CHAPTER 33

NURSING CARE OF THE CHILD WITH SPECIAL NEEDS

KEY TERMS

chronic illness
developmental delay
developmental disability
palliative care
respite care
terminal illness

LEARNING OBJECTIVES

Upon completion of the chapter, the learner will be able to:

1. Analyze the impact that being a child with special needs has on the child and family.
2. Describe ways that nurses assist children with special needs and their families to obtain optimal functioning.
3. Identify anticipated times when the child and family will require additional support.
4. Plan for transition of the special needs child from the inpatient facility to the home, and from pediatric to adult medical care.
5. Discuss early intervention and public school education for the special needs child.
6. Differentiate developmental responses to death and appropriate interventions.
7. Discuss key elements related to pediatric end-of-life care.

Preet Singh, a 2-year-old boy who was born at 27 weeks' gestation, is seen in your clinic for the first time. He has a history of hydrocephalus and developmental delay. During the examination, his mother states, "I'm concerned about finding a good, affordable preschool for Preet. His older brother attends public school, but I can't imagine Preet there." After further discussion with Preet's mother, you realize he has not been involved in an early intervention program.

Wow

The touch of a mother's hand and the sound of her voice bring comfort to her special child, and when you bring comfort, you strengthen both of them.

As medicine and scientific technology have advanced, the number of children surviving with health problems that require long-term interventions has increased significantly (Hewitt-Taylor, 2005). Children are now living with conditions that require high-tech treatments for survival. The Maternal Child Health Bureau defines children with special health care needs as those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition beyond needs generally required by children (Jackson Allen, 2004). According to the National Survey of Children with Special Health Care Needs, about 12.8% of children in the United States have special health care needs. Of those children with special needs, almost 25% are reported as having conditions that affect their activities usually, always, or a great deal of the time (U.S. Department of Health and Human Services, 2004).

In addition to the direct effects of their special needs, these children and their families are often inadequately insured, have financial needs, have unmet family support needs, or have difficulty obtaining the specialty care that the child requires. Nationwide, 11% report not having a personal doctor or nurse ("medical home") (U.S. Department of Health and Human Services, 2004). Children with special health care needs generally require more intensive and diverse health services, as well as coordination of those services, than do typical children (Child and Adolescent Health Measurement Initiative, 2006). It can be challenging for the family of a child with special needs to navigate the system and obtain all of the services their child requires.

Another difficult situation that families may encounter is losing a child to the disease process. A child's chronic illness may progress to the point of becoming terminal. Despite the increased survival rates for children with cancer as a result of improved treatment options and protocols, cancer remains the leading cause of death from disease in all children over the age of 1 year. Less frequently, other diseases also lead to **terminal illness** in children, with congenital defects and traumatic injuries being the more common causes. Caring for the dying child is a family-centered, multidisciplinary process. Nurses must respond to the child's and family's physiologic, emotional, and spiritual needs during this difficult time. Children display differing responses to the dying process and impending death depending on their developmental level. Children and their families need significant amounts of support throughout the process of dying.

For children with special needs, the pediatric nurse fills the critical role of child and family advocate and case manager. When a child is dying, nurses provide physical care of the child and also strive to meet the emotional needs of the child and family. Nurses are in a unique position, both in the inpatient and outpatient setting, to have a significant and positive influence on the lives of these children and their families.

The Medically Fragile Child

When an infant is born very prematurely, when a child is injured and requires long-term rehabilitation and special care, or when a child is diagnosed with a complex chronic health condition, the parents are often devastated initially. The parents of medically fragile children may feel they must adapt to the risk and protect their child. They are interested in preserving their family while compensating for the past, and they cautiously look to the future and become hopeful again. While the infant or child is still in the hospital, nurses can help parents build on their strengths, empowering them to care for their medically fragile infant or special needs child. Education is paramount and should begin as early in the hospitalization as possible. In many situations, particular discharge needs are known early in the course of the infant's or child's hospitalization. Nurses should provide anticipatory guidance about the course of treatment and the expected outcome.

Most children with **chronic illness**, or those who are dependent on technology, progress through stages of growth and development just as typical children do, though possibly at a slower pace. The exception is the child with significant psychomotor retardation, though some developmental progression may occur. Children with special health care needs desire to be treated as normal (Wang & Barnard, 2004), and they want to experience the same events that other children do.

Of particular concern is a growing subset of children with emotional, behavioral, and developmental problems. Children with these needs have even greater difficulty receiving the care and services they require. Many children with emotional, behavioral, or developmental problems also have health problems. Often, these children's problems are not diagnosed early and treatment is difficult. Ongoing counseling and therapy is very difficult for some families to obtain (CDC, 2005). Ultimately, this has a negative impact on the child's physical and mental health and may result in decreased achievement and productivity as the child matures. See Healthy People 2010.

HEALTHY PEOPLE 2010

Objective	Nursing Significance
Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed.	Screen children with special health care needs for depression or sadness. Refer children and their families to mental health providers as needed.

Effect of Special Needs on the Child and Family

The child with special needs and his or her family are both affected by the child's condition and way of living. Each member of the family experiences effects related to the child's special needs. Family members' experiences and their responses to the child's illness influence each other directly. They also affect the coping ability of the child with special needs. Children's ability to cope is significantly affected by the family's response to stressors.

Effects on the Child

Children with special health care needs experience differing effects of the chronic illness or disability based on their developmental level, which naturally changes over time for most children.

Infants may fail to develop a sense of trust or attach appropriately with the parents because of frequent hospitalizations, often with multiple caregivers involved, lack of consistency in nurturing, or parental detachment or grieving over the child's condition. The infant's ability to learn through sensorimotor exploration may be impaired due to lack of appropriate stimulation, confinement to a crib, or increased contact with painful experiences.

The toddler may experience difficulty developing autonomy because of increased dependency on the parent or overinvolvement by the parent. Motor and language skill development may be delayed if the toddler is not given adequate opportunities to test his or her limits and abilities.

Limited opportunity also reduces the preschooler's development of a sense of initiative. The preschooler may experience limited opportunities for socialization, causing him or her to withdraw or to feel criticized. Body image development may be hindered due to painful exposures and anxiety. In preschoolers, magical thinking may lead to feelings of guilt for having caused their own disease or condition.

The school-age child may have limited opportunities to achieve a sense of industry because of school absence and inability to participate in activities or competitive events. Lack of socialization limits the school-age child's ability to form peer relationships. The ability to learn via concrete operations is affected by the child's physical limitations or possibly the treatments required.

Adolescents may feel as though they are different from their peers because of their lack of skills/abilities or their appearance. This may hinder the teen's ability to form a sense of personal identity. Since the teen with special health care needs often requires significant amounts of support from the parents, it may be difficult for the adolescent to achieve independence. If the earlier stages of cognitive development have been delayed, then reaching the level of abstract thinking may be blocked.

The child with special health care needs may be able to focus on the positive experiences in his or her life as a method of coping, leading to as much independence as possible. Other children may always feel different from their peers (in a negative sense) and withdraw. Irritability and acting out may also occur. Some children may be compliant and/or seek support for themselves. The child's coping pattern may change over time or with certain situations, such as relapse or worsening of the condition. Children with overprotective parents may display marked dependence and may be very fearful. Children whose parents have been overly indulgent may be more independent and defiant. The nurse must assess the child's individual response to the current health care status and intervene as appropriate.

Effects on the Parents

Raising a child with special needs is generally not the life parents expected to have. Some parents may adapt over time and ultimately accept the child's illness or disability. Others may adapt but do not accept the child's condition and experience the continual fading and re-emergence of chronic sorrow. Denial of their child's problem may prevent parents from progressing through grief, but it also allows them to have hope (Rolland & Walsh, 2006).

