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## The Special Care Nursery

Linda Kahn-D'Angelo

Yvette Blanchard

*Sacred Heart University*, [blanchardy@sacredheart.edu](mailto:blanchardy@sacredheart.edu)

Beth McManus

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# 28

## The Special Care Nursery

LINDA KAHN-D'ANGELO, PT, ScD • YVETTE BLANCHARD, PT, ScD • BETH MCMANUS, PT, ScD, MPH

**P**roviding services to high-risk infants and their families in the neonatal intensive care unit is a complex subspecialty of pediatric physical therapy requiring knowledge and skills beyond the competencies for entry into practice. The newborns in the neonatal intensive care unit (NICU) are among the most fragile patients that physical therapists will treat, and detrimental effects can occur as the result of routine caregiving procedures. Pediatric physical therapists (PTs) need advanced education in areas such as early fetal and infant development; infant neurobehavior; family responses to having a sick newborn; the environment of the NICU, physiologic assessment and monitoring; newborn pathologies, treatments, and outcomes; optimal discharge planning; and collaboration with the members of the health care team.<sup>256</sup> This chapter describes the neonatal intensive care unit and the role of the physical therapist within this setting. Practice in this setting requires knowledge of neonatal physiology, development, and health complications including prematurity, pulmonary conditions, neurologic conditions, fetal alcohol syndrome, fetal abstinence syndrome, and pain. A framework for physical therapy examination, evaluation, prognosis, and interventions for infants in the special care nursery is presented. The follow-up of infants after discharge from the intensive care nursery is addressed. Two case studies are presented to apply knowledge to practice.

### HISTORY OF THE SPECIAL CARE NURSERY

Modern neonatal care was born with the development of the incubator by Couveuse in France in 1880.<sup>130</sup> The first text on the premature infant, *The Nursling*, authored by Budin, a student of Couveuse, was published in 1900. The main principles of neonatal care were support of body temperature, control of nosocomial infection, minimal handling, and provision of special nursing care. Interestingly, nurseries were quiet, and lights were dimmed at night. Dr. Martin Couney, who was one of Budin's students, used these principles of treatment for the premature infant, and in a bizarre entrepreneurial twist, exhibited them in Chicago for a fee.<sup>234</sup> Dr. Julius Hess attended this exhibition and applied these principles in the late 1940s. Dr. Hess achieved a neonatal

mortality rate for preterm infants of 20%, which was respectable for the time. In response to the increased survival rate of premature infants reported by Hess, Budin's principles of care were implemented across the United States.

During the 1950s, a number of cities developed centers for the care of premature infants and a number of states developed maternal mortality committees that gathered data to be used as a basis for planning activities directed at preventing maternal death. During the 1960s, Arizona, Massachusetts, and Wisconsin promulgated standards for maternity units and developed regional perinatal care centers. Reports from these three states and several professional organizations, including the American Medical Association, the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics, and the Academy of Family Physicians, stimulated the development of the regional organization of perinatal services.<sup>93</sup>

By the late 1960s, full-term infants with health complications were also being treated in the neonatal nursery. Advances in microlaboratory techniques for biochemical determinations from minute quantities of blood and the development of miniaturized monitoring equipment, ventilatory support systems, and means to conserve body heat improved the care of the neonate with serious illness.<sup>93</sup> Expansion of neonatal pharmacology, widespread use of phototherapy for management of hyperbilirubinemia, and methods of delivery of high-caloric solutions parenterally when oral feeding was not possible also improved the chances for survival of the very sick neonate. In 1975, the emergence of the subspecialties neonatology and perinatology affirmed the need for practitioners skilled in the care of infants in the high-technology nursery.

During the past three decades, the availability of neonatal intensive care has improved outcomes for high-risk infants, including premature infants and those with serious medical or surgical conditions.<sup>15</sup> Improved survival for very low birth weight and extremely low birth weight infants has been reported during the time frame of 1988 to 2002.<sup>94,160,248</sup> This improvement in survival is related to antenatal steroids, more aggressive resuscitation in the delivery room, and advanced treatments given in the special care nursery including surfactant therapy.<sup>153</sup>

## ORGANIZATION OF PERINATAL SERVICES

Neonatal intensive care units are designed to meet a wide range of special needs, from the monitoring of apparently well infants at risk of serious illness to the intensive treatment of infants with acute illness. The March of Dimes report *Toward Improving the Outcome of Pregnancy* published in 1976, articulated the concept of regionalized perinatal care with three levels of maternal and neonatal care.<sup>71</sup> A subsequent report restated the importance of regionalization and recommended changes in designations from levels I, II, and III to basic, specialty, and subspecialty with expanded criteria.<sup>199</sup> By the beginning of the 21st century the number of neonatal intensive care units in the United States had increased to 880 (120 level II, 760 level III).<sup>107</sup> The three levels of neonatal care and capabilities within levels recommended by the American Academy of Pediatrics are presented in Box 28-1.<sup>15</sup>

## THE NEONATAL INTENSIVE CARE ENVIRONMENT

As depicted in Figure 28-1, the newborn in the intensive care nursery transitions from the buoyant, warm, enclosed, and relatively quiet and dark environment of the womb to a bright, often noisy, technology filled, gravity-influenced environment and is subjected to procedures that often cause pain and discomfort.

The newborn is extremely vulnerable to the environmental effects of the intensive care nursery. Many studies and

recommendations have been made to decrease negative effects and actually facilitate development as well as keep the infant alive. Caregivers play an important role in assessing and controlling aspects of the environment such as noise, light, and intensity of medical procedures.

In the 1980s, concern emerged that the typical nursery stay of several weeks may have detrimental effects on later behavior of the infant born at very low birth weight (<1500 grams).<sup>130</sup> At that time, the neonatal intensive care nursery was characterized by bright lights both night and day, high noise levels, and the intrusive medical procedures characteristic of high-technology treatment.<sup>54,108</sup>

Research ensued on the effects of different sensory inputs during the NICU stay and the concept of neonatal care facilitating optimal development. This care included modulation of the environment to facilitate development, recognition of infant distress and discomfort, and family-centered care.<sup>3,8,9,104,111–113,127</sup> More recently, environmental design of the intensive care nursery and the potential impact on neurodevelopmental outcome of the neonate were appraised by representatives from multiple hospitals.<sup>154</sup> Using an evidence-based approach, potentially better practices were identified to support neonatal development. These recommendations included implementation of guidelines for tactile stimulation, providing early exposure to mother's scent, minimizing exposure to noxious odors, developing a system for noise assessment of the NICU, minimizing ambient noise near the isolette, and preservation of sleep. Deep sleep is necessary for development of the neurosensory system and the maturing brain and should be facilitated and protected while the neonate is in the intensive care unit.<sup>183</sup>

### Box 28-1 HOSPITAL PERINATAL CARE LEVELS

#### LEVEL I: BASIC CARE

Evaluate and provide postnatal care to infants 35 to 37 weeks gestation, stabilize infants <35 weeks' gestation until transfer

#### LEVEL II - SPECIALTY CARE

IIA: Provides care for moderately ill infants >32 weeks' gestation

IIB: Provides mechanical ventilation for brief periods

#### LEVEL III: SUBSPECIALTY CARE

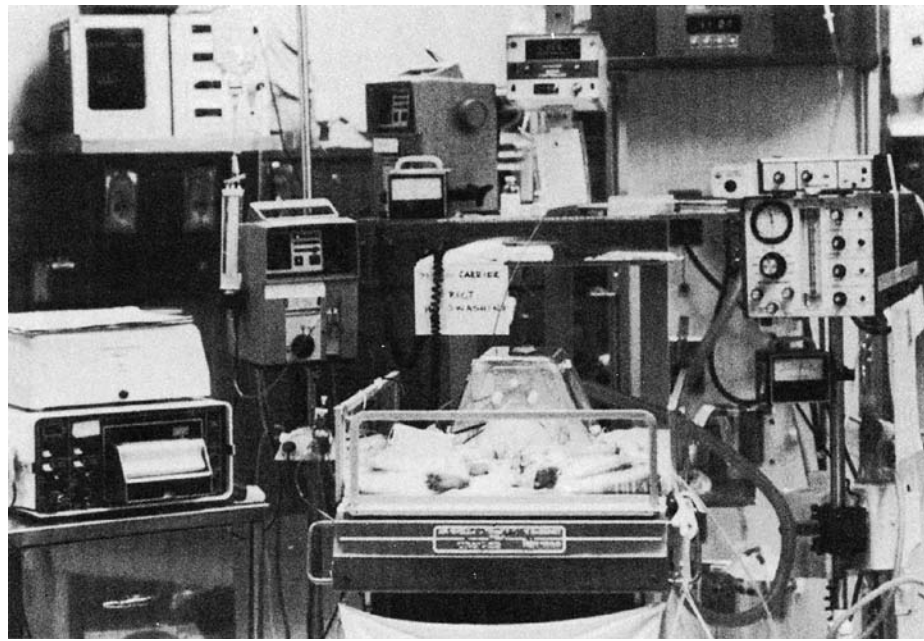
IIIA: Provides care for infants >28 weeks, performs minor surgical procedures

IIIB: Provides care for infants <28 weeks' gestation, provides advanced respiratory support (high-frequency ventilation); advanced imaging, pediatric surgical specialists, access to pediatric medical subspecialists

IIIC: Provides extracorporeal membrane oxygenation (ECMO) and complex cardiac surgery with cardiopulmonary bypass

## NOISE AND LIGHT

The intensive care unit includes many pieces of equipment that contribute to the noise level including respirators and alarms for unacceptable levels of heart rate, respiration, oxygen, temperature, and carbon dioxide exchange. Everyday activities such as conversation, closing drawers, dragging chairs, and tearing tape add to the noise level. Noise is measured on a logarithmic scale and small changes in measured decibels (db) are detectable. As a frame of reference, conversation may be at a 60-db level and dragging a chair may be at an 80-db level. Bremer et al. found that high noise levels from alarms and telephones can cause an increase in autonomic response that puts premature infants at risk for bradycardic and hypoxic episodes.<sup>48</sup> The American Academy of Pediatrics recommends noise levels not exceed 45 db with noise levels above 50 db only 10% of the time and a maximum of 65 db.<sup>275</sup> Darcy, Hancock, and Ware found that noise levels in several NICUs in the mid-Atlantic region of the United States were often louder than the 50-db level and that 60 db levels were exceeded at times.<sup>78</sup> Lasky and Williams followed 22 infants with extremely low birth weight (<1000 grams) throughout their stay in a NICU that was constructed with



**Figure 28-1** (Data from American Academy of Pediatrics, Policy Statement, Levels of Neonatal Care, *Pediatrics*, vol 114, No 5, 2004.)

a high priority on noise abatement and found that the neonates were exposed to noise levels averaging 56 db.<sup>152</sup> Noise levels increased with the use of older model ventilators and an open bed rather than an isolette. The authors concluded it is unlikely that newborns in the intensive care nursery consistently experience noise that does not exceed the recommended levels. Hearing loss has not been linked specifically to noise levels, but a synergistic relationship may occur with excessive noise and ototoxic drugs such as gentamicin.<sup>49</sup> Sound levels of the NICU may interfere with frequency discrimination and pattern recognition.<sup>111</sup>

Slevin et al. studied the impact of a designated “quiet period,” which included asking staff to keep noise levels at a minimum, switching phones to a flashing light system, and postponing caregiving activities if possible.<sup>236</sup> During the “quiet period,” the researchers noted significant reductions in infants’ median diastolic blood pressure and mean arterial pressure.<sup>236</sup> Other simple techniques such as covering the isolette with a blanket or placing a sound absorbing panel in the isolette help decrease the sound levels.<sup>12,225</sup> It is interesting to note that approximately half of the neonatal nurses interviewed reported that they never or rarely limit their conversations near the incubators/cribs.<sup>1</sup> Noise can also interfere with the development of sleep patterns in neonates.

Infants younger than 32 weeks gestational age have little ability to limit the amount of light entering the eyes because of thinness of the eyelids.<sup>112</sup> High light levels and decreased light/dark cycles may adversely affect newborn patients.<sup>14</sup> Recommended light levels are less than 646 lux (60 foot-candles) and are reported to be met more often than recommendations for noise levels.<sup>152</sup> Graven

recommended the following strategies to minimize the risk of visual impairments while the infant is in the NICU: protecting REM sleep, dark periods; limiting intense noise and other unnecessary sensory stimulation; and paying careful attention to the sensory environment of each infant.<sup>112</sup>

There is a growing body of evidence on the developmentally appropriate environment for neonates.<sup>64,275</sup> Private rooms are an alternative to the large multi-isolette/crib ward that currently characterizes the NICU. Noise levels decreased and catheter-associated bloodstream infections fell after infants moved from a ward to a single room.<sup>271</sup> An obvious disadvantage of the single room model is staff coverage.

### PREMATURITY AND LOW BIRTH WEIGHT

More than 500,000 infants are born prematurely (gestation of less than 37 weeks) in the United States every year.<sup>114</sup> Approximately 1% of live births are very preterm with gestational age younger than 32 weeks.<sup>279</sup> Preterm birth is a leading cause of infant mortality and morbidity, accounting for over 70% of neonatal deaths and half of long-term neurologic disabilities such as cerebral palsy, cognitive impairment, and behavioral problems.<sup>66,178</sup> The preterm birth rate has increased from 9% to 12% since 1981.<sup>114</sup> Infants born prematurely or who are small for gestational age (SGA) are divided into three major categories: low birth weight (LBW), from 1501 to 2500 grams; very low birth weight (VLBW), 1000 to 1500 grams; and extremely low birth weight (ELBW), less than 1000 grams.

The causes of preterm birth are not clear but seem to involve an interaction of multiple factors including genetic, social, and environmental factors.<sup>279</sup> Spontaneous preterm

delivery and birth has recently been described as a common complex disorder like heart disease, diabetes, and cancer.<sup>279</sup> Criteria for complex diseases include family history, recurrence, and racial disparities.<sup>114</sup> American black women had 1.5 times the rate of preterm birth and 4 times the rate of infant mortality because of preterm births compared with white women.<sup>146</sup> Approximately 40% of premature births are believed to be caused by intrauterine or systemic infections or both which are not diagnosed until the onset of labor.<sup>32</sup> Pregnancy-specific stress is associated with smoking, caffeine consumption, and unhealthy eating, and it is inversely correlated with healthy eating, vitamin use, exercise, and gestational age at delivery.<sup>167</sup> Maternal hemorrhage and pathologic distention of the uterus are associated with preterm labor.<sup>75</sup> Infants born after assisted reproduction have a lower birth weight and gestational age when compared to matched controls.<sup>172</sup>

There has been a significant increase in survival of infants with VLBW and ELBW<sup>153</sup> as a result of more aggressive delivery room resuscitation, surfactant therapy, and a decreased rate of sepsis.<sup>94,280</sup> Approximately half of children surviving extremely low-birth-weight deliveries have subsequent moderate to severe neurodevelopmental disabilities.<sup>153</sup> Brain injury, retinopathy of prematurity, bronchopulmonary dysplasia, and neonatal infection increase the risk of mortality or neurosensory impairment.<sup>27</sup>

There is a national focus on preventing preterm birth spearheaded by the March of Dimes National Prematurity Campaign of 2003, recently extended to 2020.<sup>176</sup> The Prematurity Research Expansion and Education for Mothers who Deliver Infants Early (PREEMIE) Act (P.L. 109-450) was passed in 2006 with a subsequent Surgeon's General Conference on the Prevention of Preterm Birth in 2008.<sup>191</sup> The conference objectives were to (1) increase awareness of preterm birth in the United States; (2) review key findings on causes, consequences, and prevention of prematurity; and (3) establish an agenda for public and private sectors to address this public health problem. Conference recommendations included (1) increased research in medicine, epidemiology, psychosocial, and behavioral factors relating to prematurity; (2) professional education and training; (3) communication and outreach to the public; (4) addressing racial disparities, and (5) improvement of quality of care and health services.

### ASSESSMENT OF GESTATIONAL AGE

The determination of gestational age of infants in the special care nursery is crucial to interpretation of findings from neurologic and behavioral examinations. The New Ballard Score (NBS) is the most widely used assessment of gestational age.<sup>241</sup> The NBS assesses neuromuscular maturity (such as posture), physical maturity (such as presence of lanugo), and external genitalia to determine gestational age from 20 to 44 weeks and is accurate within 1 week.<sup>241</sup>

Gestational age is also determined by ultrasound, measurements such as weight; length; head circumference; wrist, hip, and shoulder ranges of motion; and amniotic fluid analysis.<sup>224</sup> Although gestational age is usually determined by physicians or nurses, the physical therapist should be familiar with how gestational age is determined.

