2008).

a. Vulnerable child syndrome is recognized as a potential outcome caused by the effects of protracted neonatal hospitalization, parental anxiety or depression, impact of the illness on the family, or lack of social supports. This has been associated with excess health care use and risk of impaired infant developmental outcome (Allen et al., 2004).
b. A posttraumatic stress disorder has been reported in parents of infants in the NICU, caused by ongoing stress of the hospitalization and uncertainty of neonatal outcome (Shaw et al., 2009).

2. Infant with anticipated early death

To enhance the quality of remaining life, infants with terminal disorders may be discharged to the home for hospice care. Discharge planning and follow-up care attends to family needs and concerns, and occurs with the involvement of home nursing. Necessary elements include creating a plan for management of infant pain and discomfort; securing arrangements for equipment or supplies; and providing ongoing support to parents, siblings, or extended family members (Committee on Fetus & Newborn, 2008).

II. Database (may include but is not limited to)

A. Subjective database

1. History and review of systems
   a. Parental concerns including feelings of readiness, stress, adequacy, and support.
   b. Birth and health history to date.
      i. Birth history, including gravida and parity, pregnancy complications, delivery method and birth complications, Apgar scores
      ii. Infant birth date, weight, and gestational age
      iii. Neonatal course including complications
   c. Family, social and environmental history.
      i. Maternal age, health, occupation, and level of education
      ii. Paternal age, health, occupation, and level of education
      iii. Sibling ages, health, and history of prematurity

iv. Family history including chronic conditions
v. Parental head circumference and stature to compare with infant measurements
vi. Social or environmental concerns, such as unemployment, abuse, marital problems, and lack of support

d. Nutrition history.
i. Date feedings initiated, formula versus breast milk, nipple versus gavage, feeding tolerance, complications
ii. Parenteral nutrition support, use of hyperalimentation, peripheral versus central vascular access

e. Review of systems and clinical findings.
i. Dysmorphic features, which may suggest a genetic syndrome
ii. Skin, including rashes, birthmarks, scars, or jaundice
iii. Head, ears, eyes, nose, and throat including
a. High arched palate caused by oral intubation
b. Nostril distortion caused by feeding tube
c. Head circumference: poor head growth in the premature infant strongly predictive of impaired cognitive function, academic performance, and behavioral issues
iv. Chest and thorax, including character of respirations, respiratory rate, and shape and contour of the thorax; findings may include
a. Hyperexpansion caused by air trapping
b. Tachypnea caused by chronic hypoxia
c. Hypercarbia
v. Cardiovascular, including presence of murmurs, perfusion, and quality of pulses
vi. Abdomen and rectum, including stool pattern, distention, and inguinal or umbilical hernias
vii. Genitourinary, including voiding pattern
viii. Musculoskeletal, including symmetry of movements, strength, and tone
ix. Neurobehavioral, including activity, tone, state regulation, and tremulousness
x. Immune, including immunizations received before discharge
a. Follow Centers for Disease Control and Prevention recommendations for dosing by chronologic age (Department of Health & Human Services. Centers for Disease Control & Prevention, 2008). Refer to yearly Recommended Immunization Schedule at www.cdc.gov/vaccines or http://www.aap.org/pressroom/aappr-immunization-issuekit.htm (see *Appendix 1*, Childhood and Adolescent Immunization schedules, 2010)
xi. Supportive data from relevant diagnostic tests including
a. Results of neonatal screen (phenylketonuria, sickle cell, and congenital hypothyroidism screening mandated in all states)
b. Hearing screening
c. Vision screening
d. Developmental screening
e. Laboratory studies including baseline blood gas, oxygen saturation, electrolytes
f. Imaging studies including most recent chest radiograph, cranial ultrasound, or other cranial imaging study

B. Objective

1. Physical examination findings
a. Establish a growth trend including comparative measurements of head circumference, weight, and length from birth. Plot, and adjust for gestational age.
b. Thorough physical examination including vital signs and blood pressure.
c. Essential to take into account size at birth (Table 3-1) and to use growth charts corrected for gestational age for accurate assessment of postnatal growth.
2. Observation of parent–child interactions, including holding, comforting, responsiveness, confidence, and mutual support.
3. Laboratory studies as clinically indicated, such as blood gas, electrolytes, or complete blood count.
4. Chest radiograph as clinically indicated.

III. Assessment

A. Determine the diagnosis

Determine client's current health status, and identify general health risks based on gender, age, ethnicity, and other factors.

TABLE 3-1 Birth Weight Classifications

Extremely Low Birth Weight	Very Low Birth Weight	Low Birth Weight
< 1,000 g at birth	< 1,500 g at birth	< 2,500 g at birth

Source: World Health Organization (2010). ***Low birth weight (percentages).*** Retrieved from http://www.who.int/whosis/indicators/2007LBW/en/index.html.

B. Severity

Assess the severity of illness, as indicated.

C. Motivation and ability

Determine family willingness to understand and comply with the treatment plan.

IV. Goals of clinical management

A. Screening or diagnosing

Choose a practical, cost-effective approach to screening and diagnosis, while abiding by mandated screening protocols. Post-NICU infants need careful, ongoing assessment related to neurobehavioral and growth risks, and individualized screening based on clinical findings.

B. Treatment

Select a treatment plan that optimizes growth and development, is individualized for the caregiver and child, and maximizes caregiver acceptance.

V. Plan

A. Screening

Elicit a thorough history and perform a thorough physical examination, including growth and developmental assessment at all visits.

B. Diagnostic tests

If not already performed before discharge, these should include

1. Newborn screen as required by individual state.
2. Hearing screen.
3. Vision screen.
4. Developmental assessment, often done by referral to a specified neonatal follow-up clinic facility. Premature and at-risk infants may be seen as frequently as four to five times in the first year of life, and are followed to school age (Leonard, 1988). However, there are no standardized guidelines for high-risk follow-up care (Committee on Fetus & Newborn, 2004).

C. Management

A primary provider should be identified and accept responsibility for orchestrating care. Post-NICU patients may be managed cooperatively with a variety of consultant and subspecialty services, including but not limited to nutrition services, dysmorphology and genetics, pulmonary, cardiology, gastroenterology, hematology, neurodevelopmental, and surgery. Specific intervals vary dependent on the complexity of the infant's history and current condition (Committee on Fetus & Newborn, 2008).

D. Client education

1. Concerns and feelings

   Assist the family with expressing concerns and feelings about having a complex neonatal patient in the home, and coping with uncertainties related to the infant's health status or anticipated development.

2. Information

   Provide verbal and written information related to
   a. Health maintenance
   b. Nutrition
   c. Growth and development
   d. Safety
   e. Anticipated referrals and follow-up plans

VI. Resources and tools

A. Parent–client–provider tools

1. The AAP website contains resources for caregivers, including information about high-risk neonatal growth, development, and health needs (www.aap.org).
2. The March of Dimes provides multiple neonatal and perinatal resources for providers and parents (http://www.marchofdimes.com).

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