Caring for the special needs child at home (rather than having the child in a facility) may decrease the parents' feelings of anxiety and helplessness (Fig. 33.1). As with typically developing children, parents enjoy witnessing the emotional and social growth of the child (Wang & Barnard, 2004). Parents of special needs children experience a multitude of emotions and changes in their lives; they report that they "live worried" (Coffey, 2006). They feel helpless and overwhelmed at discharge from the hospital. Though willing to carry the burden, they may experience fear, anger,

FIGURE 33.1 The special needs child often requires a significant amount of care at home.

sadness, guilt, frustration, or resentment. Many parents experience grief as a result of losing the "perfect child" they dreamed of.

Stressors of Daily Living

Families with a child who has special health care needs experience life differently than other families. They may have to change their housing situation to accommodate the child's needs. Their sleep is affected. Constant supervision of the technology-dependent child makes it difficult to carry out other basic household activities. In addition to basic childcare and running of the household, medical and technical care must be incorporated into daily life. The family's identity and the parents' employment may be altered radically. Holidays and vacations are affected, as it is difficult to plan activities. Nursing and other health care professional visits are disruptive to family life.

Mothers appear to carry the larger burden of care, though fathers are not unaffected. Somehow, parents eventually take charge, and though they fear failure, they display vigilance, can negotiate and seek information, and become advocates for their child and experts on his or her care. Though parents may feel trapped, isolated, and experience a loss of freedom, their need to survive as a family continues to motivate them. Parents may feel a need to be with their child at all times and experience stress related to coping with the heavy load of caregiving (Case-Smith, 2004).

The extended burden of caregiving can also have adverse health effects on caregivers: only a small percentage of parents of children with special health care needs report that they routinely participate in health-promoting activities for themselves (Kuster et al., 2004). Additionally, parents of children with special health care needs are at increased risk for the development of depression (Wang & Barnard, 2004).

In addition to the caregiving burden, parents experience role conflicts, financial burdens, and the struggle between independence in providing care and the isolation associated with it. It is very difficult to enjoy spontaneous events outside the home because so much planning is necessary (Case-Smith, 2004).

The possibility of independence revolves around mobility issues, education, and assistive technology. Though education for all children is federally mandated, parents have anxiety about educational decisions and also find it difficult to obtain the support and educational services the child needs.

Additional stress is associated with transition times in the care of a special needs child. These transition times include:

- Initial diagnosis or change in prognosis
- Increased symptoms
- When the child moves to a new setting (hospital, school)
- During a parent's absence
- During periods of developmental change

Vulnerable Child Syndrome

"Vulnerable child syndrome" is a clinical state in which the parents' reactions to a serious illness or event in the child's past continue to have long-term psychologically harmful effects on the child and parents for many years. The parents view the child as being at higher risk for medical, developmental, or behavioral problems (Kerruish et al., 2005). Parents exhibit excessive unwarranted concerns and seek health care for their child very frequently. Risk factors for the development of vulnerable child syndrome include preterm birth, congenital anomaly, newborn jaundice, handicapping condition, an accident or illness that the child was not expected to recover from, or crying or feeding problems in the first 5 years of life (Pearson & Boyce, 2004). The parent has difficulty separating from the child, and the child senses that anxiety and then develops symptoms that reinforce the parent's fears. Alternatively (or additionally), the parents may to try to retain control, particularly at times of increasing independence, and fear disciplining the child as they do not want to "upset" the child (Pearson & Boyce, 2004).

Effects on Siblings

The siblings of children with special health care needs are also affected dramatically. Their relationship with their parents is different than it would have been if they had a typical brother or sister. Parents often need to spend more time with the child with special needs and have less time with their healthy children. Children exhibit emotional and psychological responses to their sibling's long-term needs. Knowledge about the sibling's illness, attitude toward and adjustment to it, the sibling's own self-esteem, how socially supported the sibling is, and the parents' awareness of sibling's feelings are all related to how well the sibling adjusts (Hewitt-Taylor, 2005).

Nursing Management of the Medically Fragile Child

Family-centered care provides the optimal framework for caring for medically fragile children and their families. Family-centered care minimizes the impact of chronic illness and maximizes the child's developmental potential. To provide the best nursing care for these children and the families, the nurse must first develop a trusting relationship with the family.

To ensure optimal functioning, children with special health care needs require comprehensive and coordinated services from multiple professionals. These professionals should work collaboratively to address the child's health, educational, psychological, and social service needs (Farmer, 2005). In addition to case management and advocacy, nursing management focuses on screening and ongoing assessment of the child, provision of home care, care of the technology-dependent child, education and support of the child and family, and referral for resources.

Developing a Therapeutic Relationship

Raising children is always challenging, but for the parent of a special needs child it is often overwhelming and exhausting. The parents' needs change continuously, so it is best if the family has a permanent relationship with a health care provider. This promotes trust and a more efficient two-way flow of information (Nuutila & Salanterä, 2006).

Respect the parents' range of emotions and work with them as a team to manage the child's care. Parents need to be recognized for complying with the treatment plan or for other small gains that are made (Jackson Allen, 2004). Empowering the family strengthens them and gives them self-confidence (Lindblad et al., 2005). Feeling supported and invigorated gives parents strength, energy, and hope. Box 33.1 lists principles related to family involvement.

Screening and Ongoing Assessment

Nurses should perform screening to identify children with unmet health care needs (Jackson Allen, 2004). A screening tool developed by the Child and Adolescent Health Measurement Initiative (Fig. 33.2) may help to identify children with special health care needs. Additional information related to the screening tool is available at http://www.cahmi.org/pages/Sections.aspx?Section=10.

Children with special health care needs may attain developmental milestones more slowly than typically developing children. If the Denver II is used for ongoing developmental surveillance of the young child, then the results should be compared from visit to visit to determine progress rather than using it as a screening tool. Assess special needs children and their families for vulnerable child syndrome.

Promoting Home Care

Home is the most developmentally appropriate environment for all children, even those who are technology dependent. The child's home provides an emotionally nurturing and socially stimulating environment. Children desire to be cared for at home, and those who are cared for at home display an improved physical, emotional, psychological, and social status (Wang & Barnard, 2004).

Technology-dependent children may require supplemental oxygen, assisted ventilation, tracheostomy care, assisted enteral or parenteral feeding, or parenteral medication administration. Traditionally, hospitalization would have been required for these children—in fact, intensive care would have been necessary for children who need assisted ventilation—but with advances in technology, today even children with extensive medical and developmental needs may be cared for at home. Early discharge planning is important, and parents will need detailed instructions and support in caring for the technology-dependent child at home.

BOX 33.1 Principles Related to Family Involvement

Families:

- Define who they are and their culture
- Need to have their basic needs met
- Need to have access to information and training
- Deserve to receive culturally competent care
- Can identify priorities and concerns that lead to policy change
- Know their strengths, limitations, and fears
- Share decision-making power and responsibility for outcomes

Adapted from Federation of Families for Children's Mental Health. (2007). *FFCMH principles for family involvement.*

Early Discharge Planning

Early discharge planning and ongoing inclusion and education of the family facilitates continuity of care (Swartz, 2005). Box 33.2 provides information about preparing the medically fragile child for discharge.