### NEONATAL HEALTH CONDITIONS ASSOCIATED WITH IMPAIRMENTS IN BODY FUNCTIONS AND STRUCTURES

Several pulmonary, neurologic, cardiac, and other health conditions in neonates are associated with increased risk for impairments in body functions and structures that affect cognitive, motor, sensory, behavioral, learning, and psychosocial development that may result in long-term activity limitations and participation restrictions.<sup>153</sup> The physical therapist providing services in the NICU should have a working knowledge of physiology of neonates, pathophysiology and associated impairments in body functions and structures, and how impairments affect the infant's behavior. Practice in the NICU is a complex subspecialty of pediatrics and knowledge and skills should be obtained through advanced didactic and practical education. Clinical guidelines and clinical training models for neonatal physical therapy are outlined by Sweeney, Heriza, and Blanchard.<sup>256</sup>

### PULMONARY CONDITIONS

#### RESPIRATORY DISTRESS SYNDROME

Respiratory distress syndrome (RDS), or hyaline membrane disease, is the single most important cause of illness and death in preterm infants and is the most common single cause of respiratory distress in neonates.<sup>247</sup> RDS occurs in 10% of all premature infants in the United States. The percentage increases to 50% to 60% for infants born less than 29 weeks gestational age.<sup>17,68</sup> The principal factors in the pathophysiology of RDS are pulmonary immaturity and low production of surfactant. Low surfactant production results in increased surface tension, alveolar collapse, diffuse atelectasis, and decreased lung compliance. These factors cause an increase in pulmonary artery pressure that leads to extrapulmonary right-to-left shunting of blood and ventilation-perfusion mismatching. Clinical manifestations of RDS include grunting respirations, retractions, nasal flaring, cyanosis, and increased oxygen requirement after birth. Prophylactic use of antenatal steroids to accelerate lung maturation in women with preterm labor of up to 34 weeks significantly reduced the incidence of RDS and decreased mortality.<sup>68</sup>

Treatment goals for RDS include improvement in oxygenation and maintaining optimal lung volume.<sup>144</sup> The type of intervention depends on the severity of the respiratory

disorder and includes oxygen supplementation, assisted ventilation, surfactant administration, and extracorporeal membrane oxygenation (ECMO). Continuous positive airway pressure (CPAP) or positive end-expiratory pressure (PEEP) is applied to prevent volume loss during expiration. Nasal and nasopharyngeal prongs are used with positive end-expiratory pressure ventilators. Mechanical ventilation via tracheal tube is used in severe cases of RDS. (See Chapter 23 for a more detailed description of ventilators.) Mechanical ventilation may injure the lungs of premature infants through high airway pressure (barotrauma), large gas volumes (volutrauma), alveolar collapse and refill (atelectrauma), and increased inflammation (biotrauma).<sup>22</sup>

The new generation of ventilators is equipped with microprocessors enabling effective synchronized (patient-triggered) ventilation.<sup>143</sup> High-frequency oscillatory ventilation (HFOV) was developed with the goal of decreasing complications associated with mechanical ventilation. Conventional intermittent positive pressure ventilation is provided 30 to 80 breaths per minute, whereas HFOV provides “breaths” at 10 to 15 cycles per second or 600 to 900 per minute. At this time, evidence is insufficient to support the routine use of HFOV.<sup>125</sup>

Prophylactic use of surfactant for infants judged to be at risk of developing RDS (infants less than 30 to 32 weeks gestation) has been demonstrated to decrease the risk of pneumothorax, pulmonary interstitial emphysema, and mortality.<sup>247</sup> Early administration of multiple doses of natural or synthetic surfactant extract results in improved clinical outcome and appears to be the most effective method of administration. When a choice of natural or synthetic surfactant is available, natural surfactant shows greater early decrease in requirement for ventilatory support.<sup>240,287</sup> Newer synthetic surfactants include whole surfactant proteins or parts of the proteins (peptides). A recent clinical trial showed that these preparations decreased mortality and rates of necrotizing enterocolitis with other clinical outcomes being similar to those of natural surfactant preparations.<sup>211</sup> A recent pilot study showed that an inhaled steroid, budesonide, delivered intratracheally with surfactant administration to very low birth weight infants with severe RDS reduced mortality and chronic lung disease with no immediate adverse effects.<sup>285</sup>

Extracorporeal membrane oxygenation (ECMO) is a technique of cardiopulmonary bypass modified from techniques developed for open-heart surgery that are used to support heart and lung function (for review of ECMO and implications for pediatric physical therapy, see Pax Lowes & Palisano<sup>207</sup>). In newborns with acute respiratory failure, the immature lungs are allowed to rest and recover to avoid the damaging effects of mechanical ventilation. Because of the need for systemic administration of heparin and the resultant risk of systemic and intracranial hemorrhage, ECMO is reserved for use with infants who are at least 34 weeks of gestational age, weigh more than 2000 g,

have no evidence of intracranial bleeding, require less than 10 days of assisted ventilation, and have reversible lung disease.<sup>250</sup> ECMO is contraindicated for infants younger than 34 weeks of age because of high rates of intracranial hemorrhage, perhaps because of systemic anticoagulation necessary with ECMO or to abnormal cerebrovascular pressures and flows accompanying ECMO. ECMO is used to manage intractable hypoxemia in near-term infants, newborns with meconium aspiration, RDS, pneumonia sepsis, and congenital diaphragmatic hernia.<sup>68</sup>

The prognosis of infants with RDS is correlated with the severity of the original disease, but today few infants die of acute respiratory failure, but rather from complications of extreme prematurity such as infections, necrotizing enterocolitis, and intracranial hemorrhage.<sup>143</sup> Infants who do not require assisted ventilation recover without developmental or medical sequelae, but the clinical course of the very immature infant may be complicated by air leaks in the lungs and BPD. Infants who survive severe RDS often require frequent hospitalization for upper respiratory tract infections and have an increased incidence of neurologic sequelae.<sup>133</sup>

Emerging technologies for management of RDS include inhalation of nitrous oxide, liquid ventilation, or a hybrid of liquid and gas ventilation. The rationale for using liquid ventilation is to decrease alveolar surface tension by eliminating the air-liquid interface by filling the alveolus with liquid.<sup>68</sup> Inhalation of nitrous oxide helps decrease pulmonary artery resistance, cytokine-induced lung inflammation, and increase gas exchange. Findings regarding the use of nitrous oxide (NO) and prevention of chronic lung disease and neurologic injury are inconclusive.<sup>21</sup> Inhaled nitric oxide for severe RDS is an experimental treatment that may decrease chronic lung disease and mortality. However, increase in intracranial hemorrhage caused a termination of a study in 2006.<sup>131</sup>

### BRONCHOPULMONARY DYSPLASIA AND CHRONIC LUNG DISEASE OF INFANCY

Bronchopulmonary dysplasia (BPD) and chronic lung disease of infancy (CLD) are two chronic pulmonary conditions that are caused by incomplete or abnormal repair of lung tissue during the neonatal period.<sup>129</sup> The National Institute of Child Health and Human Development defined infants with mild BPD as requiring oxygen supplementation for a total of at least 28 days, whereas infants with moderate or severe BPD require oxygen supplementation or ventilatory support at 36 weeks postmenstrual age and for more than 28 days.<sup>90</sup> CLD is diagnosed at 36 weeks' postmenstrual age, if there is a continued need for supplemental oxygen, abnormal physical examination, and abnormal chest radiograph. Chronic lung disease (CLD) occurs in 57% to 70% of infants born at 23 weeks gestational age; 33% to 89% of infants born at 24 weeks gestational age; and 16% to 71% of infants born at 25 weeks gestational age.

The cause of BPD is multifactorial with pathogenesis being associated with immature lung tissue, barotraumas (high airway pressure), and volutrauma (large gas volumes) resulting from mechanical ventilation. Atelectotrauma (alveolar collapse and reexpansion) occurs with increased inflammation and an imbalance in inflammatory and anti-inflammatory chemical mediators (cytokines) in infants with ELBW.<sup>33</sup> Neonatal sepsis especially because of candidemia, a systemic yeast infection, is associated with CLD.<sup>150</sup> Boys are at greater risk for developing CLDs, perhaps because of a lag of 1 to 2.5 weeks in pulmonary and cerebral maturation compared with girls.

Prevention of premature birth is the most effective preventive measure for BPD.<sup>33</sup> Antenatal steroids are still the most effective intervention in lung maturation. A decreased incidence of BPD was reported after management that included early administration of surfactant, immediately followed by nasal CPAP, lower oxygen saturation targets of 90% to 95%, and early parenteral amino acid supplementation.<sup>103</sup> The use of superoxide dismutase enzymes as an antioxidant has been investigated for treatment of BPD and CLD.<sup>129</sup> Management of BPD includes oxygen supplementation with oxygen saturation less than 95%, avoidance of mechanical ventilation if possible, diuretics after the first week of life, and steroids to help wean from oxygen during later stages of treatment.<sup>33</sup> Chronic lung disease is a major morbidity influencing development and is associated with poor nutrition, growth, feeding, prolonged hospitalization, and episodes of nosocomial infection. Treatment with early corticosteroids is associated with gastrointestinal bleeding and intestinal perforation, and there is a possibility of neurodevelopmental impairment.<sup>120</sup> Up to 50% of infants with BPD are hospitalized in the first year following discharge from the NICU.<sup>137,239</sup> Respiratory symptoms in patients with BPD persist into early adolescence<sup>121,269</sup> although most studies have shown no reduction in exercise capacity in children with BPD.<sup>34</sup> BPD seems to be associated with a global developmental impairment which correlates with BPD disease severity.<sup>90,137</sup> The reader is referred to Chapter 23 for information on children who require long-term ventilator assistance.

### MECONIUM ASPIRATION SYNDROME

Meconium aspiration syndrome (MAS) is defined as respiratory distress in an infant born through meconium-stained amniotic fluid whose symptoms cannot be otherwise explained.<sup>92</sup> It can be characterized by early onset respiratory distress in term and near-term infants with symptoms of respiratory distress, poor lung compliance, hypoxemia, and radiographic findings of hyperinflation and patchy opacifications with rales and rhonchi on auscultation.<sup>278</sup> Because of the frequent occurrence of air leaks in these infants, positive pressure ventilation is contraindicated. It is unclear whether the meconium itself causes pneumonitis severe enough to lead to the above symptoms or if the presence of meconium

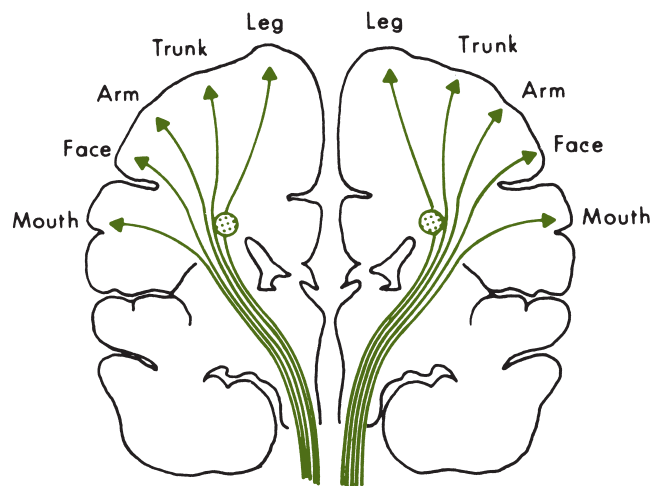
in the amniotic fluid is a result of other events such as stressed labor, postmaturity, and depressed cord pH that may have predisposed the fetus to severe pulmonary disease.<sup>68</sup> It is recommended that the infant with depressed physiologic function and meconium-stained fluid be suctioned endotracheally as pharyngeal suctioning does not reduce MAS.<sup>263</sup> Antibiotics are often given until bacterial infection is ruled out. The infant is hypersensitive to environmental stimuli and should be treated in the quietest environment possible. According to a Cochrane Review in 2007, surfactant administration may reduce the severity of MAS and decrease the number of infants requiring ECMO.<sup>91,233</sup> Obstetric approaches to the prevention of MAS such as intrapartum surveillance, amnioinfusion, and delivery room management have not demonstrated a decrease in MAS.<sup>284</sup> Approximately 20% of infants with MAS demonstrated neurodevelopmental delays up to 3 years of age even though they responded well to conventional treatment.<sup>30</sup>

## NEUROLOGIC CONDITIONS

### PERIVENTRICULAR LEUKOMALACIA

Periventricular leukomalacia (PVL) is the predominant form of brain injury and the leading known cause of cerebral palsy (CP) and cognitive impairments in premature infants.<sup>82</sup> PVL is a symmetrical, nonhemorrhagic, usually bilateral lesion caused by ischemia from alterations in arterial circulation.<sup>281</sup> Male gender, premature rupture of membranes, preeclampsia, reduced carbon dioxide in the blood, and intraventricular hemorrhage (IVH) are associated with PVL.<sup>123</sup> PVL is characterized by necrosis of white matter dorsal and lateral to the external angles of the lateral ventricles. The area affected includes the white matter through which long descending motor tracts travel from the motor cortex to the spinal cord. Because the motor tracts involved in the control of leg movements are closest to the ventricles and therefore more likely to be damaged, spastic diplegia is the most common motor impairment (Figure 28-2). If the lesion extends laterally, the arms may be involved, with resulting spastic quadriplegia. Visual impairments may also result from damage to the optic radiations.<sup>281</sup>

PVL is caused by a reduction in cerebral blood flow in the highly vulnerable periventricular region of the brain where the arterial “end zones” of the middle, posterior, and anterior cerebral arteries meet and is often associated with intraventricular hemorrhage (IVH).<sup>268</sup> Decreased cerebral blood flow leads to ischemia and a decrease in antioxidants. This results in generation of free oxygen radicals and glutamate toxicity factors that contribute to periventricular leukomalacia. The incidence of white matter damage in premature infants increases with decreased gestational age because of the immature vascular supply, impairments in cerebral autoregulation, and damage to premyelinating oligodendrites from free radicals.<sup>145,268</sup> PVL also affects subplate neurons



**Figure 28-2** Diagram of cortical spinal tracts. Dotted circular areas indicate periventricular leukomalacia that would be expected to affect descending fibers for control of lower extremity. (From Volpe, JJ. *Neurology of the newborn*, 2nd edition, Philadelphia: WB Saunders, 1987, p 314.)

which lie just below the developing cerebral cortex until programmed apoptosis (cell death). Subplate neurons play an essential role in axonal targeting of thalamocortical synapses, and their loss may contribute to motor, visual, and cognitive impairments.<sup>82</sup> Systemic hypotension associated with difficult resuscitation at birth and ECMO are also associated with PVL. Patent ductus arteriosus and severe apneic spells are other contributing factors, particularly after the first week of life.<sup>145</sup>

Serial ultrasonography one week following birth and magnetic resonance imaging are diagnostic tools for periventricular leukomalacia.<sup>82</sup> White matter echodensities and echolucencies on high-resolution cranial ultrasonography are predictive of neurologic sequelae associated with cerebral palsy.<sup>86</sup> Serial ultrasonographic studies are important because the evolution of periventricular echodensity is related to prognosis. Early periventricular echodensity that resolves during the first weeks of life is not correlated with childhood disability. Formation of cysts as a result of dissolution of brain tissue secondary to infarction, however, is correlated with cerebral palsy and cognitive impairments. Cerebral palsy occurs in more than 90% of infants who develop bilateral cysts larger than 3 mm in diameter in the parietal or occipital areas.<sup>86</sup>

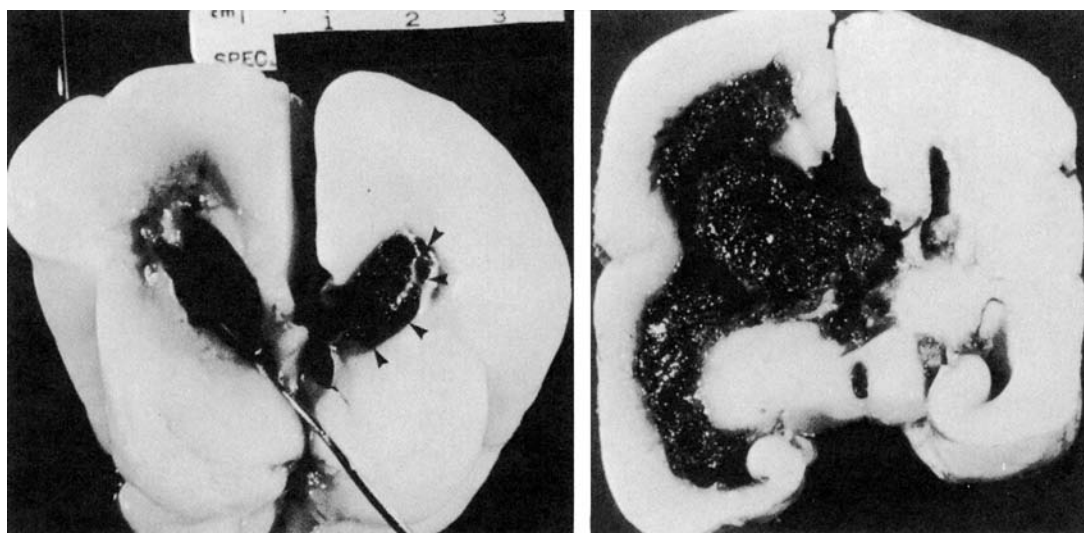
Medical management of PVL includes prevention of intrauterine asphyxia, maintenance of adequate ventilation and perfusion, avoidance of systemic hypotension, and control of seizures.<sup>38,268</sup> Prevention of intrauterine asphyxia includes identification of high-risk pregnancies, fetal monitoring, fetal blood sampling, and cesarean section as indicated. Maintenance of adequate ventilation includes avoiding common causes of hypoxemia such as inappropriate feeding, inserting or removing ventilator connections,

painful procedures and examinations, handling, and excessive noise. Adequate perfusion can be maintained with appropriate treatment if the infant exhibits apnea and severe bradycardia. Outcomes of PVL include increased incidence of CP if cysts are visible with ultrasound, whereas cognitive impairment may be the outcome if ultrasound shows increased periventricular echogenicity without cysts.<sup>86</sup>

### GERMINAL MATRIX-INTRAVENTRICULAR HEMORRHAGE AND PERIVENTRICULAR HEMORRHAGE

Germinal matrix-intraventricular hemorrhage (GM-IVH) is the most common type of neonatal intracranial hemorrhage. GM-IVH occurs in neonates younger than 32 weeks of gestational age and weighing less than 1500 grams with an inverse relationship between gestational age and incidence of GM-IVH. The incidence of GM-IVH has declined and ranges from 15% to 20%.<sup>173</sup> Most hemorrhages occur within the first 24 hours after birth and progress over 48 hours or more. By the end of the first postnatal week, 90% of hemorrhages have reached their full extent. Papile developed a four-level grading scale based on ultrasound scan to classify hemorrhages.<sup>204</sup> Grade I is an isolated germinal matrix hemorrhage. Grade II is an IVH with normal-sized ventricles that occurs when hemorrhage in the subependymal germinal matrix ruptures through the ependyma into the lateral ventricles. Grade III is an IVH with acute ventricular dilation, and grade IV is a hemorrhage into the periventricular white matter. Perinatal events that can lead to increased cerebral blood flow and GM-IVH include respiratory distress, apnea, hypotension, rapid volume expansion, routine caregiving interventions, and environmental stress such as noise and light.<sup>38</sup>

GM-IVH pathogenesis involves complex interaction of intravascular, vascular, and extravascular factors. This lesion involves bleeding into the subependymal germinal matrix, which is a gelatinous area that contains a rich vascular network supplied mainly by Heubner's artery, a branch of the anterior cerebral artery; branches of the middle cerebral artery; and the internal carotid. This matrix is prominent from 26 to 34 weeks of gestation and is usually gone by term. The vessels that traverse the matrix are primitive in appearance and structure, with a single layer of endothelium without smooth muscle, elastin, or collagen, and the area is devoid of supportive stroma. Hemorrhage occurs from these primitive capillaries. In a small number of preterm infants, hemorrhage may occur from the choroid plexus or the roof of the fourth ventricle (Figure 28-3). Cerebral autoregulation of the blood vessels normally protects the brain from significant alterations in cerebral blood flow. Hypoxia and hypoxemia in the neonate interfere with cerebral autoregulation<sup>85</sup> and increase the risk of vessel rupture.<sup>247</sup> Positive-pressure ventilation can be transmitted to capillaries of the germinal matrix, which can



**Figure 28-3** Coronal section of cerebrum showing germinal matrix - intraventricular hemorrhage. (From Volpe, JJ. *Neurology of the newborn*, 5<sup>th</sup> edition, Philadelphia, WB Saunders, 2008, p 519.)

impede venous return, leading to increased pressure and rupture. The most vulnerable area of the venous drainage system is at the level of the foramen of Monro and the caudate nucleus, the most common site of GMH-IVH.<sup>38</sup>

Extravascular factors also contribute to GMH-IVH. The germinal matrix is highly vascularized and the capillary bed is embedded in gelatinous material that provides poor support for the fragile blood vessels. This along with excessive fibrinolytic activity in the periventricular area may result in the extension of a small bleed, which may then rupture into the ventricles.<sup>268</sup> Environmental and genetic factors also may affect the risk for IVH as well as maternal infection such as chorioamnionitis.<sup>182</sup> Neuropathology associated with IVH includes hydrocephalus, germinal matrix destruction, cyst formation, and accompanying hypoxic-ischemic lesions.

The signs and symptoms of GMH-IVH may range from subtle and nonspecific to catastrophic. Clinical signs include a decreasing hematocrit, a full anterior fontanelle, changes in activity level, impaired visual tracking, increased muscle tone of lower limbs, neck flexor hypotonia, and brisk tendon reflexes.<sup>268</sup> Catastrophic deterioration involves major acute hemorrhages with clinical signs of stupor progressing to coma, respiratory distress progressing to apnea, generalized tonic seizures, decerebrate posturing, fixation of pupils to light, and flaccid quadripareisis.

The diagnosis of GMH-IVH is usually made by cranial ultrasonography. The American Academy of Neurology recommends that cranial ultrasonography be done on all preterm neonates less than 30 weeks gestation age between 7 and 14 days of chronologic age and at 36 to 40 weeks gestational age to screen for GMH-IVH.<sup>187</sup> MRI is more accurate than ultrasound and may be used at term as a

predictor of outcome at 2 to 3 years for VLBW preterm infants.<sup>82</sup>

Efforts to prevent IVH have met with varying degrees of success. Lower rates of IVH have been reported in NICUs with higher patient volume and higher neonatologist-to-house staff ratio.<sup>258</sup> Prevention of neonatal hypoxic events as such as respiratory distress, apnea, hypotension and rapid volume expansion, hypercarbia, excessive caregiving interventions, and environmental stress such as excessive noise or light may decrease incidence of IVH.<sup>38</sup> A review of the use of phenobarbital did not reveal a significant decrease in occurrence or severity of IVH, but there was an increased risk for ventilation need.<sup>276</sup> Infants treated with indomethacin have been shown to have a decrease in incidence and severity of IVH.<sup>228</sup> Outcomes for infants treated with indomethacin are better for boys than girls.<sup>188</sup>

Interventions for IVH include acute treatment, pharmacologic therapy, and management of ventricular dilation.<sup>38</sup> Acute treatment includes physiologic support to maintain oxygenation, perfusion, body temperature, and blood glucose level. Physical handling is minimized. The infant should be positioned in prone or side lying with the head in midline or to the side without neck flexion. Management of ventricular dilation includes ventriculoperitoneal shunting or temporary ventricular draining.<sup>38,288</sup>

Outcomes of IVH depend on severity and extent of the hemorrhages and the presence of associated problems. Infants with a small or mild hemorrhage survive and have a low incidence of neurologic complications. Infants with moderate hemorrhage have a mortality rate of 5% to 20%, and ventricular dilation develops in 15% to 20% of survivors. When bleeding is severe, mortality is 50%. The incidence of neurologic conditions such as cerebral palsy,

hydrocephalus, cognitive impairment, sensory and attention problems, and learning disorders varies from 15% in infants with moderate hemorrhage to 35% to 90% in infants with severe hemorrhage.<sup>85</sup>

### HYPOXIC ISCHEMIC ENCEPHALOPATHY

Hypoxic ischemic encephalopathy (HIE) is a spectrum of neurologic impairment associated with high neonatal mortality and neurologic morbidity.<sup>221</sup> HIE is a lack of oxygen and substrate delivery to the brain as a result of decreased blood flow which may occur from maternal, uteroplacental, or fetal complications.<sup>163</sup> Examples of potential causes include maternal cardiac arrest, placental abruption, and fetomaternal hemorrhage. The incidence of term gestation perinatal HIE ranges from 0.5 to 2 infants per 1000 live births.<sup>105</sup> MRI is the preferred imaging tool in the neonatal period and long-term follow-up.<sup>164</sup> Clinical signs of moderate encephalopathy include lethargy, decreased activity level, hypotonia, weak suck, incomplete Moro reflex, constricted pupils, bradycardia, and periodic breathing. Clinical signs of severe HIE include stupor or coma, no spontaneous activity, decerebrate posturing, flaccid tone, absent Moro and suck reflexes, dilated or nonreactive pupils, variable heart rate, and apnea.<sup>232</sup> The pattern of HIE occurs in two phases. The first phase is a primary energy failure related to the specific insult, which causes the lack of oxygen and glucose. The secondary or delayed brain injury phase energy failure occurs some hours later with symptoms evolving over approximately 72 hours and is postulated to be due to delayed cell death.<sup>266</sup> Delayed cell death is caused by cellular energy failure, acidosis, and neurotoxicity resulting from neurotransmitter (glutamate), calcium, and nitric oxide release and accumulation from the earlier injury phase.<sup>266</sup>

Historically the treatment of neonatal HIE has been limited to supportive care, but hypothermia either of the head or whole body is an emerging treatment to interrupt several critical steps during the process of hypoxic-ischemic injury.<sup>289</sup> Other neuroprotective interventions being studied include oxygen free radical scavengers and excitatory amino acid antagonists such as allopurinol and glutamate receptor antagonists.<sup>118,264</sup> There is a 10% risk of death with moderate HIE and up to 30% of infants manifest spastic quadriplegia and cognitive impairment resulting from cortical and subcortical injury in a parasagittal distribution.<sup>268</sup> In severe HIE mortality is 60% and the majority of all survivors will have long-term morbidity associated with damage to the thalami, basal ganglia, hippocampi, and mesencephalic structures.<sup>232,268</sup> Long-term sequelae include cognitive impairment, spastic quadriplegia, seizure disorder, ataxia, bulbar and pseudobulbar palsy, atonic quadriplegia, hyperactivity, and impaired attention.<sup>268</sup>

### NEONATAL SEIZURES

Seizures are the most frequent and distinct neurologic signs that occur in the neonatal period.<sup>268</sup> A seizure is clinically defined as a paroxysmal alteration in autonomic, behavioral, and motor function. The incidence of neonatal seizures has been reported as ranging from 1.5 to 3.5 per 1000 live births in North America, varying with risk factors such as low birth-weight, prematurity, maternal medical conditions, and perinatal obstetrical complications.<sup>186</sup> Causes of neonatal seizures include hypoxia-ischemia, stroke, metabolic disease, and drug intoxication or withdrawal or idiopathic. Seizures are classified by Volpe as subtle, such as tonic horizontal deviation of eyes in term infants and chewing movements in premature infants, tonic involving sustained posturing of a limb, and clonic involving rhythmic and slow movement.<sup>268</sup> The most frequent overt sign of neonatal neurologic disorders is the convulsive seizure. Electroencephalography (EEG) does not record some of the behaviors/signs previously described as seizures by observation. Neonatal seizures documented by EEG with or without clinical manifestations represent the most accurate diagnosis, although there is controversy regarding the possibility of seizures occurring without EEG activity because they are subcortical.<sup>259,268</sup> Although some experts argue that the diagnosis of neonatal seizures should not be based on clinical observation alone, EEGs are not available in most NICUs.<sup>235</sup>

It is imperative to recognize neonatal seizures, determine their origin, and provide specific treatment for the illness/condition causing them. It is also important to decrease their interference with feeding and respiration.<sup>259,268</sup> Management of neonatal seizures includes maintenance of the infant's airway and monitoring of vital signs and blood gases. There is not a consensus of when to treat with anticonvulsant drugs and for how long.<sup>109</sup> The most common anticonvulsant used is phenobarbital with others including phenytoin, and benzodiazepams. These anticonvulsant drugs have many side effects including respiratory, myocardial, and central nervous system depression, and jaundice, and may have toxic effects on the developing brain.<sup>38</sup>

A 2004 Cochrane Review concluded that "there is little evidence to support the use of any of the anticonvulsants currently used in the neonatal period," although it is generally agreed that recurrent or prolonged seizures require treatment to reduce the risk of brain injury.<sup>109,235</sup> Trials of new pharmacologic agents such as bumetanide are currently ongoing.<sup>101</sup> The mortality rate for neonates with seizures has declined from 40% before 1969 to less than 15%. In a recent study, neonatal mortality was 7%, and 28% of infants had poor long-term neurologic outcome such as cerebral palsy, cognitive impairment, and epilepsy.<sup>180</sup> A normal neurologic and behavioral examination and normal to mildly abnormal EEG are associated with a favorable outcome with little or no disability.<sup>180</sup>

## CARDIAC CONDITIONS

Cardiac conditions common to neonates in the NICU include congenital heart defects such as patent ductus arteriosus (PDA), pulmonary atresia, tetralogy of Fallot (TOF), coarctation of the aorta (COA), and pulmonary atresia. Cardiac conditions are presented in Chapter 26.

## OTHER MEDICAL CONDITIONS

### NECROTIZING ENTEROCOLITIS

Necrotizing enterocolitis (NEC) is an acute inflammatory disease of the bowel that occurs most frequently in premature infants weighing less than 2000 grams during the first 6 weeks of life.<sup>110,170</sup> Although the cause is not known, several factors appear to play a role in the pathogenesis of NEC. Many of these factors involve impaired blood flow to the intestine and include asphyxia, congenital heart disease, abdominal wall defects, neural tube defects, intrauterine growth restriction, exchange transfusion, and presence of umbilical catheter.<sup>260</sup> Diminished blood supply results in death of mucosal cells lining the bowel wall, decreasing secretion of lubricating mucus. The thin bowel wall becomes susceptible to proteolytic enzymes, swells, breaks down, and is permeable to exotoxins. Gas-forming bacteria invade the damaged area to produce pneumatosis intestinalis, air in the submucosal, or subserosal surfaces of the bowel. Decreased immunologic factors hamper the ability of the intestinal tract to fight organisms that are not absorbed,<sup>44</sup> and intestinal motility is not mature until the third trimester.<sup>165</sup> The digestive system of premature infants, especially those who are VLBW and ELBW, often is intolerant to enteral (tube) feedings. Enteral feedings contribute to bacterial colonization by directly introducing organisms into the intestine as well as providing substrate for organism growth. Bradshaw reported that nearly all infants who had NEC had enteral feedings.<sup>44</sup> Breast milk may have protective effects against the development of NEC.

Signs of obstruction of the bowels include vomiting, distention of the abdomen, increased gastric aspirates, passing of bloody stools, retention of stools, lethargy, decreased urine output, and alterations in respiratory status. Diagnosis of NEC is made by physical examination, laboratory tests, and radiography. Radiographic or abdominal ultrasonography is used to follow the course of the disease, with lucent bubbles appearing as the gas-forming bacteria enter the intestinal wall.<sup>134</sup> Medical treatment of NEC includes discontinuation of all oral feedings, abdominal decompression via nasogastric suction, administration of intravenous antibiotics, and correction of fluid and electrolyte imbalances.<sup>44</sup> Surgical intervention is indicated when there is radiographic evidence of fixed, dilated intestinal loops accompanied by intestinal distention, perforation, intestinal gangrene, and abdominal wall edema.

Factors that are predictive of poor outcome include prior enteral feeding, patent ductus arteriosus, indomethacin use, and perforation. Improved medical-surgical care and the use of total parenteral nutrition has reduced the mortality rate from 24% to 65% in the 1960s and 1970s to 9% to 28% in the 1990s, with even lower rates for neonates who did not require surgical intervention.<sup>260</sup> Among survivors, 10% to 30% have strictures, especially of the colon, which require surgery. A Cochrane Review recommended further large clinical trials to determine how the timing of introduction of parenteral feeding affects clinical outcomes in infants with VLBW.<sup>43</sup>

### GASTROESOPHAGEAL REFLUX DISEASE

Gastroesophageal reflux disease (GERD) is the retrograde movement of acidic stomach contents into the esophagus.<sup>260</sup> GERD occurs frequently in preterm infants because of the horizontal position and immature lower esophageal sphincter function.<sup>37</sup> Signs of GERD include frequent vomiting, regurgitation of feeds, irritability, and pulmonary aspiration. The premature infant may present with more subtle signs such as apnea and bradycardia.<sup>73,87</sup> GERD is associated with failure to thrive, recurrent apnea, recurrent respiratory infections, and ventilator dependence.<sup>260</sup>

Tests for GERD include esophageal pH monitoring, with a tube placed in through a nostril and left in place for 24 hours, and impedance monitoring, which detects the flow of fluids and gas through hollow viscera, or a combination of both techniques.<sup>73</sup> A GERD behavioral scale questionnaire called the Infant Gastroesophageal Reflux Questionnaire (I-GERQ), which has been shown to be valid and specific,<sup>200</sup> has been modified by Birch and Newell for premature infants.<sup>37</sup>

Management of GERD includes positioning the infant in prone or on the left side if cardiorespiratory monitoring is applied, using a feed thickener such as carob, pharmacologic agents; monitoring for apnea, parenteral support, and surgery if the previous treatment strategies are not successful and if there are respiratory symptoms associated with GERD.<sup>37,260</sup> Pharmacologic agents include antireflux drugs such as ranitidine, lansoprazole, and metoclopramide.<sup>26</sup> The most commonly used surgical procedure for the neonate is a fundal plication in which the proximal stomach is wrapped around the distal esophagus, creating a junction that prevents reflux.<sup>201</sup>

### RETINOPATHY OF PREMATURITY

Retinopathy of prematurity (ROP) is caused by proliferation of abnormal blood vessels in the newborn retina, which occurs in two phases. Phase I is delayed growth of retinal blood vessels after premature birth. Phase II occurs when the hypoxia created during phase I stimulates growth of new blood vessels. Growth of retinal blood vessels is stimulated

by vascular endothelial growth factor (VEGF) and insulin-like growth factor-1 (IGF-1).<sup>175</sup> Use of oxygen supplementation causes hyperoxia and suppresses VEGF and IGF-1 causing apoptosis (death) of vascular endothelial cells, which causes hyperoxia-induced blood vessel damage and scarring of the retinal vessels.<sup>237</sup> As the preterm infant matures, the metabolically active retina triggers release of VEGF and IGF-1, which leads to new vascular proliferation which causes the progression of retinopathy.

The outcome of ROP varies from normal vision to total loss of vision if there is advanced scarring from the retina to the lens resulting in retinal detachment.<sup>252</sup> ROP was called retrolental fibroplasia in the early 1940s and was virtually eliminated with the severe restriction of oxygen use between 1950 and 1970. The condition has recurred as one of the major causes of disability in preterm infants as a result of the increased survival of infants with VLBW. The incidence of ROP increases with lower gestational age, lower birth weight, and BPD.<sup>175</sup>

The classification system for ROP uses a standard description of the location of the retinopathy using zones and clock hours, the severity of the disease or stage, and presence of special risk factors.<sup>135</sup> The classification system was revised in 2005 to include a rapid progressive form of ROP.<sup>136</sup> Classification of ROP includes five stages.<sup>251</sup> Stage 1 is characterized by a visible line of demarcation between the posterior vascularized retina and the anterior avascular retina. Stage 2 is characterized by pathologic neovascularization that is confined to the retina and appears as a ridge at the vascular/avascular junction. Stage 3 includes new vascularization and migration into the vitreous gel. Stage 4 is characterized by a subtotal retinal detachment. Stage 5 is complete retinal detachment.

Prematurity and low birth weight are the most important factors associated with ROP. IVH, use of supplemental oxygen, sepsis, and blood transfusion are other risk factors.<sup>252</sup> Risk factors for infants with ELBW include birth weight less than 1000 grams, steroid use, maternal preeclampsia, number of days on ventilation, continuous positive pressure ventilation, male gender, and fluctuating PaO<sub>2</sub>.<sup>286</sup> Prevention and treatment include oxygen administration at PaO<sub>2</sub> between 50 and 70 mm Hg and administration of vitamin A, which is still under investigation.<sup>79</sup> Light reduction was not shown to be effective in altering the incidence of ROP.<sup>220</sup>

All premature infants given supplemental oxygen are at risk for ROP and should be screened. Guidelines approved by the American Academy of Pediatrics include screening 4 to 6 weeks after birth or within 31 to 33 weeks postconceptual age, whichever is later. Subsequent intervals for examination are based on initial findings.<sup>251</sup> A study conducted in Sweden recommended that the screening criterion be lowered to 31 weeks or less to identify infants with severe ROP.<sup>151</sup>

Surgical intervention can be divided into two overlapping objectives: treatment of neovascular process with retinal cryotherapy and surgical intervention for retinal detachment

(laser photocoagulation, cryotherapy, vitrectomy, and scleral buckling).<sup>251</sup> Implementation of an oxygen management policy that included strict guidelines for increasing and weaning of FiO<sub>2</sub> (fraction of inspired oxygen), monitoring oxygen saturation in the delivery room, in-house transport, and hospitalization for infants with birth weights of 500 to 1500 grams decreased the incidence of stages 3 and 4 ROP and decreased the need for laser treatment.<sup>67</sup> The oxygen level that maintains brain perfusion while minimizing the risk of ROP has not been determined.<sup>20</sup> Surgical outcome varies from complete recovery or mild myopia to blindness, depending on the extent of the disease. Emerging treatment modalities include administration of VEGF, IGF-1, and dietary supplementation with omega-3-polyunsaturated fatty acids.<sup>175</sup>

## HYPERBILIRUBINEMIA

Hyperbilirubinemia, or physiologic jaundice, is the accumulation of excessive amounts of bilirubin in the blood. Bilirubin is one of the breakdown products of hemoglobin from red blood cells. This condition is seen commonly in premature infants who have immature hepatic function, an increased hemolysis of red blood cells as a result of high concentrations of circulating red blood cells, a shorter life span of red blood cells, and possible polycythemia from birth injuries. The pathogenesis of hyperbilirubinemia may be multifactorial and associated with late preterm gestational age, exclusive breast-feeding, and ABO hemolytic disease (blood incompatibility between mother and fetus), East Asian ethnicity, and jaundice in first 24 hours of life.<sup>273</sup> The primary goal in treatment of hyperbilirubinemia is the prevention of kernicterus, which is the deposition of unconjugated bilirubin in the brain, especially in the basal ganglia, cranial nerve nuclei, anterior horn cells, and hippocampus. Kernicterus can occur in infants with ELBW at low levels of bilirubin; consequently phototherapy is often initiated at low serum bilirubin levels.<sup>13</sup> Phototherapy is administered via a bank of lights or fiberoptic blankets. For phototherapy by lights, the infant is positioned in an open radiant warmer or incubator and the eyes are shielded to avoid retinal damage. Studies show that on/off cycles of more than 1 hour are as effective as continuous treatment. Fiberoptic phototherapy uses light from a halogen lamp transmitted through a fiberoptic bundle to a blanket that is wrapped around the infant. Infants who received continuous phototherapy for 23 hours with a fiberoptic panel held against their back and kangaroo care (skin-to-skin contact with parent) showed comparable declines in bilirubin levels compared with infants who received phototherapy from a bank of lights in an isolette for 24 hours a day.<sup>171</sup> Using a lower bilirubin level threshold for phototherapy treatment (5 mg per deciliter rather than 8 mg) for infants with ELBW significantly reduced bilirubin levels and rate of neurodevelopmental impairment, but not the death rate.<sup>189</sup>

If phototherapy is not effective in reducing the total serum bilirubin concentrations to acceptable levels, or if there is a rapidly rising bilirubin level, exchange transfusion is done.<sup>84</sup> In this technique, approximately 85% of the infant's red blood cells are replaced. Care must be taken so as not to disrupt cerebral blood flow and intracranial pressure. Recent case studies and clinical trials from the 1980s and 1990s demonstrated the beneficial effects of metalloporphyrins such as tin (Sn) mesoporphyrin and tin protoporphyrin for both prophylaxis and treatment to reduce hyperbilirubinemia.<sup>83</sup> These substances are inhibitors of heme oxygenase, the enzyme in the synthesis of bilirubin that limits the rate of degradation of heme to bile. Infants with severe hyperbilirubinemia who are not responsive to phototherapy and whose parents are Jehovah's Witnesses and rejected exchange transfusion have been successfully treated with Sn-mesoporphyrin.<sup>140</sup>

### FETAL ALCOHOL SYNDROME

Chronic alcohol exposure in utero may result in a multitude of symptoms at birth, including withdrawal symptoms of irritability, tremors, apnea, hypertonia, hypersensitivity to sensory stimuli, and seizures.<sup>268</sup> Alcohol rapidly crosses the placenta and the blood-brain barrier of the fetus, and there is a dose-dependent relationship between maternal alcohol intake in the first trimester of pregnancy and the occurrence of fetal alcohol syndrome (FAS). FAS is the most recognized outcome of prenatal alcohol exposure and is characterized by pre- and postnatal growth retardation, craniofacial anomalies, as well as CNS dysfunction such as intellectual disabilities and behavior problems.<sup>117</sup> It is now recognized that the effects of prenatal exposure to alcohol make up a continuum of physical anomalies and cognitive and behavioral deficits. The term "fetal alcohol spectrum disorder" (FASD) has been described as a nondiagnostic umbrella term that describes the range of effects including FAS.<sup>117</sup>

Alcohol exposure in utero is associated with a broad range of adverse effects on placental development and function.<sup>51</sup> Symptoms of withdrawal manifest within the first 24 hours after birth. The clinical withdrawal syndrome dissipates within a week, and the treatment includes avoidance of sensory overload and administration of phenobarbital for seizures.