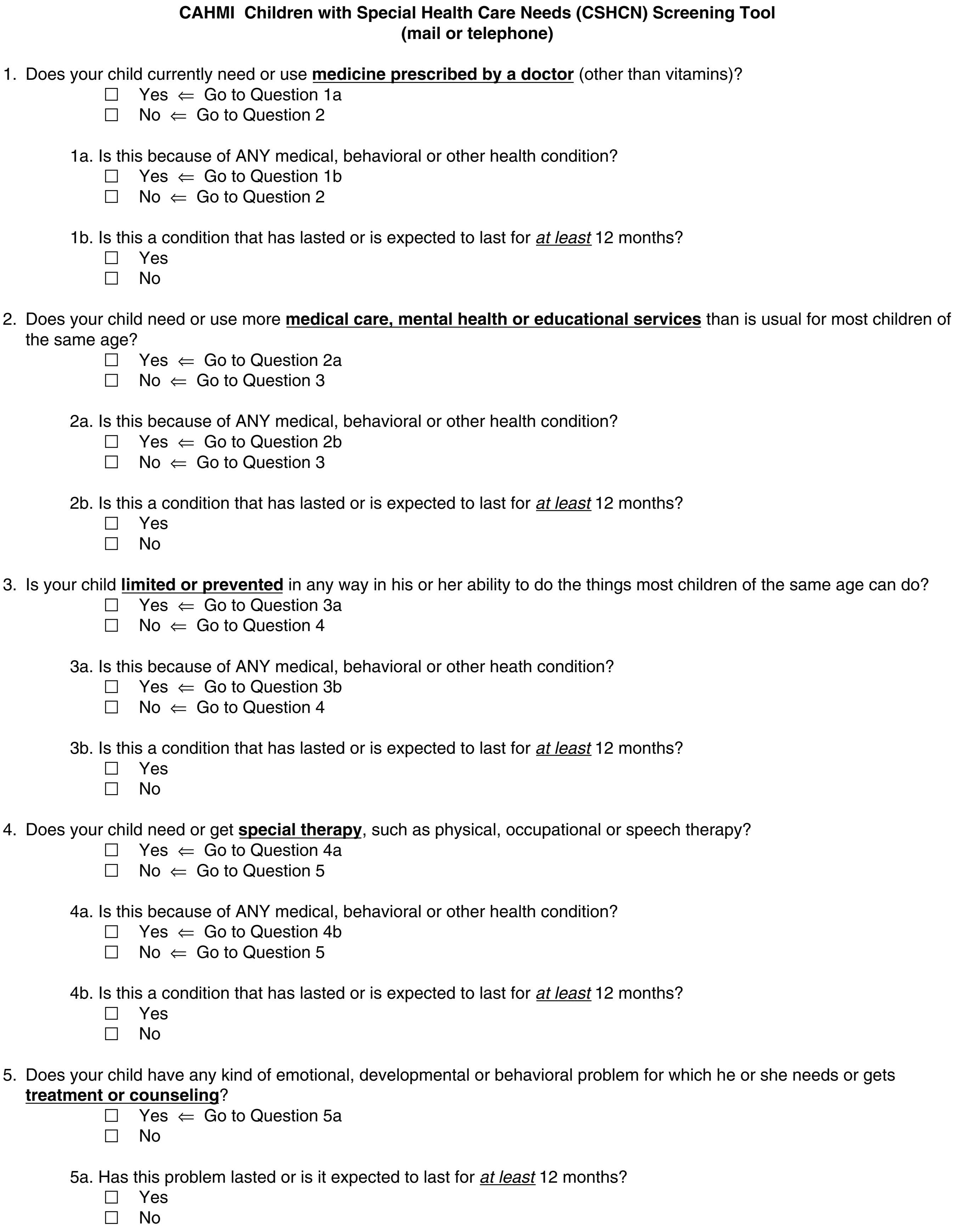
Caring for the Technology-Dependent Child at Home

Home care nurses are often involved in the care of technology-dependent children. Caring for a technology-dependent child at home is a complex process, yet children thrive in the home care setting with appropriate intervention and care. Many parents feel that rearing a technology-dependent child is different only because of the presence of the equipment. Nurses may tend to think that parents treat the technology-dependent child differently than the other children, while parents value normalization and want to raise and provide discipline to all of their children in the same manner. Parents should tell nurses about their child-rearing expectations, and nurses need to respect the parents' wishes.

Improved collaboration between parents and home care nurses may decrease the parents' stress and maximize opportunities for appropriate growth and development in the technology-dependent child. Thus, a strong relationship, good communication, and negotiation skills are assets to the family and child.

Help the family to incorporate the medical regimen into daily life to minimize the child's self-perception of being "different" (Green & Ray, 2006). Teach families about the technical issues, such as home and travel oxygen therapy, use of the ventilator, suctioning, chest percussion and postural drainage, tube feedings and care of the feeding tube, and medications. Assist parents with the planning and management of routine care, respiratory treatments, nutritional support, and developmental interventions. Reinforce exercises and techniques as prescribed by developmental therapists (Romanko, 2005). Refer to Chapter 2 for additional information about home care nursing.

(text continues on page 1016)



CAHMI Children with Special Health Care Needs (CSHCN) Screening Tool
(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ☐ Yes ⇐ Go to Question 1a
   - ☐ No ⇐ Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes ⇐ Go to Question 1b
   - ☐ No ⇐ Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ☐ Yes ⇐ Go to Question 2a
   - ☐ No ⇐ Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes ⇐ Go to Question 2b
   - ☐ No ⇐ Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ☐ Yes ⇐ Go to Question 3a
   - ☐ No ⇐ Go to Question 4

   3a. Is this because of ANY medical, behavioral or other heath condition?
   - ☐ Yes ⇐ Go to Question 3b
   - ☐ No ⇐ Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ☐ Yes ⇐ Go to Question 4a
   - ☐ No ⇐ Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes ⇐ Go to Question 4b
   - ☐ No ⇐ Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ☐ Yes ⇐ Go to Question 5a
   - ☐ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

FIGURE 33.2 The CSHCN Screener. (Reprinted with permission from the Child and Adolescent Health Management Initiative.)

Scoring the Children with Special Health Care Needs (CSHCN©) Screening Tool

Conceptual background

The CSHCN Screener uses consequences-based criteria to screen for children with chronic or special health needs. To qualify as having chronic or special health needs, the following set of conditions must be met:

a) The child currently experiences a specific consequence.
b) The consequence is due to a medical or other health condition.
c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

1) Use or need of prescription medication
2) Above-average use or need of medical, mental health or educational services
3) Functional limitations compared with others of same age
4) Use or need of specialized therapies (OT, PT, speech, etc.)
5) Treatment or counseling for emotional or developmental problems

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

**NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.*

<u>All three</u> parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet CSHCN Screener criteria for having a chronic condition or special health care need.

The CSHCH Screener has three “definitional domains.” These are:

1) Dependency on prescription medications
2) Service use above that considered usual or routine
3) Functional limitations

The definitional domains are not mutually exclusive categories. A child meeting the CSHCN Screener© criteria for having a chronic condition may qualify for one or more definitional domains (see diagram below).

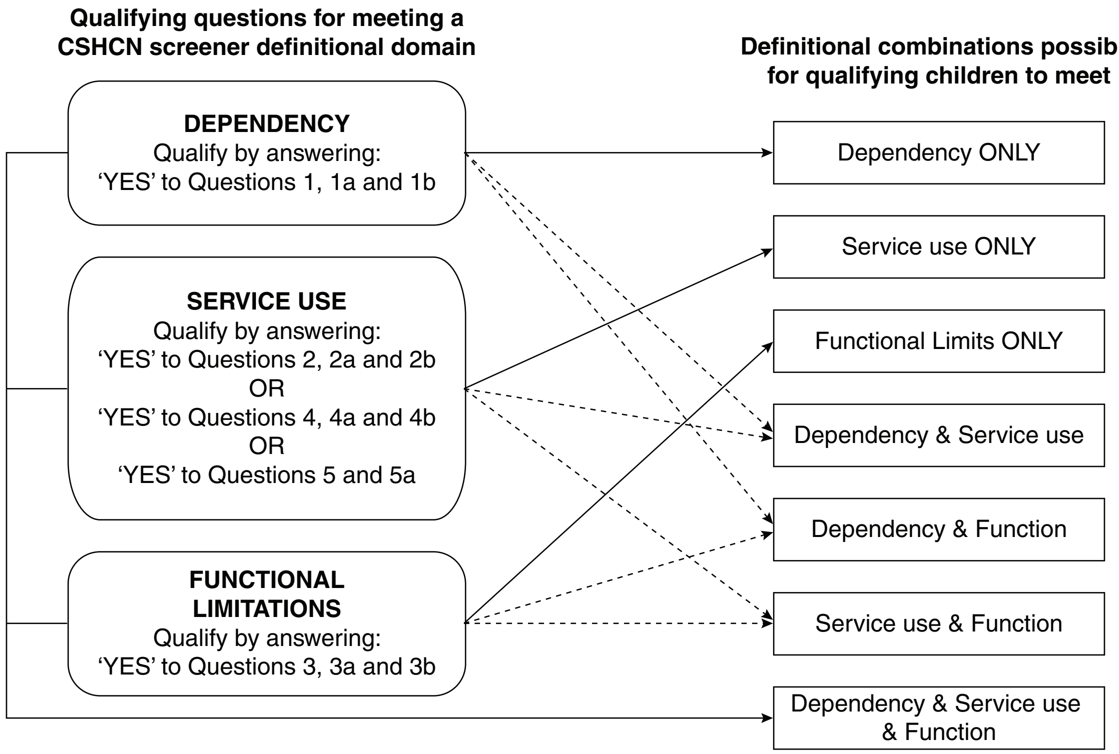


FIGURE 33.2 (continued)

BOX 33.2 Preparing for Home Care Before Discharge

- Promote liaison with community resources. Develop communication between various services. Plan appointments. Set up home nursing care (either private duty or visits).
- Teach skills, encouraging active caregiving in the hospital setting to increase the parents' self-confidence
- Discuss psychological and emotional issues with parents.
- Obtain/organize equipment and supplies (running out of supplies may cause significant stress on families).
- Refer the family for necessary financial resources.
- Ensure the family's home environment is adequate (enough room for equipment, electricity on, air conditioner for warm weather, heater for cold weather, and refrigeration for food).
- For the baby being discharged from the NICU:
  - Teach the parents about the infant's cues and behaviors and the preemie's different sleep–wake patterns.
  - Encourage kangaroo care and infant massage while in the NICU (as the infant's condition allows).
  - Educate the parents about possible effects on short- and long-term neurodevelopment.
  - Refer to local early intervention program.
  - Assist the family with finding a primary care provider who is experienced in the ongoing follow-up of high-risk infants.

Data from Bakewell-Sachs, S., & Genarro, S. (2004). Parenting the post-NICU premature infant. *MCN, 29*(6), 398–403; and Hewitt-Taylor, J. (2005). Caring for children with complex and continuing health needs. *Nursing Standard, 19*(42), 41–47.

BOX 33.3 Nursing Interventions for Families of Children with Special Health Care Needs

- Flag the special needs child's chart.
- Develop written health plans.
- Provide care coordination and collaboration with specialists in other disciplines, early intervention, schools and public agencies.
- Address needs for prior authorization for treatments, medication or specialist referrals; retain copies in the child's chart of authorization forms and approvals.
- Modify office routines to promote family and child comfort.
- Assist parents with childcare decisions. Help parents to understand the child's limits and abilities and the potential health issues (e.g., infections and injuries) associated with childcare.
- Know community resources available to children with special health care needs.
- When the child is hospitalized, encourage high levels of parental participation (if desired by the parent).
- Provide care coordination across multiple health settings.
- Educate childcare providers on child health needs.
- Help parents get involved with parent support networks.

Data from Jackson Allen, P. L. (2004). Children with special health care needs: National survey of prevalence and health care needs. *Pediatric Nursing, 30*(4), 307–314; and Onufer, C. N. (2006). New momentum on building a medical home for the child with a chronic health problem. *Contemporary Pediatrics, 23*(10), 65–66, 66–70, 72–73.

Providing Care Coordination

Once a child with special health care needs has been identified and has been discharged to the home setting, the nurse plays a vital role in care coordination. Any child with special health care needs benefits from a medical home. The nurse in the medical home is a critical team member, providing ongoing care coordination and follow-up. If such services are available in the local area, refer the child and family with special needs to an integrated health program that provides interdisciplinary, collaborative care for children requiring complex, coordinated care. Box 33.3 lists nursing interventions for families of children with special health care needs.

Providing Ongoing Follow-Up of the Former Premature Infant

Many former premature infants experience a myriad of medical and developmental problems throughout infancy, early childhood, and beyond. Upon or following discharge, many former premature infants display one or many of the following medical or developmental problems:

- Chronic lung disease (bronchopulmonary dysplasia)
- Cardiac changes such as right ventricular hypertrophy and pulmonary artery hypertension
- Growth retardation, poor feeding, anemia of prematurity, other nutrient deficiencies
- Apnea of prematurity, gastroesophageal reflux disease, bradycardia
- Sudden infant death syndrome (SIDS)
- Rickets (osteopenia) of prematurity
- Hydrocephalus, ventriculomegaly, abnormal head MRI results, ventriculoperitoneal shunt
- Inguinal or umbilical hernias
- Retinopathy of prematurity, strabismus, decreased visual acuity
- Hearing deficits
- Delayed dentition
- Gross motor, fine motor, and language delay, sensory integration issues

Over the long term, former premature infants are at higher risk than typical infants of developing cognitive delay, cerebral palsy, attention-deficit disorder, learning disabilities, difficulties with socialization, and vulnerable child syndrome. Additionally, many former premature infants display alterations in muscle tone at or shortly after discharge from the neonatal intensive care unit (NICU) that require physical therapy intervention.

For these reasons, high-risk infants require special attention and thorough, appropriate assessment to discern subtle changes that may affect their long-term physical, cognitive, emotional, and social outcome. The pediatric nurse should have an understanding of the special concerns that former premature infants and children as well as their families may face.

From the beginning, encourage families to keep a binder that includes all of the infant's pertinent check-up, insurance, and medical and developmental information; this will serve as a resource for the parents, and they will be able to supply complete information when visiting various providers (Kelly, 2006c).

Providing Routine Well-Child Care of the Former Premature Infant

Former premature infants require similar well-child care as typical infants do, with additional visits for management of multiple complex medical issues and developmental screening/intervention. Teach families routine newborn care, including bathing, dressing, and avoidance of passive cigarette smoke. All visits for primary care follow-up will be scheduled based on the infant's chronological age.

Prior to discharge from the NICU, the infant will be tested for oxygen desaturation while seated in the car seat. Clearance will be obtained prior to the infant's discharge. Former preemies require car seat use just as other infants do. Help the parents to find methods of padding the car seat or adding an additional semi-firm cushion inside the seat for the infant to ride in the car safely. Some infants may need to continue cardiac/apnea monitoring while in the car seat.

Since the former premature infant is at increased risk for SIDS compared to the general population, it is critical to teach parents to put the infant on his or her back to sleep (although this is contraindicated with gastroesophageal disease).

Give immunizations according to the current CDC-recommended immunization schedule, based on the infant's chronological age (Kelly, 2006a). All former preemies should receive the flu vaccine as recommended after 6 months chronological age. Respiratory syncytial virus (RSV) prophylaxis is critical for certain groups of premature infants. Administer palivizumab (Synagis) vaccine according to the recommended schedule (refer to Chapter 39 for additional information about RSV prophylaxis) (Kelly, 2006b; Romanko, 2005).

Assessing Growth and Development of the Former Premature Infant

When assessing growth and development of the infant or child who was born prematurely, determine the child's adjusted or corrected age so that you can perform an accurate assessment. The corrected or adjusted age should be used for evaluating progression in growth as well as development. For example, if a 6-month-old infant was born at 28 weeks' gestation (12 weeks or 3 months early), his growth and development expectations are those of a 3-month-old (corrected age). Continue to correct age for growth and development until the child is 3 years old.