FAS is one of the most common causes of intellectual disability in the world, and it is characterized by a triad of symptoms composed of growth deficiency, cardiac defects, and CNS disturbances, such as microcephaly and dysmorphism (including facial, genital, and joint abnormalities).<sup>268</sup> Neuroimaging studies have demonstrated overall and regional volumetric and surface area reductions; abnormalities of particular areas of the brain including the basal ganglia, corpus callosum, cerebellum, and hippocampus; and reduced and increased densities for white and gray

matter with disproportionate reduction in the size of the frontal lobes.<sup>193,268</sup>

Neurobehavioral effects of FASD include a continuum of long-lasting impairments in cognition and behavior, including problems in learning, memory, executive functions, hyperactivity, impulsivity, and poor communication and social skills.<sup>117</sup> Prenatal exposure to alcohol also had adverse effects on neuroendocrine functions including increased activity of the hypothalamic-pituitary-adrenal (HPA) axis, which is the putative regulatory mechanism for response to stressful sensory stimuli.<sup>274</sup> A number of ocular and neuro-ophthalmic impairments occur in FASD such as refractive errors, strabismus, and amblyopia, which can lead to lifelong visual impairment if not treated.<sup>51</sup>

Maternal and family education and support programs play important roles in prevention of FASD.<sup>149</sup> Once FASD is suspected or diagnosed, evidence-based treatment programs that support the family environment through enhancing parenting skills, facilitating parent-child attachment, and early intervention services may improve children's health and cognitive outcomes.<sup>149</sup> Interventions with the child include psychostimulant pharmacologic agents and cognitive control therapy.<sup>216</sup>

### NEONATAL ABSTINENCE SYNDROME

Maternal use of narcotics during pregnancy leads to the fetus developing dependency on that drug. The most commonly used drugs that lead to fetal dependence and withdrawal are heroin, cocaine, methadone, and pain medication. There is often maternal use of several drugs during pregnancy, including alcohol and tobacco, which accompanies socioeconomic factors, poor nutrition, stress, infections, and poor perinatal care.<sup>227</sup> The fetus experiences withdrawal or neonatal abstinence syndrome (NAS) when the mother is withdrawn from her drug or drugs or when the fetus is delivered.<sup>77</sup> The onset of withdrawal symptoms usually occurs within 72 hours after birth.<sup>230</sup> Symptoms of withdrawal include irritability, tremors, seizures, apnea, increased muscle tone, inability to sleep, hyperactive deep tendon reflexes, incoordination, inefficient sucking and swallowing, and high-pitched, shrill cry.<sup>267</sup> The diagnosis of NAS is made based on maternal history, maternal and infant toxicology lab tests, and clinical examination of the infant. Measures for evaluation and treatment of neonatal abstinence include the Neonatal Intensive Care Unit Network Neurobehavioral Scale (NNNS), which was designed to provide a comprehensive assessment of both neurologic integrity and behavioral functions,<sup>161</sup> and the Neonatal Drug Withdrawal Scoring System, also known as the Lipsitz tool, which scores tremors, irritability, reflexes, stools, muscle tone, skin abrasions, tachypnea, repetitive sneezing, yawning, vomiting, and fever.<sup>28</sup> Infants with withdrawal symptoms should receive supportive care including swaddling, non-nutritive sucking, and decreased sensory stimulation. Small frequent feedings

and additional calories may be needed. If necessary, medications such as tincture of opium, morphine, methadone, and buprenorphine are used.<sup>139,267</sup>

## PAIN

Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage and is best described by self-report.<sup>119</sup> Obviously the neonate cannot report on pain but may express pain through specific pain behaviors, physiologic changes, changes in cerebral blood flow, and cellular and molecular changes in pain processing pathways. Adverse sequelae may “include death, poor neurologic outcomes, abnormal somatization and response to pain later in life.”<sup>119</sup> The peripheral nervous system is capable of responding to stimuli by 20 weeks postconception. Both the number and types of peripheral receptors are similar to those of adults by 20 to 24 weeks of gestation with a resulting increased density of receptors in the newborn as compared with adult. Spinal cord and brain stem tracts are not fully myelinated, therefore, central nerve conduction is slow. There is evidence that pain pathways, cortical and subcortical centers of pain perception, and neurochemical systems associated with pain transmission are functional in premature neonates of 20 to 24 weeks gestational age.<sup>98</sup> Most nociceptive impulses are transmitted by nonmyelinated C fibers but also by A delta and A beta fibers, which transmit light touch and proprioception in adults.<sup>119</sup> However, the pain modulatory tracts, which can inhibit pain through release of inhibitory neurotransmitters such as serotonin, dopamine, and norepinephrine, are not developed until 36 to 40 weeks of gestation. As a consequence, the preterm infant is more sensitive to pain than term or older infants.<sup>119,246</sup> Painful stimuli resulting from medical conditions and medical procedures (such as heel sticks, intubation, ventilation, ocular exam, and IV placement) can lead to prolonged structural and functional alterations in pain pathways that may persist into adult life.<sup>36,99</sup> The infant also may associate touch with painful input, which can interfere with bonding and attachment.

Although it is difficult to assess pain in the neonate, the physical therapist working in the NICU should be aware of methods of examination and nonpharmacologic intervention to alleviate pain. Both physiologic and behavioral responses of the neonate to nociceptive or painful stimuli have been identified. Physiologic manifestations of pain include increased heart rate, heart rate variability, blood pressure, and respirations, with evidence of decreased oxygenation. Skin color and character include pallor or flushing, diaphoresis, and palmar sweating. Other indicators of pain are increased muscle tone, dilated pupils, and laboratory evidence of metabolic or endocrine changes.<sup>217</sup> Neonatal behavioral responses to nociceptive input include sustained and intense crying; facial expression of grimaces, furrowed brow, quivering chin, or eyes tightly closed; motor behavior

such as limb withdrawal, thrashing, rigidity, flaccidity, fist clenching, finger splaying, and limb extension; and changes in behavioral state.<sup>115</sup> Pain may lead to poor nutritional intake, delayed wound healing, impaired mobility, sleep disturbances, withdrawal, irritability, and other developmental regression.<sup>270</sup>

There are 40 methods to assess pain in infants.<sup>217</sup> Recommended pain measures include the Neonatal Facial Coding System,<sup>116</sup> the Neonatal Infant Pain Scale,<sup>157</sup> the CRIES,<sup>148</sup> and the Premature Infant Pain Profile.<sup>246</sup> These measures include biologic items, behavioral items, or both. The Bernese Pain Scale for Neonates was specifically developed for preterm neonates who require ventilation.<sup>69</sup> Recent studies indicate that extremity movements such as extremity flexion, extension, finger splay, hand on face, fisting, and frown are associated with pain, especially at early gestational age and may increase the accuracy of examination of pain.<sup>132</sup> New avenues for assessment of neonatal pain include the use of noninvasive EEG, neuroimaging, and near infrared spectroscopy to attempt to measure perception of pain.<sup>217</sup>

Nonpharmacologic methods to alleviate pain include decreasing the number of noxious stimuli, decreasing stimulation, swaddling, non-nutritive sucking, tactile comfort measures, rocking, containment, and music.<sup>270</sup> Preterm neonates demonstrated a lower mean heart rate, shorter crying time, and shorter mean sleep disruption after heel stick with facilitated tucking (containing the infant with hands softly holding the infant's extremities in soft flexion) than without.<sup>72,272</sup> Administration of breast milk, sucrose solution, and non-nutritive sucking may help decrease the pain response in newborn infants.<sup>159,231</sup> Sensorial saturation, which includes subtle tactile, vestibular, gustative, olfactory, auditory, and visual stimuli, was found to be effective in decreasing pain responses of premature infants receiving heel sticks.<sup>31</sup>

Morphine, fentanyl, and topical mixture of a local anesthetic cream such as a eutectic mixture of lidocaine and prilocaine (EMLA) are the most common analgesics administered to neonates.<sup>19,246</sup> Other pharmacologic agents under investigation include methadone and ketamine.<sup>19,35</sup>

## FAMILY RESPONSE TO THE NEONATAL SPECIAL CARE NURSERY

Premature birth, followed by the intensity of the experience of the NICU, is highly stressful and sometimes traumatic not only for the baby but also for the parents and the whole family. The NICU experience for parents may vary depending on the severity of the infant's illness and the level of preparedness parents have prior to the infant's admission to the NICU.<sup>196,265</sup> Although prior knowledge of a possible premature or complicated birth may soften the intensity of the experience at first, all parents of premature infants are particularly vulnerable throughout their infant's neonatal period. The foremost concern is for survival. Once survival

is certain, concern shifts to the quality of the infant's developmental outcome. The parents themselves can be considered to be "premature parents" and may be mourning the loss of the "imagined" or "wished for baby" as they struggle to develop a bond with their "real baby."<sup>50,147</sup> Parents report that the NICU experience often leaves them with a temporary loss of their parental role and identity and at time of discharge may feel overwhelmed, worried, and even panicked, especially if their infant had required ventilation while in the NICU.<sup>219</sup> The phase immediately after discharge from the hospital is often one of anxious adjustment during which mothers express their lack of confidence and insecurity in caring for their preterm infant.<sup>184</sup>

The length of stay for infants admitted to the NICU varies widely according to the severity of the condition leading to the admission. Some infants may spend as little as one day in the NICU (respiratory distress); others may spend months (e.g., extreme prematurity, short gut). Research on parental response to having their newborn admitted to the NICU has been fairly consistent in reporting a high level of parental stress and anxiety, which may lead to a post-traumatic stress reaction (PTSR). PTSR is a predictor of infant sleep and eating problems at 18 months.<sup>214</sup> The prevalence of postpartum depression (PPD) in mothers of newborns admitted to the NICU (45%) is higher compared to PPD in first-time mothers of healthy infants (8% to 15%).<sup>29</sup> On a more positive note, a recent study reported that the implementation of the "parent-friendly" changes as seen in most hospitals across the United States contributed to helping parents make a more successful adaptation to having an infant in the NICU.<sup>65</sup>

Admission of the newborn to the NICU happens at a critical time in the development of the family unit. For the infant, biobehavioral transition from intrauterine to extrauterine life occurs in the first months of life.<sup>196</sup> For the parents, the first months are a time when they search for "the goodness of fit" between themselves and their new baby.<sup>261</sup> The core challenge for parents is to engage with their baby in a way that is unique to them and fosters the baby's development.<sup>245</sup> Many factors may render the relationship between parents and their premature infant vulnerable. Premature infants have poor abilities to self-regulate physiologic rhythms and attention is limited, which can disrupt the parent-infant synchrony so critical during interactive episodes.<sup>95</sup> Preterm infants are more irritable, smile less, and have facial signals that are less clear than full-term infants,<sup>242</sup> which affect the parents' ability to read and respond to their infant's cues.<sup>95</sup> Steinberg contended that posttraumatic stress reaction and depression interfere with the parents' ability to read their baby's cues and respond sensitively to the baby's needs.<sup>244</sup> Nevertheless, a number of studies have demonstrated that during this difficult hospital time, helping parents understand their baby's behavior appears to be critical in helping them maintain their role as parents and mitigate levels of stress.<sup>155,169,219</sup> Physical thera-

pists, with their unique skills in infant behavioral observation and developmental intervention, play an important role in the support offered parents during this difficult time. The physical therapist can help the parents read their baby's cues and provide feedback on their baby's responses. Several studies have reported long-term effects ranging from 9 months to 2 years of behaviorally based interventions on infant development, parent-infant interaction, maternal confidence and self-esteem, and paternal attitudes toward and involvement in caregiving.<sup>80,106,206,218</sup> Primarily derived from the Neonatal Behavioral Assessment Scale (NBAS), behaviorally based intervention tools that have been developed to promote parent and child outcomes are summarized in Table 28-1.

### FRAMEWORK FOR PHYSICAL THERAPY

The primary role of the physical therapist in the NICU is to promote the neonate's movement; postural control; and adaptation to extrauterine life through collaboration with caregivers of infants identified with, or at risk for, a developmental delay or disability and provision of developmental interventions. Another important role is to support parental adaptation to the experience of having a sick child in the NICU and facilitate their participation in the infant's care. Updated clinical practice guidelines for physical therapists working in the NICU have recently been published in a two-part article series.<sup>256,257</sup> Part 1 articulates the path to professional competence and describes the clinical competencies for physical therapists, NICU clinical training models, and a clinical decision-making algorithm.<sup>256</sup> Part 2 presents the evidence-based practice guidelines and recommendations and theoretic frameworks that support neonatal physical therapy practice.<sup>257</sup> Three theoretic frameworks for serving infants in the NICU are the enablement model, family-centered care, and infant neurobehavioral functioning. Those theoretic frameworks address the three main components of physical therapy intervention: communication and coordination, information sharing with parents, and procedural interventions (for more details, refer to Chapters 1 and 29).

### INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

The International Classification of Functioning, Disability and Health, commonly referred to as the ICF, is a framework for understanding relationships between health and disability at both individual and population levels (see Figure 1-4).<sup>283</sup> The ICF was developed to create a common language to improve communication among health care providers, researchers, policy makers, and people with disabilities and to provide a scientific basis for understanding and studying health and health-related states, outcomes, and determinants.<sup>202</sup> The health-related domains are classified from body,

TABLE 28-1 Behaviorally Based Assessments Used to Promote Parent and Child Outcomes

Assessment	Description
Newborn Behavioral Observation system (NBO) <sup>196</sup>	The NBO is an individualized, infant-focused, family-centered observational system that is designed for use by practitioners to elicit and describe the infant's competencies and individuality. Its explicit goals are to strengthen the relationship between the parent and the child and promote the development of a supportive relationship between the clinician and the family.
Mother's Assessment of the Behavior of the Infant (MABI; Field et al., 1978)	The MABI is an abbreviated version of the Neonatal Behavioral Assessment Scale (NBAS) designed to be administered by parents to their own infant. The 15 items are based on the NBAS items, omitting all reflex testing. The items are grouped into four dimensions (social, motor, state organization, and state regulation) and are scored on a 4-point scale.
Combined Physical and Behavioral Neonatal Examination (CPBNE; Keefer, 1995)	The CPBNE incorporates behavioral items from the NBAS into the routine neonatal physical examination. It allows the practitioner to assess the infant's behaviors and to generate an individual behavioral profile.
Family-Administered Neonatal Activities (FANA; Cardone & Gilkerson, 1990; 1995 NBAS manual)	The FANA is designed to elicit from parents their initial perceptions of their newborn and then to use the behavior of the baby as the vehicle through which parents can affirm or challenge their initial perceptions. The FANA integrates the practices of short-term, focused, psychodynamic interviewing with a family-empowerment approach.

individual, and societal perspectives by means of two lists: a list of body functions and structures and a list of domains of activity and participation. Because an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental and personal factors (for more information, see [www.who.int/classifications/icf/en](http://www.who.int/classifications/icf/en)).

High-risk neonates frequently demonstrate impairments in muscle tone, range of motion, sensory organization, and postural reactions. These *impairments in body functions and structures* may contribute to limitations in *activity* such as difficulty in breathing, feeding, visual and auditory responsiveness, and motor activities such as head control and movement of hands to mouth. The interaction between impairments and activity limitations may contribute to restrictions in parent-infant interaction (*participation*). The ICF model also considers personal and environmental factors as relevant influences on body functions and structures, activity, and participation. *Personal factors* include an infant's health complications and temperament. *Environmental factors* range from levels of lighting and noise in the special care nursery to family and community support such as maternity leave that will directly influence the infant's outcome and well-being (see Table 28-2 for an example of the ICF model adapted for the infant in the neonatal intensive care unit).