Many former premature infants require special diets to foster catch-up growth. Extra calories are needed for increased growth needs. Additional calcium and phosphorus are required for bone mineralization. For these reasons, former preemies should be fed breast milk fortified with additional nutrients or a commercially prepared formula specific for premature infants. When former preemies demonstrate consistent adequate growth (usually by 6 months corrected age), they may be switched to a "term infant formula" such as Similac or Enfamil, concentrated to higher caloric density if needed. Assess the infant's ability to suck efficiently and refer him or her to occupational or speech therapy if the infant is a slow feeder or has difficulty feeding.

All anticipatory guidance related to nutrition is based on the child's corrected age. In other words, begin solids at 6 months corrected age, not chronologic age, and delay the addition of whole milk until 12 months corrected age, rather than 1 year chronologic age. Signs that the former premature infant may be ready to attempt spoon feeding include interest in feeding, decrease in tongue thrust, and adequate head control (Kelly, 2006a).

Early screening and intervention for issues related to development are critical to the attainment of optimal development in the former preemie. The comorbidities that ex-preemies exhibit in the form of prior and current medical problems place these infants at high risk for **developmental delay** (Kelly, 2006b). Even mild developmental delays warrant evaluation and intervention. The Denver II may be used as a screening tool for developmental concerns in the ex-preemie, though it does not always identify children at risk. Parent-report questionnaires demonstrate fairly accurate estimations of developmental problems, and their use is recommended by the American Academy of Pediatrics (AAP, 2006). Most importantly, assess the child's development based on corrected age until the child is 3 years old. Refer infants and children early if developmental concerns are suspected.

Identifying and Managing Failure to Thrive and Feeding Disorders in Children With Special Needs

Failure to thrive (FTT) is a term used to describe inadequate growth in infants and children. The child fails to demonstrate appropriate weight gain over a prolonged period of time. Length or height velocity and head circumference growth may also be affected. Typical children may experience FTT, but it is much more common in the child with special needs. Adequate nutrition is critical for appropriate brain growth in the first 2 years of life and obviously for growth in general throughout childhood and adolescence. **Developmental disability** may contribute to FTT, as the child's ability to consume adequate nutrition is impaired because of sensory or motor delays, such as with cerebral palsy. Other organic causes of failure to thrive include inability to suck and/or swallow correctly, malabsorption, diarrhea, vomiting, or alterations in metabolism and caloric/nutrient needs associated with a variety of chronic illnesses. Infants and children with cardiac or metabolic disease, chronic lung disease (bronchopulmonary dysplasia), cleft palate, or gastroesophageal reflux disease are at particular risk. Feeding disorders or food refusal may occur in infants or children who have required prolonged mechanical ventilation, long-term enteral tube feedings, or an unpleasant event such as a choking episode. Inorganic causes of FTT include neglect, abuse, behavioral problems, lack of appropriate maternal interaction, poor feeding techniques, lack of parental knowledge, or parental mental illness. Poverty is the single greatest contributing risk factor (Block et al., 2005).

The two categories of causes are not mutually exclusive. Organic causes of FTT may lead to behavioral problems that potentiate problems with adequate growth; hence FTT is thought of as a multifactorial problem.

Screen all children for FTT to identify them early (Locklin, 2005). In addition to poor growth, the infant or child with FTT may present with a history of developmental delay or loss of acquired milestones. Infants or children with feeding problems may display nipple, spoon, or food refusal; difficulty sucking; disinterest in feeding; or difficulty progressing from liquid to puréed to textured food. Perform a detailed dietary history and instruct the parents to complete a 3-day food diary to identify what the child actually eats and drinks. Assess the parent–child interaction, with particular attention to the parent's ability to read and respond to the infant's or child's cues. Observe feeding, noting the child's oral interest or aversion, oral–motor coordination, and swallowing ability, as well as parent–child interactions before, during, and after the feeding (Block et al., 2005). Further aversion to eating may occur as the parent's anxiety over the thought of the child not eating or losing weight leads to attempts to force-feed the child.

Significant FTT may require hospitalization for evaluation and management. Sometimes enteral tube feedings are necessary in order for children with FTT or feeding disorders to demonstrate adequate growth. Box 33.4 lists nursing interventions for the hospitalized child with FTT.

BOX 33.4 Nursing Interventions During Hospitalization for Failure to Thrive

- Observe parent/child interactions, especially during feedings.
- Develop an appropriate feeding schedule.
- Provide feedings as prescribed (usually 120 kcal/kg/day is needed to demonstrate proper weight gain).
- Weigh the child daily and maintain strict records of intake and output.
- Educate parents about proper feeding techniques and volumes.
- Provide extensive support to alleviate parental anxiety related to the child's inability to gain weight.

▶ *Take* NOTE!

Infants with FTT related to maternal neglect may be less interactive than other infants and avoid eye contact.

Promoting Growth and Development

When caring for the infant with special health care needs in the hospital, provide consistent caregivers to encourage the infant to develop a sense of trust. Allow and encourage the parent to stay with the infant, providing a comfortable place for the parent to sleep. To promote attachment, emphasize the baby's positive qualities. Encourage developmentally appropriate skills and allow the infant to have pleasurable experiences through all of the senses.

For the toddler, begin developmentally appropriate limit-setting and discipline. Encourage independence as the toddler is able. Modify gross motor and sensory activities to accommodate the toddler's limitations. To encourage a sense of control, offer the toddler simple choices. As the preschooler develops, encourage mastery of self-help skills as the child is able. Encourage socialization with same-age peers to develop a sense of friendship. Reinforce to the child that the illness or disability is not a punishment for wrongdoing or the child's fault in any way.

Encourage the school-age child to attend school and make up work that must be missed for medical treatments or appointments. Provide education to the school staff and other students about the child's special needs. Promote involvement in appropriate sports activities; music, drama, or art activities; and clubs such as Boy Scouts or Girl Scouts. Educate the child about the illness or disability and the course of treatment.

Inform parents of teens that those with chronic illness often participate in the same activities as typical teens, such

EVIDENCE-BASED PRACTICE 33.1

Life Skills Intervention for Children With Cystic Fibrosis and Effects of Intervention on Psychosocial Adjustment, Functional Health Status, and Physiological Status Over Time

Study

Improved survival and an altered course for cystic fibrosis have led to a need to balance psychosocial and developmental needs in affected children. The authors performed a blinded, randomized controlled trial at four university cystic fibrosis (CF) centers. One hundred and sixteen children were participants in the study over a 9-month period of time. The intervention performed consisted of a home visit to assess each child's knowledge and management of CF. Information was provided using an educational problem-solving approach. Subsequent focus groups were held and the children discussed how to deal with peer issues.

Findings

Children who participated in the intervention group had greater improvements in loneliness, global self-worth, and perceived illness experience. The intervention did not demonstrate an impact upon physical or functional health status but did improve psychosocial status.

Nursing Implications

In addition to CF, many chronic and debilitating conditions affect children's quality of life. Any school-age or older child with a chronic condition that impairs physical functioning would benefit from interventions similar to those performed in this study. In particular, nurses who work in settings that allow them to have long-term relationships with these children have the potential to positively influence their lives. Nurses should help children learn communication and problem-solving skills that could lessen the impact of their chronic condition.

Christian, B. J., & D'Auria, J. P. (2006). Building life skills for children with cystic fibrosis: Effectiveness of an intervention. *Nursing Research, 55,* 300–307.

as risk-taking, rebelling, and trying out different identities. Assist the teen with coping and interpersonal skills. Promote involvement in activities with other teens with special needs as well as typical adolescents. Ensure that the teen participates in rites of passage as able, such as attending the prom or obtaining a driver's license. Discuss future plans with the teen, such as college or vocation, as well as transition to an adult health care provider. See Evidence-Based Practice 33.1.