### INFANT NEUROBEHAVIORAL FUNCTIONING

Since the late 1980s, advances in perinatal and newborn intensive care have dramatically decreased the mortality rates of preterm and sick newborns at high risk for developmental problems. As premature infants have become younger in gestational age at birth (as young as 23 weeks

of gestation) and smaller in birth weight (as little as 450 grams), there has been a growing concern among health care professionals not only to assure their survival but to optimize their developmental course and outcome. Better known as developmental care, the intervention model designed to address these issues focuses on the detailed observation of infant neurobehavioral functioning to design highly individualized plans of care and provide developmentally appropriate experiential opportunities for the newborn in the hospital setting and the provision of supportive care for the infant's family.<sup>9</sup> Recent research suggests that individualized developmental care may improve some medical complications and short-term outcomes such as length of stay, level of alertness, and feeding progression.<sup>179,210</sup>

Als's synactive theory provides a theoretic framework for the neurobehavioral functioning of the young infant.<sup>2</sup> Infant neurobehavioral functioning is understood as the unfolding of sequential achievements in four interdependent behavioral dimensions organized as subsystems.<sup>2</sup> The infant (1) stabilizes her autonomic or physiologic behavior, (2) regulates or controls her motor behavior, (3) organizes her behavioral states and her responsiveness through interaction with her social and physical environment, and (4) orients to animate and inanimate objects. Through maturation and experience, the infant is able to organize her behavior subsystems and actively participate in her social world including interactions with caregivers to meet her needs.<sup>2,46</sup> Competency in behavioral organization can be determined through the careful observation of the behaviors displayed by the infant within each of the behavioral dimensions. Als has categorized behaviors within each of the behavioral dimensions as either "*approach/regulatory*" or "*avoidance/stress*."<sup>2</sup> Regulatory behaviors indicate a state of

**TABLE 28-2 Application of the International Classification of Functioning, Disability, and Health for Infants in the Neonatal Intensive Care Unit**

Health Condition (Includes Disease or injury)		
Examples: prematurity, respiratory distress, intraventricular hemorrhage, periventricular leukomalacia, arthrogryposis, spina bifida, failure to thrive, short gut, Down syndrome		
Body Functions and Structures	Activities	Participation
Physiologic and Psychologic Functions of Body Systems	Execution of a Task or Action by an Individual	Individual's Involvement in NICU Life Situations
Examples: muscle tone, postural reactions, range of motion, sensory organization, behavioral state control, neurobehavioral functioning, physiologic stability↓	Examples: breathing, sucking, crying, head control, hand to mouth, kicking, grasping, visual and auditory responsiveness↓	Examples: parent-infant interaction, communication, being held by parents, feeding, sleeping, growing↓
Impairments	Activity Limitations	Participation Restrictions
Examples: skeletal deformity, fluctuating tone, startles, deafness, decreased range of motion, behavioral disorganization	Examples: cannot breathe on own, tube fed, cannot locate sound	Examples: cannot be held by parents because of the inability to maintain physiologic stability and neurobehavioral organization
Environmental Factors		Personal Factors
Physical, Social, and Attitudinal Features of the Family and NICU Setting		Personal Characteristics of the Individual
Examples: lighting and noise levels, maternity leave, family support, family's distance to travel to hospital, siblings		Examples: medical complications, temperament, sensitivity, preferences

well-being and are observed when an infant's self-regulatory abilities are able to support the social and environmental demands placed on her; she is then described as *organized*.<sup>76</sup> Stress behaviors indicate a state of exhaustion and are observed when the infant's threshold for self-regulation is exceeded by the demands placed on her; she is then described as *disorganized*.<sup>76</sup>

The application of neurobehavioral observations to clinical practice has been formalized with the Newborn Individualized Developmental Care and Assessment Program (NIDCAP).<sup>3,4</sup> The NIDCAP proposes a structured method of weekly observation and assessment of infant behavior by a developmental specialist or NIDCAP certified physical therapist. Based on these observations and following consultations with the infant's family and medical team, an individualized care plan is developed and implemented. Within this perspective, intervention is aimed at facilitating prolonged periods of organization by reinforcing the infant's individual self-regulatory style while supporting families to nurture and care for their infant.<sup>7,9,42</sup>

### FAMILY-CENTERED CARE

Family-centered care (FCC) was first defined in 1987 as part of former surgeon general Everett Koop's initiative for family-centered, community-based, coordinated care for

children with special health care needs and their families. The American Academy of Pediatrics (AAP) recognizes the importance of FCC as an approach to health care<sup>192</sup> and stresses the importance of the role that families play in patient outcomes.<sup>174</sup> At the heart of family-centered care is the recognition that the family is the constant in a child's life. For this reason, family-centered care is built on partnerships between families and professionals. The Institute for Family-Centered Care has identified eight core concepts of FCC that guide the delivery of services to families with children with health care needs: (1) respect, (2) choice, (3) information, (4) collaboration, (5) strengths, (6) support, (7) empowerment, and (8) flexibility ([www.familycenteredcare.org](http://www.familycenteredcare.org)). Many medical institutions and NICUs across the country have instituted their own FCC guidelines and practices, but for the most part they all share the pursuit of being responsive to the priorities and choices of families. Cleveland published a systematic review of the literature to identify the needs of parents in the NICU and the type of nursing support most helpful during their stay in the NICU (Table 28-3).<sup>70</sup> Parents need accurate information, to have contact with their infant, and to be fully included in their infant's care. Individualized care and knowing that the NICU staff is watching over and protecting their infant is also important to parents. The types of behaviors that best support parents in the NICU are those where they feel welcome at all times,

TABLE 28-3 Needs of Parents Who Have Infants in the NICU and the Types of Support That Are Most Helpful<sup>70</sup>

Needs of Parents	Behaviors That Support Parents
1. Accurate information	• Emotional support
2. Contact with the infant	• Parent empowerment
3. Inclusion in the infant's care	• A welcoming environment with supportive unit policies
4. Vigilant watching-over and protecting the infant	• Parent education with an opportunity to practice new skills through guided participation
5. Being positively perceived by the nursery staff	
6. Individualized care	
7. A therapeutic relationship with the nursing staff	

are encouraged to participate in their child's care, and are engaged in a therapeutic relationship with the nursing staff. Parent-to-parent groups provide families with additional emotional support.<sup>70</sup> The physical therapist in the NICU can consider those recommendations in the implementation of family-centered physical therapy interventions in the neonatal intensive care unit.

### DEVELOPMENTAL EXAMINATION AND EVALUATION

The purposes of the neonatal physical therapy examination and evaluation are to identify (1) impairments in body function and structure that contribute to activity limitations and participation restrictions, (2) the developmental status of the child, (3) individualized responses to stress and self-regulation, (4) needs for skilled positioning and handling, and (5) environmental adaptations to optimize growth and development. The examination and evaluation of infants in the NICU must support the goals of physical therapy intervention aimed at facilitating the infant's participation in age-appropriate developmental activities (e.g., feeding, tucking, self-soothing, social interaction with caregivers) and interactions with the family (e.g., relationship-building, attachment).

The examination and evaluation of high-risk infants are best conducted using a combination of observation and handling techniques that ideally occur over the course of several sessions. Infants hospitalized in the NICU will often not tolerate a full standardized developmental examination. Rather, the physical therapist often formulates a neurobehavioral profile based on observation of the infant's behaviors. That is, the physical therapist describes the infant's successes and difficulties in achieving and maintaining self-regulation and identifies the strategies that best support the needs and developmental level of the infant (Box 28-2).<sup>42</sup>

As handling of medically fragile infants can impose physiologic stress, physical therapy procedures must be appropriately timed and modulated to match the neurobehavioral competencies of the infant. Under the guidance of family-centered practice, any examination or intervention with an infant should be in partnership with families to assist

#### Box 28-2 RECOMMENDATIONS FOR PHYSICAL THERAPIST EXAMINATION AND EVALUATION OF INFANTS IN THE NICU

1. Protect the infant's fragile neurobehavioral system, particularly for infants who may not tolerate handling or a standardized evaluation.
2. Repeat observations over time.
3. Partner with parents and members of the NICU team.
4. Observe, interpret, and communicate infant behaviors to parents and members of the NICU team.

with bonding, facilitate developmentally supportive positioning and handling, and allow for continuous carry-over of therapeutic strategies. Lastly, the physical therapist is part of an interdisciplinary team of health care providers. Consistent with the Guide to Physical Therapist Practice,<sup>18</sup> effective communication and collaboration with professionals from all disciplines and accurate documentation are critical. The next section utilizes a neurobehavioral framework to describe the examination of the high-risk infant with examples of considerations for specific diagnoses.

### BEHAVIORAL STATE

States of consciousness were originally proposed by Wolff and have been expanded to include six behavioral states: (1) deep sleep, (2) light sleep, (3) drowsy, (4) quiet awake, (5) active awake, and (6) crying.<sup>282</sup> Als has expanded this paradigm to include 12 states to distinguish between the adaptive and maladaptive self-regulation strategies of fragile infants compared to full-term infants.<sup>3</sup> Increasing gestational age is associated with demonstration of more robust state organization. That is, as infants mature, they are able to transition smoothly and predictably between states. For example, an infant who is 25 weeks corrected gestational age (CGA) will likely spend most of the day in a light sleep state and will have brief periods of quiet awake. Comparatively, an infant who is 40 weeks CGA should have longer periods of quiet awake time, particularly before

and following feedings. An infant's ability to achieve and maintain sleep and awake states will be compromised by her medical and neurodevelopmental status. The physical therapist plays a key role in educating parents and staff to identify state transitions and optimize the environment (e.g., modifications to light, sound, and interaction) to facilitate smooth transitions to and from sleep.

Infants with neonatal abstinence syndrome (NAS) demonstrate difficulty with state organization.<sup>226</sup> Examination of the infant with NAS requires careful observation of state transitions. The therapist should observe how readily the infant moves from one state to the next, the duration of each state, and her self-soothing strategies. Before the examination, the infant's care team should be consulted to determine how NAS symptoms are being assessed (e.g., a standardized scoring method) and managed medically.

### AUTONOMIC NERVOUS SYSTEM

During the examination of the autonomic system, the physical therapist obtains the infant's heart and respiratory rate from the cardiorespiratory monitor. In the neonate, heart rates range from 120 to 180 beats per minute, and respiratory rate ranges from 40 to 60 breaths per minute.<sup>168</sup> In addition, respiratory effort and digestive function during rest, routine care, handling, and social interaction should be noted. Irregular respirations or paling around the mouth, eyes, and nose; spitting up; straining; bowel movements; and hiccoughs indicate instability or difficulty in achieving self-regulation. Smooth respirations; even color; and minimal startles, tremors, and digestive instability indicate that the demands of the situation have not exceeded the infant's capacity for self-regulation.

Infants with chronic lung disease (CLD) have limited endurance for functional activities. Changes in respiratory effort during the examination should be carefully observed. Costal retractions, head bobbing, and nasal flaring are evidence of increased work of breathing, and their presence, timing, and resolution should be carefully noted.<sup>205</sup> Collaboration with nursing and respiratory therapy staff to facilitate the developmental examination is necessary in order to coincide with optimal timing of diuretic therapy, how modification to oxygen therapy will be managed including the upper and lower parameters of oxygen, and whether the mode of oxygen therapy can be modified for the examination to allow for greater bedside mobility. The examination of the infant with CLD requires frequent breaks, appropriate pacing of activity, and modification of the environment (e.g., lighting, sound, and social interaction) to allow the infant to utilize strategies for self-regulation.

### MOTOR SYSTEM

Physical therapists are perhaps the most highly qualified members of the health care team to examine and interpret

the motor system of a fragile infant. Examination should include observation of the infant's posture at rest and active flexion movements during quiet awake periods, routine care, social interaction, and feeding. Functional movements should be interpreted according to the progression of active flexion patterns that emerge with increasing gestational age. Typically these occur at 32 weeks for lower extremities, 35 weeks for upper extremities, and 37 to 39 weeks for head and trunk.<sup>265</sup> Thus, the immature neuromotor system of the preterm infant often precludes independent antigravity flexion movements and predisposes the infant to compensations, including retracted scapulae, externally rotated and abducted lower extremities, and extension and rotation postures of the cervical spine and trunk.<sup>255</sup> As contemporary frameworks such as those described in the previous section guide practice, less emphasis is placed on testing a battery of infant reflexes. Rather, the physical therapist examination evaluates reflexes deemed more "functional" (e.g., suck, swallow, palmar and plantar grasp, and early righting responses).<sup>56</sup>

Infants with intraventricular hemorrhage (IVH) are at risk for neuromotor impairments that range from mild to severe.<sup>128,177</sup> When examining an infant with IVH, the therapist should note asymmetries in postural muscles and active movements of the extremities, including absence of isolated distal or rotational movements. Clonus should be tested in both ankles. Changes in muscle tone at rest and during active movement should be observed and noted. The emergence of flexor tone and antigravity movements should be evaluated when the infant is awake and alert, as behavioral state influences motor system activity and hence infant motor control.

### SOCIAL INTERACTION

Infants enter this world predisposed to socialize. Many healthy, full-term infants can visually track faces or brightly colored objects and alert to familiar voices.<sup>196</sup> Many preterm or medically fragile infants can complete these tasks with some modifications.<sup>3,40</sup> A developmental examination may include presenting visual and auditory stimulation to an infant. Physical therapists should judiciously offer opportunities for the infant to socially interact, as these complex tasks can be distressful and overwhelm the infant's capacity for self-regulation. The physical therapist plays a critical role in facilitating social interaction between infants and caregivers by modeling developmentally supportive interactions, modifying the environment as needed, and providing parents with anticipatory guidance about the progression of their infant's social interaction skills.

### TESTS AND MEASURES

Tests and measures provide (1) objective documentation of infant functioning over time, (2) justification for developmental interventions in the NICU, (3) documentation of

TABLE 28-4 Tests and Measures Used to Assess Infants in the Neonatal Intensive Care Unit

Name	Description
Neurological Assessment of the Preterm and Full-Term Newborn Infant (Dubowitz & Dubowitz, 1981)	Purpose: To determine gestational age Divided into six sections examining posture and tone, tone patterns, reflexes, movements, abnormal signs/patterns, orientation and behavior.
Neonatal Behavioral Assessment Scale (NBAS; Brazelton & Nugent, 1995)	Purpose: To assess neurobehavioral functioning Composed of 28 behavioral items, each scored on a 9-point scale, and 18 reflex items, each scored on a 4-point scale. Also includes a set of seven supplementary items designed to summarize the quality of the infant's responsiveness and the amount of examination facilitation needed to support the infant during the assessment.
Newborn Behavioral Observation System (NBO; Nugent et al., 2007)	Purpose: relationship-building tool with parents. Composed of 18 neurobehavioral items designed to help practitioners sensitize parents to their child's competencies and uniqueness, support the development of a positive and nurturing parent-infant relationship, and foster the development of the practitioner-parent relationship.
Newborn Individualized Developmental Care and Assessment Program (NIDCAP; Als, 1986)	Purpose: To identify individualized developmental care strategies Composed of a neurobehavior checklist marked every 2 minutes before, during, and after a caregiving event. A narrative is written that describes the caregiving event from the infant's perspective and offers suggestions for caregiving modification that best support the infant's current level of self-regulatory abilities.
Assessment of Preterm Infant Behavior (APIB; Als et al., 1982a)	Purpose: To assess neurobehavioral functioning of the high-risk infant Composed of behavioral items and reflex items, the APIB provides a valuable resource in support of developmental care (NIDCAP). It is also used as a neurodevelopmental diagnostic instrument for clinicians and developmental consultants in the nursery setting.
NICU Network Neurobehavioral Scale (NNNS; Lester & Tronick, 2004)	Purpose: To assess neurobehavioral functioning of drug-exposed and high-risk infants Composed of 115 items, 45 of which require manipulation of the infant, whereas 70 are observed. Divided into three parts: Examination Scale, Examiner Ratings Scale, and Stress/Abstinence Scale.
Test of Infant Motor Performance (TIMP; Campbell et al., 2001)	Purpose: To assess infant functional motor behavior Composed of 13 items on the Observed Scale, each scored on a dichotomous scale, and 29 items on the Elicited Scale, each scored on a 5-, 6-, or 7- point hierarchic scale.
Neonatal Oral-Motor Assessment Scale (NOMAS; Braun & Palmer, 1985)	Purpose: To measure components of nutritive and non-nutritive sucking Composed of variables such as rate, rhythmicity, jaw excursion, tongue configuration, and movement.
Nursing Child Assessment Feeding Scale (NCAFS; Barnard & Eyres, 1979)	Purpose: To assess parent-infant feeding interaction Observational tool assessing parental responsiveness to infant's cues and signs of distress and social interaction during feeding.
Early Feeding Skills Assessment (EFS; Thoyre, Shaker & Pridham, 2005)	Purpose: To assess infant readiness and tolerance for feeding. Used to create a profile of an infant's feeding skills in relation to predetermined oral feeding competencies.

the effectiveness of those interventions, and (4) identification of infants in need of developmental follow-up and intervention after discharge from the NICU. Most useful to the physical therapist are tests and measures of neurologic function, neurobehavioral functioning, motor behavior, and oral-motor function. Table 28-4 provides a list of tests and measures commonly used by physical therapists in the NICU. Certification on many of these tools requires extensive training (e.g., NBAS, APIB, NIDCAP, and TIMP) and will greatly enhance the clinical skills of physical therapists working with this medically complex population. The use of these tools

varies widely between NICU physical therapists but the TIMP, designed by and for physical therapists working with infants as young as 32 weeks of gestation, has become the most widely used assessment of infant functional motor behavior in the NICU.<sup>57</sup> The Dubowitz, used to establish the gestational age of the infant at birth, provides physical therapists with an excellent opportunity to learn about neurologic maturity of infants in the weeks before term age.<sup>89</sup> The Newborn Behavioral Observation (NBO) is a relationship-building tool that supports the efforts of the physical therapist to establish a rapport with families and share with them

developmental information about their infant in a positive context.<sup>196</sup> Some of these tests require significant time in administration, scoring, and interpretation (NIDCAP, NBAS, APIB); whereas the time required to complete these tests decreases with practice, the physical therapist needs to evaluate the importance of the information gathered and the category of infants most likely to benefit from those tests. A team approach and sharing of information between professionals (e.g., NIDCAP) may help in addressing some of the time and cost issues associated with those tests.

The administration of tests to fragile and medically complex infants in the NICU requires clinical judgment and constant monitoring of physiologic stability to determine whether the administration of the test is well tolerated by the infant. Many infants will not have the physiologic stability required to withstand the stress caused by the handling imposed during the administration of the test (e.g., APIB, TIMP). For infants without sufficient physiologic stability, testing will have to be either postponed or done in multiple brief testing periods in order to gather the necessary information. The following includes a detailed description of tests and measures commonly used by physical therapists in the NICU.

### NEUROLOGICAL ASSESSMENT OF THE PRETERM AND FULL-TERM NEWBORN INFANT

The Neurological Assessment of the Preterm and Full-Term Newborn Infant, commonly known as the Dubowitz, is a systematic, quickly administered, neurologic and neurobehavioral assessment developed to document changes in neonatal behavior in the preterm infant after birth, to compare preterm infants with newborn infants of corresponding postmenstrual age, and to detect deviations in neurologic signs and their subsequent evolution.<sup>88,89</sup> The assessment takes 15 minutes or less to administer and is divided into six sections: (1) posture and tone, (2) tone patterns, (3) reflexes, (4) movements, (5) abnormal signs/patterns, and (6) orientation and behavior. Scoring is based on patterns of response rather than a summary or total score. Although the Dubowitz has a long tradition in the NICU, it is mostly used by physicians and medical residents to establish gestational age at birth by observation. For physical therapists working in the NICU, learning to administer the Dubowitz will contribute to the knowledge and expertise in evaluating the tone and posture of very young infants.