Providing Resources to the Child and Family

Nurses should be familiar with community resources available to children with special health care needs. Educational opportunities for children with special health care needs include early intervention programs and programs offered through the public school system. Financial resources, respite care, and complementary therapies are other areas the nurse should become familiar with.

Educational Opportunities for the Special Needs Child

The foundation for health and development in children is laid during the first years of life. Children with special health care needs often require multiple developmental interventions and special education in the early years in order to reach their developmental potential later in childhood. Children learn best when they are at the stage of maximal readiness, and the early years must not be missed as an opportunity for development. See Healthy People 2010.

Early intervention programs are intended to enhance the development of infants and toddlers with, or at risk for, disabilities, thereby minimizing educational costs and special education. Early intervention is also directed toward enhancing the capacity of families to meet their child's needs as well as to maximize the likelihood of independent living.

The Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (formerly called Public Law 99-457) mandates government-funded care coordination and special education for children up to 3 years of age. This early intervention program is administered through each state. Federal law allows each state to define

HEALTHY PEOPLE 2010

Objective	Nursing Significance
Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.	Ensure that children under age 3 years who may qualify are referred to the local early intervention program. Encourage families to advocate for their child's needs on the individualized education plan.

"developmental disability" differently, but in general an evaluation of the child's physical, language, emotional, and social capabilities is performed by qualified personnel to determine eligibility. The law guarantees that eligible children will obtain access to services that will enhance their development. Children who qualify for services receive care coordination, and an individualized family service plan is developed by the service coordinator in conjunction with the family. The service coordinator manages the developmental services and special education that the child requires.

The intent of the program is that the child receives services in a "natural environment," so most services occur in the home or daycare center. Home visits by the service coordinator and maintenance of regular contact with the family ensure the success of the program.

Refer children suspected of developmental delay to the local early intervention program. For children receiving these services, collaborate with the service coordinator on an ongoing basis, with particular involvement at hospital discharge and when transition of services occurs at age 3 years.

Think back to Preet, the 2-year-old boy with a history of hydrocephalus and developmental delay, from the beginning of the chapter. Discuss with his mother the educational opportunities that are available for Preet. Explain what early intervention is and why it is important for Preet.

Schools may have a profound impact on the child's overall health and development. Some children with special needs do not require additional services to succeed in school. For these children, the nurse's role is to assess for school success or failure and determine the effect of the school environment on the child's health. The Individuals with Disabilities Education Act, reauthorized in 2004, provides for the education of children with special needs through the public school system, from age 3 to 21 years. These services are provided within the public school system.

According to the law, each special needs student is entitled to an individualized education program (IEP), which is a written plan designed to meet the preschool, primary, or secondary school student's individual needs. A committee consisting of the child's parent, a regular teacher, a special education teacher, and various other specialists develops the IEP. Nurses may be called to serve upon this committee. The IEP must include measurable short- and long-term goals. Parents are informed of the student's progress routinely and the IEP is reviewed at least annually.

Preschool special education through the local public school system is provided from age 3 to 5 years; access to the curriculum is ensured for all children. A child is eligible for special needs preschool when a significant delay is present in the cognitive, language, adaptive, social-emotional, or motor development domains to the extent that it adversely affects the child's learning ability. The child receives (in the school setting) developmental therapy as needed to augment his or her ability to participate in the education process. The least restrictive environment is preferred, with special needs children participating in classes containing age-appropriate typical peers whenever possible. Special needs preschool services are often offered in the elementary school setting.

Financial and Insurance Resources

Many special needs children whose families demonstrate financial need may be eligible for Supplemental Security Income (SSI). This program was created in 1972 through Public Law 92-603. SSI is a cash assistance program, and monthly benefits vary per individual. SSI qualification also qualifies the child for state-administered Medicaid. Medicaid benefits vary slightly from state to state but generally cover medical visits, medication, hospitalization, and limited adjuvant therapies. The State Children's Health Insurance Program (SCHIP) provides low-cost health insurance to eligible children. Eligibility and the extent of benefits provided by SCHIP vary by state.

Public Law 94-566 provides for state-administered Title V programs under the Maternal and Child Health Bureau Block Grant program. State Title V programs provide community-based, comprehensive service coordination for children with special needs (USA.gov, 2007).

Internet Resource for Special Children (www.irsc.org) is an online directory providing a wealth of links to resources for special needs children. Additional online resources include www.childrensdisabilities.info and www.specialchild.com.

Respite Care

Primary caregivers of children with special health care needs must be dedicated, skillful, vigilant, and knowledgeable. Constant care is a stress on the primary caregiver, who needs temporary relief from the daily caregiving demands. **Respite care** provides an opportunity for families to take a break from the daily intensive caregiving responsibilities. Respite care should meet the child's health care needs and offer the child developmental opportunities. Finding and using respite care that the family is comfortable with and trusts may decrease the family's stress and lead to an enhanced quality of life for special needs children and their families. Nurses can facilitate access to respite care, educate respite providers, and ensure quality respite care practices through involvement in community agencies.

Complementary Therapies

Adjuvant therapies are often used by families of children with special health care needs. These may include, among others, homeopathic and herbal medicine, pet therapy, hippotherapy, music, and massage. Many families desire to blend natural or Eastern medicine with traditional allopathic medicine for their special needs child in search of palliation or a cure. When obtaining the health history, ask specifically about homeopathy or herbal medications the child may be taking.

Pet therapy may be used to decrease stress or as a component of psychotherapy.

Hippotherapy is also referred to as horseback riding for the handicapped, therapeutic horseback riding, or equine-facilitated psychotherapy. Individuals with almost any cognitive, physical, or emotional disability may benefit from therapeutic riding or other supervised interaction with horses. The unique movement of the horse under the child helps the child with physical disabilities to achieve increased flexibility, balance, and muscle strength. Children with mental or emotional disabilities may experience increased self-esteem, confidence, and patience as a result of the unique relationship with the horse. A physical therapist or psychotherapist (depending on the situation) generally works very closely with specially trained equine staff. Box 33.5 lists chronic medical conditions for which hippotherapy may be beneficial. Additional information may be obtained through the North American Riding for the Handicapped Association (www.narha.org) or the American Hippotherapy Association (www.americanhippotherapyassociation.org).

Music may be used to induce positive behavioral changes or various other positive effects (Gasalberti, 2006).

Massage therapy may be beneficial to a wide variety of children. It may be used to reduce pain, promote relaxation, or demonstrate a specific positive effect related to the child's particular medical condition (Gasalberti, 2006).

BOX 33.5 Conditions Benefiting from Hippotherapy

- Muscular dystrophy
- Cerebral palsy
- Visual impairment
- Down syndrome
- Mental retardation
- Autism
- Multiple sclerosis
- Emotional disabilities
- Brain injury
- Myelomeningocele
- Spinal cord injury
- Amputation
- Attention-deficit disorder
- Learning disabilities
- Deafness
- Cerebrovascular accident (stroke)

Take NOTE!

Become familiar with the risks and benefits of homeopathic and herbal medications, as many families use these treatments in an effort to improve their child's quality of life or outcome.

Providing Support and Education

At the time of initial diagnosis, allow and encourage the family to express their feelings. Parents of children with special health care needs require emotional, practical, economic, and social support. Encourage parents to obtain help with daily routines. Encourage stress reduction for the parents through exercise and allowing time for themselves. Be a supportive and encouraging listener, making sure to nurture the whole child, not just his or her special condition (Jackson Allen, 2004).

Parents value peer support groups, sometimes feeling that only other parents of disabled or chronically ill children could understand the heartache, fear, and other emotions they often experience. Pediatric nurses should be proactive in helping families find support systems (Coffey, 2006).

Fathers have the same concerns about their children as mothers do, but they may show this concern differently. It is important for nurses to involve them in the child's care. Teach skills to both parents, and actively involve fathers by asking about their observations and opinions (Ahmann, 2006).

Parents become the experts on their child's needs and care and they should be recognized as such. Parents want to be taken seriously and do not like being ignored (Lindblad et al., 2005). They should be viewed as having reliable and valuable information about their children. By being an active and reflective listener, the nurse can demonstrate to the parents that their opinion is valued, in addition to finding out what the child really needs. Some parents may hesitate to volunteer information, unsure about which information the nurse needs. Show respect for the parents' knowledge of their child's needs by seeking advice on the child's daily care, medical/physical needs, and current developmental level, no matter what the site of care is (Bowie, 2004). See Healthy People 2010.

HEALTHY PEOPLE 2010

Objective	Nursing Significance
(Developmental) Increase the proportion of children with special health care needs who have access to a medical home.	In the primary care setting, build a relationship with the family to establish a medical home. If available, refer families to multidisciplinary programs for medically complex children.

Families may need additional support from the nurse at times of transition (discussed previously). As the equipment or treatment needs change, adjust the teaching plan. Educate the child and family about the use of adaptive equipment. Ensure that families understand how specific activities must be modified to accommodate the child's needs. Provide anticipatory guidance related to expected developmental changes, including resources and laws related to education. Act as a liaison between the family and the daycare center or school. As the child grows and matures, encourage parents to relinquish caregiving tasks to the child as appropriate to encourage independence and promote self-esteem.

Assisting the Adolescent With Special Health Needs Making the Transition to Adulthood

Adolescence is a time of physical changes, psychosocial challenges, and initiation of independence from parents. The adolescent with a chronic illness or one who is technology dependent may experience this period differently than other teens. Puberty is often affected by chronic illness (either delayed or earlier). Chronic illness may lead to isolation from peers at a time when peer interaction is the core of psychosocial development. Teens may struggle to fit in with their peers by hiding their illness or health care needs (ignoring them), complying poorly with treatment regimens, or participating in risky behaviors. At a time when the child should be developing independence from the parents, he or she may be experiencing significant dependence related to the special health condition. Adolescents with chronic health disorders demonstrate mental illness at a rate three to four times higher than normally developing adolescents (Burns et al., 2006). For these reasons, the adolescent with special health care needs may require increased amounts of support from the nurse.

With the tremendous increase in technology and health care, over 85% of all children with chronic illness or special health care needs live into adulthood (Yeo & Sawyer, 2005). Making the transition to adult care for a child with special health care needs can be difficult. A written plan for transition to adult care should be initiated in mid-adolescence. Advance planning leads to a smoother transition to adult care. Have ongoing conversations with the teen about this transition. Issues to be resolved prior to the transition include financial resources for medical care, college or vocational school attendance, living arrangements, and caretaking arrangements.

The Adolescent Health Transition Project (AHTP) recommends the following schedule:

- By age 14, ensure that a transition plan is initiated and that the IEP reflects post–high school plans.
- By age 17, explore health care financing for young adults. If needed, notify the local division of vocational rehabilitation by the autumn before the teen is to graduate from high school of the impending transition. Initiate guardianship procedures if appropriate.
- Notify the teen that all rights transfer to him or her at the age of majority. Check the teen's eligibility for SSI the month the child turns 18. Determine if the child is eligible for SSI work incentives.
- If the youth is attending college, contact the college's campus student disability service program.
- By age 21, ensure that the young adult has registered with the Division of Developmental Disabilities for adult services if applicable.

Prior to moving to adult care (with an adult medical specialist), ensure that the adolescent understands the treatment rationale, symptoms of worsening condition, and especially danger signs. Teach the adolescent about when to seek help from a health professional. Introduce the teen to the medical insurance process. At transition, coordinate a seamless transfer by providing a detailed written plan to the care coordinator or advanced practice nurse (after verbal collaboration).

After the transition, serve as a consultant to the adult office in relation to the teen's needs. Consult with a transition services coordinator or other service agency as available in the local community (AHTP, 2007).

The Dying Child

The idea that a child may die is simply unimaginable to most people, yet children die daily. Each year, about 50,000 children die in the U.S. (Himelstein, 2006), and about 28,000 children who die each year are infants (Mellichamp, 2007). Pediatric nurses will inevitably encounter situations in which a child dies. These situations are extremely difficult for all persons involved, and the nurse plays a key role in caring for the dying child and his or her family.

Grieving

Anticipatory grief may be experienced by the family when the diagnosis of terminal illness is made. Families may deny the prognosis, become angry at the health care system or a higher power, or may experience depression. Acute grief is an intense process that occurs around the time of the actual death. Family members may feel short of breath or as though the throat is tight. They may verbalize that the situation is unreal to them or search for reasons why the death was not prevented. Families may also display hostility or restlessness. Each individual will express grief in his or her own manner. Mourning the death of a loved one takes a long time, and families should be supported throughout the process.

Palliative Care of the Dying Child

Appropriate **palliative care** is essential for any child with a life-threatening or progressive incurable condition. Whether palliative care is provided in the home, hospital, or hospice setting, the goal is to provide the best quality of life possible at the end of life while alleviating physical, psychological, emotional, and spiritual suffering. The Last Acts Palliative Care Task Force has established principles on which palliative care of children should be based. These include:

- Respecting patients' goals, preferences, and choices
- Comprehensive caring
- Using the strengths of interdisciplinary resources
- Acknowledging and addressing caregivers' concerns
- Building systems and mechanisms of support (Association of Pediatric Oncology Nurses, 2003)

Hospice Care

Hospice allows for family-centered care in the child's home or a hospice facility. As with adult hospice care, the comfort of the entire family is important. The goals of pediatric hospice care are enhancement of quality of life for the child and family through an individualized plan of care (Children's Hospice International, 2007). The recommended standards for pediatric hospice care do not preclude involvement in ongoing treatment (this is in contrast to adult hospice), but certain eligibility criteria must be met. Parents are educated on ways to comfort and interact with their dying child, such as massage, movement, or singing. Spiritual support is available through a chaplain, social worker, or the family's minister. The nurse not only educates the family about the dying process but also assists them with providing basic care and pain management. The decision to withhold nutrition or hydration may be made in certain instances. Pain management is of utmost importance for the terminally ill child. Ongoing bereavement care is also provided to the family by the hospice after the child's death.

Nursing Management of the Dying Child

Though interdisciplinary care is essential for quality care at the end of life, it is the nurse who plays the key role of child/family advocate and who is usually the constant presence throughout the dying process. Nursing management of the dying child focuses on end-of-life decision making, meeting the child's and family's needs, and assisting the family after the child's death. Throughout the process, focus on the family as the unit of care (Malloy et al., 2006).

Assisting the Family With End-of-Life Decision Making

Parents are obligated not only to protect their children from harm but also to do as much good for them as possible, both from an ethical and legal standpoint (Rushton, 2004). When the time comes for end-of-life decision making, parents are often torn about the "right" course of action. Parents may be asked to make decisions about stopping treatment, withdrawing treatment, providing palliative care, or consenting to do not resuscitate (DNR) orders. Patients, parents, and health care providers are generally in agreement that continued suffering is not desired for any child with a terminal illness. When all possible curative attempts have been made, then survival is no longer possible.

Nurses involved in this process must examine their own values related to dying and consider the American Nurses Association's code of ethics for nurses as well. The family's feelings must also be acknowledged. During the process of end-of-life decision making, health care providers must assure families that the focus of care is changing and that the child is not being abandoned (Rushton, 2004). Emphasize to parents that no matter what their decision is, the health care team is dedicated to the comfort and expert care of their child.

Ensure that communication is family-centered. Quality of life must be taken into consideration when making decisions to continue or withhold treatment (Jacobs, 2005). Provide parents facing end-of-life decisions with honest information and education from the time of the diagnosis/prognosis forward. Anticipate that parents may vacillate in the decision-making process. Clarify information for them and allow them private time to discuss the options. Do not make judgments about or question the parents' decision. Be sensitive to any ethnic, spiritual, or cultural preferences during the terminal stage of the illness. Encourage parents to interact with other parents who have a child with a terminal illness.