### NEONATAL BEHAVIORAL ASSESSMENT SCALE

The Neonatal Behavioral Assessment Scale (NBAS) is the most commonly used assessment of infant neurobehavioral functioning in the world today.<sup>47</sup> Used extensively in research, the NBAS includes 28 behavioral items scored on a 9-point scale and 18 reflex items scored on a 4-point

scale. The reflex items can be used to identify gross neurologic abnormalities but are not intended to provide a neurologic diagnosis. The NBAS also includes a set of seven supplementary items designed to summarize the quality of the infant's responsiveness and the amount of examination facilitation needed to support the infant during the assessment. These supplementary items were originally included to better capture the quality of behaviors seen in high-risk infants. Therefore, the NBAS is well suited for use with the high-risk population. The NBAS is appropriate for use with term infants and stable high-risk infants near term age until the end of the second month of life postterm.

The NBAS has been used extensively in research to study and document the effects of prematurity; intrauterine growth retardation; and prenatal exposure to cocaine, alcohol, caffeine and tobacco on newborn behavior.<sup>197</sup> The NBAS has also inspired others to develop scales for use with diverse populations. Examples include the Assessment of Preterm Infant Behavior for use with premature infants<sup>5</sup> and the NICU Network Neurobehavioral Scale for use with drug-exposed infants,<sup>162</sup> both described in this section. The NBAS's central focus on the facilitation of infant competence by a trained and sensitive examiner has also brought to light its powerful qualities as an intervention tool for use with a wide range of families. This subsequently led to the development of a number of NBAS-based relationship-building tools such as the Mother's Assessment of the Behavior of the Infant (MABI),<sup>277</sup> the Combined Physical Exam and Behavioral Exam (PEBE),<sup>141</sup> the Family Administered Neonatal Activities (FANA),<sup>63</sup> and most recently the Newborn Behavioral Observation system described in this section (NBO).<sup>196</sup> More information on the NBAS is available at [www.brazelton-institute.com](http://www.brazelton-institute.com).

### NEWBORN BEHAVIORAL OBSERVATION SYSTEM

The Newborn Behavioral Observation system (NBO) is a relationship-building tool designed to help practitioners sensitize parents to their child's competencies and uniqueness, support the development of a positive and nurturing parent-infant relationship, and foster the development of the practitioner-parent relationship.<sup>196</sup> The NBO consists of 18 neurobehavioral items used to elicit infant competencies and make observations of newborn behavior, such as sleep behavior, the baby's interactive capacities and threshold for stimulation, motor capacities, crying and consolability, and state regulation.<sup>195</sup> As it is conceptualized as an interactive behavioral observation, the NBO is always administered in the presence of the family so that it can provide a forum for parents and the practitioner to observe and interpret the newborn's behavior. The NBO takes about 45 minutes or longer to administer and can be completed from the first day of life up to the end of the second month of life postterm. The NBO is designed to be flexible and

has been used in diverse settings such as routine pediatric postpartum exams, either in hospital, clinic, or home setting, in a way that is compatible with the demands of clinical practice. Recent research suggests that the NBO may be an effective tool in helping professionals support parents in their efforts to get to know and understand their infants' development and can promote a positive relationship between parents and clinicians.<sup>194,223</sup> More information on the NBO is available at [www.brazelton-institute.com](http://www.brazelton-institute.com).

### NEWBORN INDIVIDUALIZED DEVELOPMENTAL CARE AND ASSESSMENT PROGRAM

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is a comprehensive approach to care for infants in the NICU that is developmentally supportive and individualized to the infant's goals and level of stability.<sup>3,4</sup> The NIDCAP is inclusive of families and professionals. Completion initially involves direct and systematic observation—without the observer manipulating or interacting—of the preterm or full-term infant in the nursery before, during, and after a caregiving event. Observation is guided by a behavioral checklist to record the caregiving event; positioning; environmental characteristics such as light, sound, and activity; and the infant's behaviors. The observation begins 10 minutes before care, to observe the infant's stability and behavioral reactions when undisturbed; observation continues until care is completed and for another 10 minutes thereafter or until the infant reaches preobservation stability levels. The behavior observation checklist is marked every 2 minutes for heart and respiratory rates, oxygen saturation levels, position of the infant, and the caregiving event taking place. The observation time can be minutes or hours long depending on the caregiving event and the stability of the infant. Following this observation, a narrative is written that describes the caregiving event from the infant's perspective, highlighting in great detail the neurobehaviors of the infant in relationship with the caregiving and environmental events taking place simultaneously. Suggestions for caregiving modifications to support the infant's physiologic maturation and strategies at self-regulation are developed from the narrative. The physical therapist who is NIDCAP trained and certified can share this information with the NICU team and provide suggestions for modifying the environment and caregiving activities. These suggestions may pertain to lighting, noise level, activity level, bedding, aids to self-regulation, interaction, timing of manipulations, and facilitation of transitions from one activity to another. The NIDCAP has been found to be most effective in influencing medical outcome,<sup>7,9</sup> and it is suggested to be a causative agent in altering brain function and structure.<sup>6</sup> More information and a list of NIDCAP training centers may be obtained at [www.nidcap.org](http://www.nidcap.org).

### ASSESSMENT OF PRETERM INFANT BEHAVIOR

The Assessment of Preterm Infant Behavior (APIB) is a comprehensive and systematic neurobehavioral assessment of preterm and high-risk infants<sup>5,10,11</sup> that is based on the Neonatal Behavioral Assessment Scale.<sup>47</sup> Also viewed as a neuropsychologic assessment, the APIB provides a detailed assessment of infants' self-regulatory efforts and thresholds to disorganization as viewed through the infant's behaviors. The exam proceeds through a series of maneuvers that increase in vigor as well as tactile and vestibular demands to determine the infant's self-regulatory abilities. The APIB may take up to an hour, depending on the level of stability of the infant, whereas scoring may take between 30 and 45 minutes. Writing the clinical assessment report from the APIB may take up to 3 hours, depending on the complexity of the medical history, developmental issues, and recommendations.<sup>5</sup> To be safely handled for the duration of the assessment, the infant must be physiologically stable and 32 weeks postconceptional age or older. The APIB is appropriate for use with high-risk infants until approximately 44 to 48 weeks of postconceptional age. Training is extensive and available for clinicians and developmental professionals in the NICU and follow-up clinical settings. More information is available at [www.nidcap.org](http://www.nidcap.org).

### NICU NETWORK NEUROBEHAVIORAL SCALE

The NICU Network Neurobehavioral Scale (NNNS) is designed for the neurobehavioral assessment of medically stable drug-exposed and other high-risk infants, especially preterm infants between the ages of 30 and 46 to 48 weeks postconceptional age.<sup>162</sup> The NNNS is used to document and describe developmental and behavioral maturation, central nervous system integrity, and infant stress responses. Although similar to the NBAS in its content, the NNNS differs from it in the order of item administration. For example, items are skipped if the infant is not in the appropriate behavioral state, and deviations in administration are recorded. Additionally, the time required to administer the NNNS is shorter than the NBAS, because the NNNS is less focused on infant best performance and the infant-examiner interaction. The NNNS comprises 115 items, 45 of which require specific manipulation of the infant, whereas the other 70 items are observed over the course of the examination. It is divided in three parts: (1) an Examination Scale that includes neurologic items that assess passive and active tone and primitive reflexes and items that reflect central nervous system integrity; (2) an Examiner Ratings Scale that includes behavioral items including state, sensory, and interactive responses; and (3) a Stress/Abstinence Scale that includes seven categories of items designed to capture behavioral signs of stress typical of high-risk infants and signs of neonatal abstinence or withdrawal commonly seen in drug-exposed infants.<sup>162</sup> The

NNNS has been used to describe the neurobehavioral profile of infants exposed to methamphetamine,<sup>208,238</sup> cocaine,<sup>222</sup> and marijuana.<sup>81</sup>

### TEST OF INFANT MOTOR PERFORMANCE

The Test of Infant Motor Performance (TIMP) is a test of functional motor behavior in infants for use by physical and occupational therapists and other professionals in the NICU and early intervention or diagnostic follow-up settings.<sup>57</sup> The TIMP can be used to assess the infants between the ages of 34 weeks postconceptional age and 4 months postterm. The test examines postural and selective control of movement needed for functional motor performance in early infancy. The TIMP requires approximately 25 to 45 minutes for administration and scoring.<sup>57</sup> Spontaneous and elicited movements constitute separate subscales. The Observed Scale consists of 13 dichotomously scored items that assess the infant's spontaneous attempts to orient the body, to selectively move individual body segments, and to perform qualitative movements such as ballistic or oscillating movements.<sup>60</sup> Examples of observed behaviors include individual finger and ankle movements, reaching, and aligning the head in midline while supine. The Elicited Scale consists of 29 items scored on a 5-, 6-, or 7-point hierarchic scale.<sup>55</sup> Elicited behaviors reflect the infant's response to positioning and handling in a variety of spatial orientations and to visual and auditory stimuli. Examples include rolling prone with head righting when the leg is rotated across the body and turning the head to follow a visual stimulus or to search for a sound in prone.

The TIMP has been shown to have excellent test-retest and rater reliability,<sup>55</sup> good construct validity,<sup>60,190</sup> concurrent validity,<sup>59</sup> and predictive validity.<sup>57,61,100,243</sup> The TIMP can be used for the early identification of very young infants at risk for poor motor performance<sup>61,100</sup> and cerebral palsy as early as 2 months of adjusted age.<sup>23,24</sup> A shorter version used for screening purposes, the Test of Infant Motor Performance Screening Items (TIMPSI), is now available.<sup>62</sup> The TIMPSI takes half the time to administer when compared to the TIMP and is considered useful for fragile babies or for rapid screening that reduces the need for full TIMP testing in infants who do well on the TIMPSI. Users of the TIMPSI must have previous knowledge and training of the full TIMP in order to use it effectively. More information about the TIMP and TIMPSI can be found at [www.timp.com](http://www.timp.com).

### ORAL-MOTOR EXAMINATION

Oral-motor examination is an advanced competency. Two useful measures are the Neonatal Oral-Motor Assessment Scale (NOMAS)<sup>45,102</sup> and the Nursing Child Assessment Feeding Scale (NCAFS).<sup>25,254</sup> The NOMAS measures components of nutritive and nonnutritive sucking. Variables

assessed during sucking include rate, rhythmicity, jaw excursion, tongue configuration, and tongue movement. A pilot study determined cutoff scores for oral-motor disorganization and dysfunction. The NCAFS assesses parent-infant feeding interaction and evaluates the responsiveness of parents to their infant's cues, signs of distress, and social interaction during feeding. Both of those assessment tools require highly specialized training but provide an excellent diagnostic framework for fragile feeders. Neonatal physical therapists may also find useful the Early Feeding Skills Assessment (EFS) as a tool to assess infant readiness and tolerance for feeding and to identify a profile of an infant's specific skills relative to a developmental progression of oral feeding competencies.<sup>262</sup> There are also instruments to study the pressure generated by each suck and the length of sucking bursts such as the Kron Nutritive Sucking Apparatus and the Actifier,<sup>97</sup> which can also be used as a method for stimulation of intraoral tissue in neonates.

### DEVELOPMENTAL INTERVENTIONS

Since the 1980s, state-of-the-art medical care has progressed substantially, leading to the increased survival rate of high-risk infants. But surviving premature birth and severe illness in the neonatal period is not sufficient. Attention also has to be given to the developmental outcome of these infants. Because a high proportion of prematurely born children show some degrees of learning disabilities that cannot be linked to a known cerebral insult, it has been suggested that some of the medical and developmental problems resulting from premature birth arise from the immature organism's difficulty in adapting to the caregiving environment outside the womb.<sup>39</sup> Therefore, continual evaluation and modification of care is necessary to ensure that the quality, quantity, and type of care provided to infants and their families promotes optimal developmental outcomes. Because of physiologic, sensory, and neurologic immaturity, neonates admitted to the NICU are vulnerable to environmental conditions, making quality care critical. The pioneering work of Heidi Als and her colleagues on developmental care made us keenly aware that the NICU environment was poorly matched to the needs of preterm infants.<sup>2,9</sup> The goal of developmental interventions, therefore, is to provide sensory experiences that are appropriate in type and intensity and are closely matched to the infant's needs and level of sensory integration capacity, which can be monitored through the infant's behaviors and responses.<sup>39</sup> It is also stressed that interventions of all forms, including physical therapy-based interventions, need to carefully examine the cost-benefit to the infant on an individual basis and should be framed within a 24-hour care perspective. The Annual Graven Conference on the Physical and Developmental Environment of the High Risk Infant held at the University of Florida every year has made the environment in which these infants grow its mission (for more

information, visit [www.cme.hsc.usf.edu/hri](http://www.cme.hsc.usf.edu/hri)). Spearheaded by Graven, study groups have been formed and have established guidelines for the regulation of sensory stimuli in the NICU.<sup>112,113,154,166,213</sup>

Physical therapists should carefully assess and reflect on the relevance of all interventions provided in the NICU. Intervention of any kind, even though theoretically believed to be helpful or even scientifically shown to be effective, may in fact be harmful unless individualized attention is given to an infant's physiologic, sensory, and neurologic responses to the event. An infant whose sleep is already interrupted numerous times during the day and night may benefit more from sleep protection than from additional handling. Developmental interventions that are integrated into the needs of the infant and her day/night routine are most promising. Therefore, the success of an intervention program such as kangaroo care, along with its effect on the development of infants and their families, is not surprising.<sup>96,138,198</sup> The experience of kangaroo care has been shown to foster maternal attachment, improve maternal confidence in caring for her premature infant,<sup>138</sup> and improve the odds of breastfeeding at discharge from the NICU and into the first year of life.<sup>198</sup> Feldman has shown that preterm infants receiving kangaroo care in the NICU had more mature neurobehavioral profiles on the NBAS when compared to control infants.<sup>95</sup> The approach is now widely accepted and is part of the care of the infant rather than being an intervention approach specific to a particular discipline. Physical therapists should strive toward identifying developmental approaches that could easily be integrated into the routine care of the infant rather than be seen as separate interventions. Taking sound as an example, the Graven group's most recent recommendations on sound exposure to the in utero and ex utero fetus states that sound exposure "should provide an environment that will protect sleep, support stable vital signs, improve speech intelligibility, and reduce potential adverse effects on auditory development."<sup>113</sup>

Infants in the NICU present with a wide range of conditions that have an impact on their later developmental outcome, including prematurity, neonatal seizures, intraventricular hemorrhage, stroke, hydrocephalus, respiratory distress syndrome, bronchopulmonary dysplasia, cystic fibrosis, spina bifida, arthrogryposis, and osteogenesis imperfecta. These conditions lead to impairments that affect the infant's activity levels and participation in interactions with parents and caregivers. A review of the literature on interventions in the NICU indicates that various interventions are provided. Interventions include hammock positioning,<sup>142</sup> handling,<sup>53</sup> nursing staff education on positioning,<sup>209</sup> tucking,<sup>126</sup> and physical therapy.<sup>52</sup> The research is vast and consensus is difficult to reach because of the wide range of intervention protocols and study limitations. But some consensus is available on a range of intervention modalities through the Cochrane Collaboration, an international not-for-profit organization that provides up-to-date systematic reviews

about the effects of health care. Table 28-5 presents statements on Cochrane reviews relevant to the developmental interventions of the high-risk infant in the NICU. For the most part, the Cochrane reviews on kinesthetic stimulation, massage, non-nutritive sucking, and developmental care show modest short-term benefits with no negative effects reported. A review of the literature on the effects of bright lights in the NICU, long believed to play a role in retinopathy of prematurity (ROP), suggests that bright lights are not the cause of ROP.<sup>212</sup> More recently, a Cochrane review concluded that physical activity for hospitalized preterm infants may have small short-term but no long-term effects on bone mineralization and growth; the reviewers do not recommend these programs based on the limited research at this time.<sup>229</sup>

Additional protocols currently being implemented include cycled light; supine versus nonsupine sleep position for preventing short-term morbidity and mortality in hospitalized spontaneously breathing preterm infants, push versus gravity for intermittent bolus gavage tube feeding of premature and low-birth-weight infants, home-based postdischarge parental support to prevent morbidity in preterm infants, body position for spontaneously breathing preterm infants with apnea, instruments for assessing readiness to commence suck feeds in preterm infants, and effects on time to establish full oral feeding and duration of hospitalization.

## DEVELOPMENTAL FOLLOW-UP

For many high-risk infants and their families, life after discharge from the NICU may involve referrals to a number of medical specialists (e.g., pulmonary, neurology, neurosurgery, ear nose and throat, gastroenterology, craniofacial, orthopedics), a local early intervention program, and developmental follow-up to a hospital-based multidisciplinary clinic. Public law 108-446, known as the Individuals with Disabilities Education Improvement Act of 2004, or IDEA, ensures access to a free and appropriate public education to all children with disabilities. Part C of that law guarantees access to physical therapy services in the home or other natural settings through local early intervention programs for children from birth up to age 3. Once a child is determined eligible to receive early intervention services, an Individualized Family Service Plan (IFSP) is developed and reviewed every 6 months or as necessary. The IFSP includes statements of developmentally appropriate, measurable annual goals and a description of how the child's progress toward meeting the goals will be measured.<sup>253</sup> More can be found on the role of the physical therapist in Chapter 29.

The physical therapist plays an important role in the transition of infants and families to early intervention services. The physical therapist needs to communicate with the therapist or agency providing services to the infant and

TABLE 28-5 Cochrane Reviews on Topics Relevant to Developmental Interventions of the High-Risk Infant in the NICU (Full Reviews and Plain Language Summaries Are Available at [www.cochrane.org](http://www.cochrane.org))

Topic of Review	Conclusive Statement
<p><i>Developmental care</i> Symington, A. J., &amp; Pinelli, J. (2006). <i>Cochrane Database Systematic Reviews</i>, 2, CD001814.</p>	<p>The evidence suggests that these interventions may have some benefit to the outcomes of preterm infants; however, there continues to be conflicting evidence among the multiple studies. Therefore, there is so far no clear evidence demonstrating consistent effects of developmental care interventions on important short- and long-term outcomes.</p>
<p><i>Light reduction in the prevention of ROP</i> Phelps, D. L., &amp; Watts, J. L. (2001). <i>Cochrane Database Systematic Reviews</i>, 1, CD000122.</p>	<p>Considerable research has been done on this, and the evidence suggests that bright light is not the cause of this problem and it does not add to the problem.</p>
<p><i>Infant position during mechanical ventilation</i> Balaguer, A., Escribano, J., &amp; Roqué, M. (2006). <i>Cochrane Database Systematic Reviews</i>, 4, CD003668.</p>	<p>There is no clear evidence that body position during mechanical ventilation in newborn babies is effective in producing relevant and sustained improvement. However, putting infants on assisted ventilation in the face-down position for a short time slightly improves their oxygenation and infants in the prone position undergo fewer episodes of poor oxygenation.</p>
<p><i>Non-nutritive sucking</i> Pinelli, J., &amp; Symington, A. (2005). <i>Cochrane Database Systematic Reviews</i>, 4, CD0010701.</p>	<p>The review of literature suggests that weight gain was similar with and without use of a pacifier. In two studies, preterm infants with pacifiers had shorter hospital stays (lower hospital costs), showed less defensive behaviors during tube feedings, spent less time in fussy and active states during and after tube feedings, and settled more quickly into sleep than those without pacifiers. Their transition to full enteral (by tube or mouth) or bottle feeds (three studies) and bottle-feeding performance, in general (one study), was easier. No negative outcomes were reported.</p>
<p><i>Cot-nursing versus incubator care</i> Gray, P. H., &amp; Flenady, V. (2003). <i>Cochrane Database Systematic Reviews</i>, 4, CD003062.</p>	<p>Four studies (two in developed countries) randomly assigned 173 preterm infants to being cared for in cots or incubators. In one study, the cot-nursed infants had a higher mean body temperature in the first week of life. Another study showed less weight gain for infants in cots when in a heated room for the first week of life. Higher numbers of infants cared for in cots were breast-fed when leaving the health care facilities in a study from Ethiopia, but the authors argued that it is not necessarily comparable to feeding practices elsewhere. Lack of information on infections from cot nursing, lack of comparable data, as well as the small number of babies involved restrict the findings of this review.</p>
<p><i>Predischarge "car seat challenge"</i> Pilleary, E., &amp; McGuire, W. (2006). <i>Cochrane Database Systematic Reviews</i>, 1, CD005386.</p>	<p>There is no evidence that undertaking a predischarge "car seat challenge" benefits preterm infants, and it is not clear whether the level of oxygen desaturation, apnea, or bradycardia detected in the car seat challenge is actually harmful for preterm infants. The use of the car seat challenge may cause undue parental anxiety about the safety of transporting the infant in a car seat.</p>
<p><i>Physical activity programs for promoting bone mineralization and growth</i> Schulzke, S. M., Trachsel, D., &amp; Patole, S. K. (2007). <i>Cochrane Database Systematic Reviews</i>, 2, CD005387.</p>	<p>This review found that physical activity might have a small benefit on bone development and growth over a short term. There were inadequate data to assess long-term benefits and harms. Based on current knowledge, physical activity programs cannot be recommended as a standard procedure for premature babies.</p>
<p><i>Early discharge home with gavage feeding for stable preterm infants</i> Collins, C. T., Makrides, M., &amp; McPhee, A. J. (2003). <i>Cochrane Database Systematic Reviews</i>, 4, CD003743.</p>	<p>There is not enough strong evidence regarding the effects of early home discharge for preterm babies who are stable but still need gavage (tube) feeds. Although early discharge of babies who are stable but still need gavage (tube) feeds could unite families sooner and might reduce costs; this could also be a burden for the family and might increase complications in the transition from tube feeding.</p>

**TABLE 28-5 Cochrane Reviews on Topics Relevant to Developmental Interventions of the High-Risk Infant in the NICU (Full Reviews and Plain Language Summaries Are Available at [www.cochrane.org](http://www.cochrane.org))—cont'd**

Topic of Review	Conclusive Statement
<p><i>Massage</i> Vickers, A., Ohlsson, A., Lacy, J., &amp; Horsley, A. (2004). <i>Cochrane Database Systematic Reviews</i>, 2, CD000390.</p>	<p>The review only included randomized controlled trials, studies in which a group of babies received massage or “still, gentle touch,” in which nurses put their hands on babies but did not rub or stroke them. In most of these studies, babies were rubbed or stroked for about 15 minutes, three or four times a day, usually for 5 or 10 days. On average, the studies found that babies receiving massage, but not “still, gentle touch,” gained more weight each day (about 5 grams). They spent less time in the hospital, had slightly better scores on developmental tests, and had slightly fewer postnatal complications, although there were problems with how reliable these findings are. The studies did not show any negative effects of massage.</p>
<p><i>Early developmental intervention programs after hospital discharge</i> Spittle, A. J., Orton, J., Doyle, L. W., &amp; Boyd, R. (2007). <i>Cochrane Database Systematic Reviews</i>, 2, CD005495.</p>	<p>The early developmental intervention programs in this review had to commence within the first 12 months of life, focus on the parent-infant relationship or infant development, and, although they could commence while the baby was still in hospital, they had to have a component that was delivered postdischarge from hospital. A review of trials suggests those programs for preterm infants are effective at improving cognitive development in the short to medium term (up to preschool age). There is limited evidence that early developmental interventions improve motor outcome or long-term cognitive outcome (up to school age). The variability in the intervention programs limits the conclusions that can be made about the effectiveness of early developmental interventions.</p>
<p><i>Kinesthetic stimulation for preventing or treating apnea</i> Henderson-Smart, D. J., &amp; Osborn, D. A. (2002). <i>Cochrane Database Systematic Reviews</i>, 2, CD000373. Osborn, D. A., &amp; Henderson-Smart, D. J. (2000). <i>Cochrane Database Systematic Reviews</i>, 2, CD000499.</p>	<p>Laying preterm babies on oscillating mattresses has not been shown to help prevent apnea. Three controlled studies have used different gentle rocking motions (irregularly oscillating water beds, regularly rocking bed trays, or a vertical pulsating stimulus) to reduce the occurrence of apnea in a total of 49 babies. However, there was no clinically useful reduction of periods of apnea, although only a small number of infants were studied. Shorter breathing pauses were reported to be reduced by one study, but it is not thought to be clinically important. No harm has been reported to have been done to the preterm infants with these interventions.</p>
<p><i>Positioning for acute respiratory distress</i> Wells, D. A., Gillies, D., &amp; Fitzgerald, D. A. (2005). <i>Cochrane Database Systematic Reviews</i>, 2, CD003645.</p>	<p>A total of 21 studies were assessed altogether. Three quarters of the 436 children were preterm babies and were mostly (71%) ventilated by machine. The prone position was better than supine for oxygenating the blood, but the difference was small. The increase in oxygen saturation on average increased by 2%. This finding was based on eight studies (183 children, 153 preterm and 95 ventilated) measuring this outcome. The rapid rate of breathing with respiratory distress was slightly lower in the prone position (on average four breaths/min lower) based on five studies (100 infants aged up to 1 month, 59 ventilated). There were no obvious differences with other positions. Note: It is important to remember that these children were hospitalized. Therefore, given the association of the prone position with sudden infant death syndrome (SIDS), the prone position should not be used for children unless they are in hospital and where their breathing is constantly monitored.</p>
<p><i>Kangaroo mother care to reduce morbidity and mortality in low birthweight infants</i> Conde-Agudelo, A., &amp; Belizán, J. M. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. (2003). <i>Cochrane Database Systematic Reviews</i>, 2, CD002771.</p>	<p>Kangaroo mother care (KMC) involves skin-to-skin contact between mother and her newborn, frequent and exclusive or nearly exclusive breast-feeding, and early discharge from hospital. Compared with conventional care, KMC was found to reduce severe illness, infection, breast-feeding problems, and maternal dissatisfaction with method of care and improve some outcomes of mother-baby bonding. There was no difference in infant mortality. However, serious concerns about the methodological quality of the included trials weaken credibility in these findings. More research is needed.</p>

family. Ideally, providers from the local early intervention agency would meet the family before the infant is discharged from the NICU and thus ensure a smooth and less stressful transition into the family's community. When this situation is not possible, the physical therapist can make contact with the community therapist and provide as much information as possible on the infant's current development and interventions while in the NICU.

Many level III nurseries have a developmental follow-up clinic for high-risk infants. Clinics vary in staffing and criteria for follow-up care. Factors such as birth weight, gestational age, Apgar scores, time on a ventilator, IVH, seizures, and environmental factors such as maternal drug or alcohol use are commonly used criteria. These follow-up programs monitor the health outcomes of graduates of the NICU and provide feedback to the developmental follow-up clinic.<sup>249</sup>

Results of developmental assessments administered at the follow-up clinic are useful in determining whether specialized therapy services are necessary beyond the provision of general recommendations for development and parent education. Referrals for nutrition, audiology, and ophthalmology are also made when necessary. As a team member in the follow-up clinic or early intervention, the physical therapist plays an important role in the examination and monitoring of neuromotor development, provides parent education and anticipatory guidance, and assists the family with coordination of care and referrals to other professionals and community agencies when appropriate.

On average, infants remain hospitalized in the NICU until 38 to 40 weeks of corrected gestational age.<sup>181</sup> For a subpopulation of infants, although intensive medical care is no longer required, discharge home is not yet appropriate because nutritional needs are not being met through oral feeding.<sup>122</sup> These infants typically present with severe chronic lung disease and concomitant feeding issues, neonatal abstinence syndrome requiring continued medical management, severe neurologic impairments, and in some cases are postsurgical. They typically require more intensive physical therapy than can be provided by admission to a pediatric rehabilitation hospital or a community early intervention program. In both settings, the physical therapist examines and evaluates infants and, in consultation with the physical therapist from the NICU, develops an individualized plan to facilitate progression of developmental milestones, age-appropriate feeding skills, and social interaction.

### PRACTICE IN THE NICU: REWARDS AND CHALLENGES

Newborn medicine changes rapidly with the advent of new drugs and technology. The NICU work environment is cutting edge, fast paced, and high stress, but it affords the physical therapist incomparable learning opportunities because of the exceptional range of medical conditions

and level of acuity of the infants, numerous exchanges with health care professionals working together in the NICU, and the opportunity to positively shape this new family unit. This highly technical subspecialty area offers the opportunity for physical therapists to provide developmental services within a framework that is family centered and that views the infant as fully participating in the development process, principles that are central to pediatric physical therapy practice. Although each physical therapist's experience is unique and will differ based on practice setting (e.g., children's hospital, birthing hospital), we highlight three challenges to physical therapist practice in the NICU.

### PREPARATION

According to the practice guidelines endorsed by the American Physical Therapy Association (APTA),<sup>256</sup> physical therapists in the NICU should meet a series of competencies across multiple domains of neonatal clinical practice ranging from theoretic frameworks to social policy governing practice involving high-risk infants. In addition, physical therapists should participate in a minimum of 6 months of precepting in the NICU. Many NICUs lack an established training program where experienced clinical specialists provide precepting and ongoing mentoring to physical therapists new to neonatal care. Physical therapists may need to advocate for education and training resources. One resource is the NICU Special Interest Group within the Section on Pediatrics of the APTA (see [www.pediatricapta.org/special-interest-groups/neonatology/index.cfm](http://www.pediatricapta.org/special-interest-groups/neonatology/index.cfm) for more information).

### METHOD OF SERVICE DELIVERY

Traditional models of service delivery for inpatient pediatric rehabilitation may not match the needs of infants and families in the NICU. Although therapists in other subspecialties within the hospital typically see 8 to 10 patients per 8-hour day (from 9 a.m. to 5 p.m.), physical therapists in the NICU are constrained by frequent medical procedures, strict feeding schedules, evening parental visiting schedules, and infection considerations for patients seen outside of the NICU. As such, the model of service delivery needs to be flexible with regard to productivity demands, work hours, and managing schedules of patients other than those in the NICU. The needs and realities of the rehabilitation department and assuring equity of responsibility among all therapists are additional considerations.

### PROFESSIONAL ROLE DELINEATION

Depending on NICU staff resources, physical therapists may work closely with occupational therapists, speech language pathologists, and developmental specialists. As such,

professional role delineations related to oral feeding, positioning, infant massage, and facilitation and handling may become blurred. According to the APTA, physical therapists are experts in examination and intervention of impairments in body functions and structures and motor activity limitations of the musculoskeletal and neuromuscular system.<sup>256</sup> To this end, this expertise may cross traditional professional boundaries and physical therapists should work collaboratively with colleagues from other disciplines while advocating for the growth of our profession.

## SUMMARY

The special care nursery is a specialized setting for providing high technological medical interventions to newborn infants who are unable to sustain basic physiological processes secondary to premature birth or other neonatal complications. Provision of services to infants and families in the special care nursery is a subspecialty area of pediatric physical therapist practice. Knowledge of fetal and infant development, medical complications, and competency in monitoring

vital signs and behaviors are essential for providing therapy services in the special care nursery. The examination and evaluation process includes issues identified by families and members of the team and observation of how the infant is positioned and responds to caregiving procedures. Standardized tests and measures are useful in evaluation of infant development and identification of areas of need.

Depending on an infant's needs and ability to tolerate sensory stimulation and movement, interventions may include positioning, strategies to minimize physiological stress, and sensory-motor development. Prevention of musculoskeletal impairments is an important outcome of intervention. Communication and coordination of care with team members, families, and external agencies such as early intervention providers are important components of intervention. Perhaps the most important role of the physical therapist is education and instruction of family members in the infant's behavioral cues and responses and handling and caring for the infant in anticipation of the transition to home. After discharge, an important role of the physical therapist in high-risk follow-up clinics is to monitor infant motor development, address family information needs and concerns, and coordinate care with community service providers.



## CASE STUDIES

Two case studies are presented to illustrate how the contents of the chapter apply to practice in the NICU. The first case is about a little boy, born extremely preterm, who spent over 4 months in the NICU. He presents with significant respiratory difficulties, which affect his oral feeding development. As a result, the family faces a decision about surgical intervention versus further hospitalization in a rehabilitation setting. The second case is about a little girl, born full-term, with Down syndrome. There is concern from the medical team that the infant's mother has not bonded with her daughter. Following a particularly powerful session with the physical therapist, the parents gain a new appreciation for their daughter's strengths and competencies.

Both patients were hospitalized in the same level III NICU. The NICU rehabilitation team consists of a physical therapist who is an APTA board-certified pediatric clinical specialist employed full time and two therapists (one physical therapist and one occupational therapist) employed half time. Rehabilitation team members are part of a larger interdisciplinary team that includes medicine, social work, nutrition, and nursing. Physical therapists generally spend approximately 30 to 60 minutes with each patient and family, depending on the context of the session (e.g., oral feeding, developmental evaluation, discharge teaching). In addition to patient care, physical therapists participate in daily medical rounds and weekly developmental and feeding rounds.

### "Travis"

#### Examination

#### History

Travis was born precipitously at 24 2/7 weeks weighing 590 grams. His ApGARS were 4, 7, and 8 at 1, 5, and 10 minutes, respectively. He was intubated in the delivery room, received mechanical ventilation, and was transferred to the NICU. Upon admission, he received one dose of artificial surfactant. During the first 2 weeks of life, he required dopamine, received two blood transfusions, and was treated with hydrocortisone to maintain a stable blood pressure and adequate perfusion. Travis's cardiovascular system was compromised by a patent ductus arteriosus, which was treated with ibuprofen. He required phototherapy treatment for 12 days for hyperbilirubinemia, and he was treated with antibiotics for presumed early-onset infection.

Travis remained on mechanical ventilation until 33 weeks CGA when he transitioned to continuous positive airway pressure (CPAP). Travis remained on CPAP until 36 weeks when he was able to be weaned to 50 ml of oxygen that he received through a low-flow nasal cannula. At 33 weeks, Travis received a 14-day course of antibiotics for medical necrotizing enterocolitis. At 36 weeks, he was diagnosed with gastroesophageal reflux (GER) and was started on antireflux medications. All Travis's head ultrasounds revealed no intraventricular

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### CASE STUDIES—cont'd

hemorrhage. His eye exams revealed state II retinopathy of prematurity in both eyes.

Travis's mother visits the NICU daily and is very involved in Travis's care. His 13-year-old sister and father visit on weekends. The majority of Travis's extended family resides in Korea, and the family has few social supports.

Travis was referred to physical therapy at 4 weeks of age (28 weeks PCA). His primary nurse reported that Travis was "stiff," "arched a lot," and "seemed irritable" during his routine care.

#### Observation

Travis was seen at 28 weeks PCA for an initial physical therapy examination. Travis's mother was present. The physical therapist introduced herself and described her role in the NICU. She explained that Travis was referred to physical therapy because he is at risk for developmental difficulties. Moreover, once home, babies like Travis are likely eligible and would benefit from physical therapy as part of early intervention services. There are many interventions, however, that can start even earlier—while Travis is still in the hospital—to promote his development and help family members to care for his needs when he goes home. The physical therapist described for Travis's mother what the examination would consist of—observing Travis's likes and dislikes during his routine care, his ability to self-soothe, and his movements with his arms and legs. The therapist acknowledged that Travis's mother knows him best and asked her to participate in the evaluation.

Travis was supine with his head turned to right side, swaddled, and he had a positioning roll around his lower body. Medical fragility precluded administering a formal, standardized evaluation. The physical therapist completed a neurobehavioral observation during Travis's routine care in order to identify factors with deficits.<sup>257</sup> The developmental evaluation consisted of taking Travis's temperature, changing his diaper, and repositioning him, which took approximately 25 minutes.

#### Body Functions and Structures

**Autonomic.** Upon arrival, Travis's heart rate was in the 160s, respiratory rate was in the 60s, and oxygen saturation ( $\text{SaO}_2$ ) was 95% to 98%. His color was pink and his respirations appeared rhythmic. He demonstrated decreased autonomic stability at several points during the evaluation. He paled and startled when his blanket was unwrapped; his movements became tremulous while his temperature was being taken; and he had several oxygen desaturations during his diaper change ( $\text{SaO}_2 < 85$ ), especially when his legs were lifted. Travis's autonomic instability resolved with gentle containment to his head and feet during all aspects of his care, offering Travis breaks and opportunities to self-regulate (e.g., tucking, grasping, bracing his feet) and minimizing the environmental stimuli (e.g., shielding the light and speaking softly during his care). **Motor.** While supine, Travis was observed to retract his scapulae and externally rotate his arms; his legs were externally rotated and abducted, and his trunk and head were not in midline. His grasp was moderately strong on both sides, and his suck was weak and nonrhythmic when tested with

his pacifier in supine. Overall, Travis's tone was low, and he made infrequent attempts at active flexion movements. When repositioned in left side lying, Travis demonstrated more active flexion movements (hands to mouth and midline, tucking of his lower extremities) and the quality of his suck improved.

#### State and Social Interaction

Travis was in a drowsy state during most of the examination. During his diaper change, he became irritable, demonstrating a weak cry. With containment and environmental modifications (e.g., shielding the light), he was able to open his eyes briefly and make attempts to focus on the therapist's face. At this point, the therapist encouraged Travis's mother to engage in eye contact with him. Travis maintained social interaction for a few brief seconds, and Travis's mother shared that she had never seen him open his eyes for that long.

Throughout the examination, the physical therapist described Travis's thresholds for overstimulation and, more important, his attempts and successes at self-regulation. Travis's mother had already noticed that he was "sensitive" to the bright lights in the room, and she attempted to reduce the light while changing his diaper. During the examination, she learned that Travis benefits immensely from containment during and after diaper changes. She shared with the therapist that she was excited to use this new technique because she often feels "helpless" at the bedside.

#### Activity and Participation

Travis's immature autonomic, motor, and state systems limit his ability to fully participate in the developmental tasks of a newborn. Travis requires increased supports to achieve and maintain self-regulation during routine care. He has limited ability to achieve a calm awake state to interact with his caregivers. Travis's immature feeding and oral motor skills coupled with his gastroesophageal reflux often prevent feeding from being a positive experience for Travis.

Based on Travis's participation limitations and his mother's concerns (e.g., his sensitivity to light and limited ability to keep his eyes open to look at her), the goals of physical therapy were to (1) minimize signs of autonomic instability during routine care; (2) increase active flexion movements, first in side lying, and then progressing to supine; (3) increase postural control, first in side lying, and then progressing to supported sit; (4) increase strength and coordination of his non-nutritive suck and then his nutritive suck when developmentally appropriate; (5) increase time in calm alert state; and (6) increase visual fixation and auditory processing skills with decreasing environmental modifications.

Outcomes for Travis were to (1) demonstrate age-appropriate neuromotor skills, such as full active flexion patterns in side lying and supine to allow for self-soothing skills (e.g., hands to mouth and midline), maintaining head in midline for brief periods to allow for visual fixation on caregiver's face, and emerging postural reactions to allow for tolerance of a variety of upright positions for caregiving and social interaction; (2) take all nutrition by bottle, demonstrating age-appropriate suck-swallow-breathe coordination, with each feeding lasting no more than 30 minutes; (3) demonstrate organized sleep/



### CASE STUDIES—cont'd

wake cycles; (4) have parents be independent in all of Travis's care, handling, and developmental activities; and (5) initiate referrals for family and community supports before discharge.

#### Intervention

The physical therapist saw Travis two to three times per week. Therapy sessions took place at a care time when Travis's mom was present in order to facilitate parent-infant bonding and shared observations of Travis and to partner with Travis's mother in his physical therapy plan of care (*patient/client instruction*). An individualized developmental care plan was created for Travis, reviewed with his parents, and

incorporated into his medical chart. The plan included a physical therapy clinical pathway, developed by the therapist, that delineated his goals, plan of care (e.g., progression of developmental interventions), and recommendations for caregivers.

Interventions (*procedural interventions*) to promote autonomic stability during care included implementing side-lying diaper change, whereby the diaper change is completed with the infant in side-lying to prevent excessive lifting of the legs, which contributes to autonomic instability (Duplesis, 2008). In addition, gentle containment to Travis's head and feet were provided during routine care to promote self-regulation and autonomic stability.



### EVIDENCE TO PRACTICE 28-1

#### CASE STUDY "TRAVIS"

##### PLAN OF CARE DECISION

The decision to provide gentle containment during care was based on a review of the literature examining the effect of gentle touch on medically fragile infants. In this review, Harrison included six studies that examined the effect of gentle touch provided daily (ranging from 20 minutes total per day to 10 to 15 minutes, three times per day) to infants in the NICU who were medically fragile. The results suggest that gentle touch is associated with immediate neurobehavioral benefits (e.g., decreased motor activity, fewer stress signals), but the long-term benefit (e.g., decreased length of stay, improved weight gain, fewer days on supplemental oxygen) has not been established.

Interventions to increase active flexion movements included side lying positioning with gentle facilitation to decrease scapular retraction, shoulder elevation, hip external rotation, and abduction. Positioning strategies included use of a length-wise towel roll under the abdomen during prone positioning and a long postero-lateral blanket roll placed at the infant's back and between the legs and in front of the abdomen while side lying. In addition, a large "U"-shaped blanket roll supported the infant's lower body and trunk to provide additional boundaries and containment. Pictures of the infant in optimal positions were taken and hung at the bedside to promote continuity of care (*coordination, communication, and documentation*). When Travis transitioned to a low-flow nasal cannula, the physical therapist treated him at the bedside and encouraged supported upright activities and adapted prone positioning with a small towel roll under Travis's chest. These activities encouraged age-appropriate activation of postural muscles to reduce the likelihood of atypical head molding.<sup>185</sup>

Interventions to promote quiet awake state and age-appropriate social interaction included environmental modifications and parent and staff education. Travis's incubator was covered with a dark blanket to reduce environmental light exposure,<sup>158</sup> his eyes were

#### FAMILY PREFERENCES

In a meta-analysis of literature examining parent preferences, Cleveland examined 60 studies of the needs and preferences of parents of infants in the NICU.<sup>2</sup> A common theme, germane to the intervention of containment, emerged. Parents often reported feeling excluded from the care of their infant and wished to have more contact with their infant (i.e., holding, touching). The authors suggested that NICU practitioners provide opportunities for "guided participation" for parents.

1. Harrison, L. L. (2001). The use of comforting touch and massage to reduce stress in preterm infants in the neonatal intensive care unit. *Newborn and Infant Nursing Reviews*, 1(4), 235–241.
2. Cleveland, L. M. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 37, 666–691.

shielded during procedures and physical examinations, the ambient lights were kept low as often as possible,<sup>9</sup> and strategies were implemented to reduce noise<sup>138</sup> proximate to Travis's incubator (e.g., not placing items on top of the incubator, opening and closing incubator doors slowly, and speaking quietly during social interaction).

Bottle-feeding was introduced at 39 weeks when Travis's respiratory system was more stable and he began to demonstrate feeding readiness cues (e.g., waking for his feedings, rooting, and bringing his hands to his mouth). To promote age-appropriate feeding skills and feeding as a positive experience, Travis was offered non-nutritive sucking before feeding<sup>215</sup>; the physical therapist externally paced Travis during feeding<sup>156</sup> and utilized a slow-flow nipple.<sup>74</sup>

During each session, the therapist and mother partnered to complete Travis's routine care (i.e., diaper change and temperature), and then the therapist demonstrated increasingly more complex developmental tasks and caregiving activities (e.g., sessions began in the incubator in side lying and progressed to activities on the therapist's lap, first in side lying, then supine, prone, and upright). Typically, when the therapist introduced a new developmental task or caregiving activity, she demonstrated it to Travis's mother, discussed how it could promote Travis's development, and described Travis's response—including his

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### CASE STUDIES—cont'd

strengths and difficulties with the task. Then the therapist encouraged Travis's mother to engage in the development task with Travis and provided support and guidance (oral and hands on) as needed.

#### Reexamination

##### **Test of Infant Motor Performance (TIMP)**

At 36, 38, and 40 weeks, the physical therapist evaluated Travis's development using the TIMP. The TIMP was chosen because (1) the test is appropriate for use from 32 weeks' PCA until 4 months post term; (2) it is a valid and reliable test; (3) the TIMP discriminates infants with various risks for delays; and (4) the TIMP can identify very young infants at risk for poor motor performance.<sup>57,61,100,243</sup> Moreover, the PT chose a time when Travis was awake and alert and would likely tolerate the 45- to 60-minute TIMP session. At 36 weeks, Travis's TIMP raw score was 41, which indicates that Travis is at increased risk for developmental difficulties.<sup>58</sup> He has limited selective motor control, poor postural control, and immature visual and auditory tracking skills.

##### **Neonatal Oral Motor Assessment Scale (NOMAS)**

Because of slow progression with bottle-feeding skills (i.e., poor endurance and decreased oral motor coordination) and a hoarse cry, Travis underwent further evaluation of his oral motor skills. The physical therapist completed a feeding evaluation at 40 weeks with Travis using the NOMAS. The NOMAS was chosen because the scale is (1)

appropriate for use with fragile feeders and can be completed in one feeding session, (2) reliable and valid, (3) identifies infants with feeding delays and dysfunction, and (4) identifies very young infants at risk for long-term feeding difficulties.<sup>124,203</sup>

Based on Travis's atypical jaw excursion, tongue movement, and suck-swallow-breathe pattern, his feeding was categorized as dysfunctional. The attending neonatologist ordered a modified barium swallow (videofluoroscopic examination), which revealed that Travis was aspirating thin, but not thick, liquids.

A family meeting with Travis's care team was held when Travis was 40 weeks CGA. The physical therapist reported on Travis's progress with the plan of care. Travis had achieved several of his outcomes. He demonstrated organized sleep/wake cycles, and his parents were independent in all Travis's care and his developmental program. However, Travis's motor skills continued to be delayed and he was not fully bottle-feeding. At the team meeting, discharge plans presented to the parents included transfer to a pediatric short-term rehabilitation hospital or the placement of a gastrostomy tube and transfer home with community supports. Travis's parents were apprehensive about the surgery associated with the gastrostomy tube and opted to transfer Travis to the short-term rehabilitation facility. At this point, the physical therapist completed a full discharge report describing Travis's progress as well as his current physical therapy needs.



### EVIDENCE TO PRACTICE 28-2

#### CASE STUDY "TRAVIS"

##### PLAN OF CARE DECISION

There is growing evidence to suggest that preterm infants have long-term feeding difficulties.<sup>1</sup> These include coughing and choking with feedings, not tolerating food textures, and developmental of oral aversions. Furthermore, oral feeding difficulties are particularly stressful for parents.

There is a paucity of literature investigating the effect of short-term rehabilitation on improved feeding development of preterm infants. The purpose of a short-term rehabilitation program is to achieve optimal feeding outcomes—that is, take all nutrition by bottle demonstrating age-appropriate suck-swallow-breathe coordination, with each feeding lasting no more than 30 minutes. This is often achieved through interdisciplinary interventions to increase oral motor coordination, promote endurance and self-regulation during feeding, and foster parental independence in positioning, handling, and feeding-specific interventions. This intensity and specificity of therapeutic intervention is not available in the NICU setting. Furthermore, in Travis's NICU, an experienced interdisciplinary feeding team conducts feeding evaluations, creates feeding plans, and facilitates discharge planning for infants who reach 42 weeks

CGA and are not fully bottle or breast-feeding. Based on Travis's presentation, the team drew from its practice knowledge in feeding-related discharge planning to suggest that Julia may be a good candidate for short-term rehabilitation and that her prognosis for safe, efficient bottle-feeding in 8 to 10 weeks was good.

#### FAMILY PREFERENCES

In a meta-analysis of literature examining parent preferences, Cleveland examined 60 studies of the needs and preferences of parents of NICU hospitalized infants.<sup>2</sup> A common theme, germane to the clinical decision making of discharge planning for infants with feeding difficulty, emerged. Parents often reported feeling excluded from the care of their infant and wished to be more involved in the clinical decision making related to their infant's care. The author suggested that NICU practitioners provide opportunities for parent empowerment and inclusion in decision making.

1. Hawdon, J. M., Beauregard, N., Slattery, J., & Kennedy, G. (2000). Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine and Child Neurology*, 42, 235–239.
2. Cleveland, L. M. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 37, 666–691.



## CASE STUDIES—cont'd

### "Julia"

Julia is a full-term (38 2/7 weeks) little girl born via cesarean section weighing 3025 grams. She was diagnosed prenatally with Down syndrome and tetralogy of Fallot. Her Apgar scores were 5, 7, and 8 at 1, 5, and 10 minutes, respectively. She received supplemental oxygen via mask initially but then transitioned to room air. She presented with hyperbilirubinemia and received phototherapy treatment. Initially, Julia received intravenous fluids and then began to bottle-feed small amounts. She tolerated increasing amounts of formula but then developed bloody stools. Julia remained on IV fluids for 4 days until a repeat abdominal x-ray revealed normal bowel. She tolerated increasing volumes of formula well.

Julia's parents live 2 hours away and visit every third day. Julia has three older sisters at home, ages 2, 5, and 7. Julia's nurse shared with the physical therapist that Julia's mother had a lot of questions and concerns about Julia's development, and the nurse was concerned that Julia's mom had not yet bonded with Julia.

### Observation

Julia was referred to physical therapy at 5 days of life. The physical therapist conducted a neurobehavioral observation, using the Neurobehavioral Observation system (NBO), with Julia's parents.



## EVIDENCE TO PRACTICE 28-3

### CASE STUDY "JULIA"

#### PLAN OF CARE DECISION

The decision to use the NBO to guide the initial observation and subsequent interventions is supported by the tool's purpose as a relationship-building instrument to highlight, for parents, the infant's unique strengths and competencies.<sup>3,4</sup> Furthermore, the NBO can be readily implemented in a busy NICU setting, and it is easy and quick to administer, making it ideal for medically fragile infants with limited endurance and low threshold for loss of self-regulation. Evidence suggests that the NBO is effective in helping in promoting the clinician-family relationship and the parent-infant relationship, and it helps parents to better understand their infant's unique strengths.<sup>2</sup> Furthermore, the NBO has been adapted to offer a clinical framework for providing

interventions for the medically fragile or developmentally vulnerable infant.<sup>1</sup>

1. Blanchard, Y., & McManus, B. M. (under review). *Clinical framework for physical therapist intervention with families of high-risk infants*. Pediatric Physical Therapy.
2. Nugent, J. K., & Blanchard, Y. (2005). Newborn behavior and development: Implications for health care professionals. In K. M. Thies, & J. F. Travers (Eds.), *The handbook of human development for health care professionals*. Sudbury, MA: Jones & Bartlett.
3. Nugent, J. K., Keefer, C. H., Minear, S., Johnson, L., & Blanchard, Y. (2007). *Understanding newborn behavior & early relationships: The newborn behavioral observations (NBO) system handbook*. Baltimore: Brookes.
4. Nugent, J. K., Blanchard, Y., & Stewart, J. S. (2008). Supporting parents of premature infants: An infant-focused family-centered approach. In D. Brodsky & M. A. Ouellette (Eds.), *Primary care of the premature infant*. Elsevier.

The physical therapist selected the NBO because it is a relationship-building tool rather than an assessment. That is, although the therapist could develop her clinical impressions of Julia based on the NBO, the main purpose is to partner with parents to observe their baby. Moreover, the NBO utilizes a strength-based approach (i.e., rather than highlighting the infant's impairments), which the therapist employed to empower Julia's parents and encourage them to participate in the social interaction.

During the NBO, the physical therapist engaged the parents by asking questions about Julia's likes and dislikes and the parents' observations of Julia's developmental competencies. For example, when asked what Julia liked, the mother reported, "I don't really know. ... She's so different from my other kids." When asked if he noticed if Julia was starting to look and listen to things in her environment, Julia's father responded, "She can't really do any of that. ... She has Down syndrome. She failed her hearing exam. ... We think she might be deaf." As the physical therapist

administered the NBO, the parents moved closer and became more engaged in the observation. At one point when Julia brought her hands to her face and began to suck on her thumb, Mom became teary and stated, "She might be a thumb-sucker; all of her sisters sucked their thumb!" The physical therapist asked the father to call Julia's name. Almost immediately she turned her eyes toward her father. The dad became quite excited and said, "She can hear. She knows my voice!"

### Body Functions and Structures

**Autonomic.** Upon arrival, Julia's heart rate was in the 140s, respiratory rate was in the 40s and oxygen saturation was between 90% to 94%. Julia's color was generally pink with slight paling around her mouth and forehead. Julia demonstrated difficulty regulating her autonomic system (i.e., mottled skin on her chest and increased paling around her mouth, eyes, and nose) when she was unswaddled, was required to hold her head up in supported sit, and while prone. She

*Continued*



### CASE STUDIES—cont'd

demonstrated pink coloring and rhythmical respirations when she was tucked with positional supports with her hands near her face and mouth. **Motor.** Julia was observed to have generalized hypotonia. She demonstrated difficulty with active flexion movements, hand grasp, and coordinated suck when positional supports were removed. Because she had an initial moderate head lag, the physical therapist opted not to perform pull-to-sit. When supported at the trunk and assistance was provided to maintain flexed and midline position of her extremities, Julia made attempts at righting her head in supported sit. Julia was able to bring her hands to midline and was observed to have a stronger, more coordinated suck while in side lying. **State.** Julia was able to maintain a quiet awake state when tasks were modulated and appropriately paced to reduce her fatigue. Julia became fussy and then appeared in a diffuse state between sleep and awake while prone and when asked to look and listen simultaneously. **Social Interaction/Responsivity.** Julia was able to visually fixate to face and the red ball when swaddled and with limited auditory environmental stimuli. She had difficulty coordinating looking and listening.

#### Activity and Participation

Julia is limited by her ability to fully participate in the developmental tasks of a newborn. She requires increased supports to achieve and maintain self-regulation during routine care. She has limited endurance to maintain a calm awake state to interact with caregivers. Julia's immature feeding and oral motor skills often prevent feeding from being a positive experience for Julia.

#### Goals and Outcomes

Based on Julia's participation limitations and concerns voiced by Julia's parents, the goals of physical therapy were to (1) tolerate handling and care with less fatigue and autonomic instability, (2) increase active flexion patterns, (3) increase postural control of head and neck muscles, (4) increase time in quiet awake state, and (5) increase visual tracking and auditory processing skills.

Outcomes for Julia were to (1) demonstrate age-appropriate neuromotor skills, such as full active flexion patterns in side lying and supine to allow for self-soothing skills (e.g., hands to mouth and midline) maintaining head in midline for brief periods to allow for visual fixation on caregiver's face and emerging postural reactions to allow for tolerance of a variety of upright positions for caregiving and social interaction; (2) take all nutrition by bottle demonstrating

age-appropriate suck-swallow-breathe coordination with each feeding lasting no more than 30 minutes; (3) demonstrate organized sleep/wake cycles; (4) have parents be independent in all care, handling, and developmental activities for Julia; and (5) initiate referral for family and community supports before discharge.

#### Intervention

Julia remained in the hospital for an additional week and was seen every other day by the physical therapist. Interventions to increase endurance and promote autonomic stability during motor activities included modulating Julia's activity (e.g., adapting timing, pacing, and activity requirements to match Julia's capacity for self-regulation) and offering frequent rest breaks at regular intervals rather than waiting until she could not maintain self-regulation (Blanchard & McManus, under review). Interventions (*procedural interventions*) to promote active flexion patterns included the use of posterior shoulder and pelvic positional rolls during therapy sessions. Parents were educated (*patient/client instruction*) about the benefits of positional supports (i.e., to promote forward shoulders and flexed hips) while Julia is awake and alert. In addition, the physical therapist reviewed the American Academy of Pediatrics guidelines for safe sleep, including supine sleeping without use of positional rolls or supports.<sup>16</sup> Interventions to increase social interaction skills included presenting one form of stimulation (i.e., visual or auditory) at a time.<sup>41</sup> In addition, social interaction activities were completed when Julia was in a position that supported her motor system (e.g., supine with towel rolls posterior to her shoulders and hips or semiupright and swaddled). The physical therapist wrote a developmental plan of care for Julia. The physical therapist shared the plan of care with Julia's parents and care team and elicited feedback before including the plan in Julia's medical chart (*coordination, communication, and documentation*).

#### Reexamination

A discharge meeting was held with Julia's family and team. The physical therapist shared updates on Julia's progress from a rehabilitation perspective. Julia made excellent progress with her plan of care and had achieved her developmental outcomes. The physical therapist completed a referral for early intervention and the Down syndrome follow-up clinic at a children's hospital about an hour away from Julia's home.

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