Allowing Natural Death

The decision to institute a DNR order is one of the most difficult decisions a family may ever have to make. DNR refers to withholding cardiopulmonary resuscitation should the child's heart stop beating. Parents may initially feel like this means they are giving up on their child. Nurses must educate families that resuscitation may be inappropriate and lead to more suffering than if death were allowed to occur naturally. The parents need to understand that when a palliative care route is chosen, rather than continuing a curative or treatment route, the focus of the child's care is changing but that the child and family are not being abandoned. Families may wish to specify a certain extent of resuscitation that they feel more comfortable with (e.g., allowing supplemental oxygen but not providing chest compressions). Some institutions are now replacing the DNR terminology with "allow natural death" (AND), which may be more acceptable to families facing the decision to withhold resuscitation (Knox & Lenehan, 2005).

Involving the Dying Child in the Decision-Making Process

End-of-life decision making often involves ethical dilemmas for the patient, family, and health care team. This is particularly true when the parents' wishes conflict with the child's or adolescent's desires. Children should be involved in decision making to the extent that they are able. Discuss intervention within the context of the child's condition and wishes. Children over the age of 7 may "assent" to the continuation or withdrawal of treatment (Kon, 2006). Be available to the older child or adolescent to provide support and information if he or she desires. Talk with the child or adolescent with the parents present, as well as in private. Maintain the child's comfort and dignity. Encourage the child to spend time with other children with a terminal illness. Assure the child that everything will be done to make him or her comfortable.

Consult parents about the timing and depth of end-of-life discussions. Just as parents do, the terminally ill child may vacillate in the decision-making process. Remain sensitive, and respect the child's decisions.

Organ or Tissue Donation

With large numbers of organ transplant candidates on waiting lists and the shortage of viable organs, pediatric organ and tissue donation is a priority. For many families, knowing that a child's organs or tissues may save another child's life provides a way to help others despite their own loss. A healthy child who dies unexpectedly is an excellent candidate for organ donation. Many chronic illnesses in children preclude the option of organ or tissue donation, though individual determinations of eligibility should be made.

The discussion of organ donation should be separated from the discussion of impending death or brain death notification. Written consent is necessary for organ donation, so the family must be appropriately informed and educated. Many families who never thought about it before may consider the option of donation if adequately educated about the process. All expenses for organ procurement are borne by the recipient's family, not the donor's. Ask whether the dying child ever expressed a wish to donate organs and whether the parents have considered it.

Families need to know that procurement of the organs does not mar the child's appearance, so that an open casket at the child's funeral is still possible if the family desires. The donating child will not suffer further because of organ donation. The organs or tissues will be harvested in a timely fashion after the declaration of death, so the family need not worry about delay of the wake or funeral. The family's cultural and religious beliefs must be considered, and the team discussing organ donation with the family must do so in a sensitive and ethical manner.

Managing Pain and Discomfort

Pain management is an essential component of care for the child with a terminal illness. Providing for comfort enhances the child's quality of life and minimizes suffering. Assess pain using a developmentally appropriate tool (see Chapter 35 for further information). Provide pain medication around the clock rather than on an "as needed" basis to prevent recurrence or escalation of pain. Determine the child's preferred comfort measures and use them to provide additional relief. Change the child's position frequently but gently to minimize discomfort. Limit nursing care to comfort measures that ease the child's discomfort. Maintain a calm environment, minimizing noise and light.

Easing Anxiety or Fears

Involve the parents and other family members in all phases of the child's care. Explain all aspects of care to the child to minimize anxiety related to nursing interventions. Answer the child's questions honestly. Involve the child in decision making whenever possible. Limit interventions to those related to palliation, rather than treatment, advocating for the child as needed. Remain with the child when a parent or family member is not in the room so the child will not fear dying alone.

Providing Nutrition

Since the body naturally requires less nutrition as the child is dying, do not excessively coax the child to eat or drink. Offer frequent small meals or snacks of the child's choosing. Soups and shakes require less energy to eat and so may be desirable. If the child desires a different food, provide that one. Keep strong odors away from the child to decrease nausea. Administer antiemetics as needed. Provide mouth care and keep the lips lubricated to keep the mouth feeling clean and prevent the discomfort associated with chapped lips. Make sure the environment is a pleasant one for eating.

Supporting the Dying Child and Family

To foster a holistic connection with the child and family, be attuned to the entire family's needs and emotions. Nurses provide physical care through specific tasks and interventions for the dying child, but they also need to be fully present with the child and family. In general, people are uncomfortable with the concept of a dying child. Nurses should work through their own feelings about the situation to be able to be "in the moment" with the child and family. Ask yourself: Can I be fully present with this family? If not, then what can I change to be so?

Families and dying children benefit from the presence of the nurse, not just the interventions he or she performs. Families report that the simple of act of being present with the family is very healing (Mellichamp, 2007). Listen to the child and family; be still and silent for a time to accomplish this. Foster respect for the whole child by attending to him or her as such.

Respect the parents of the dying child by helping them honor the commitments they have made to their child. Acknowledge that parents have diverse needs for information and participation in decision making. Allow and encourage family customs or rituals in relation to death and dying. Families may desire the pastor or priest to be present when the child's death is imminent. Certain rituals may be desired, depending on the family's religious or spiritual background. Ensure that these important events occur, and alter nursing care routines as needed to accommodate them. Respect the family's need to participate in these rituals and customs.

Work collaboratively with the family and health care team to provide for the needs of the child and family (Rushton, 2005). Resources for families of a dying child are listed in Box 33.6. The Make-a-Wish Foundation (www.wish.org) works to grant the wishes of terminally ill children, giving the child and family an experience of hope, strength, and love.

Meeting the Dying Child's Needs According to Developmental Stage

It is important to provide the type of support and education that the dying child needs according to his or her developmental stage. For the infant, unconditional love and trust are of utmost importance. Ensure that the infant's family is available to the child. The toddler, 1 to 3 years old, thrives on familiarity and routine. Maximize the toddler's time with parents, be consistent, provide favorite toys, and ensure physical comfort. Spirituality in the preschool years focuses on the concept of right versus wrong. The 3- to 5-year-old may see death as punishment for wrongdoing; correct this misunderstanding. Use honest and precise language. Help the parents to teach the child that though the family will miss the child, it will continue to function without him or her.

The school-age child has a concrete understanding of death. Children who are 5 to 10 years old need specific, honest details (as desired). Encourage the child to help make decisions, and help the child to establish a sense of control.

The young adolescent (10 to 14 years old) will benefit from reinforcement of self-esteem, self-respect, and a sense of worth. Respect the child's need for privacy and time alone as well as time requested with peers. Support the need for independence and encourage the child to participate in decision making. The older teen (14 to 18 years of age) has a more adult-like understanding of death and will need further support through honest, detailed explanations and will want to feel truly involved and listened to.

BOX 33.6 Resources for Families of a Dying Child

Websites

- www.joyandhope.org: Project Joy and Hope
- www.chionline.org: Children's Hospice International
- www.compassionatefriends.org: Compassionate Friends

Books

- *Gentle Willow: A Story for Children about Dying* by Joyce Mills
- *35 Ways to Help a Grieving Child* by the Dougy Center for Grieving Children
- *Sad Isn't Bad* by Michaeline Mundy
- *A Child Asks. . . . What Does Dying Mean?* by Lake Pylant Monhollon
- *Talking with Children and Young People about Death and Dying: a Workbook* by Mary Turner
- *The Worst Loss: How Families Heal from the Death of a Child* by Barbara Rosof
- *I Have No Intention of Saying Goodbye: Parents Share Their Stories of Hope and Healing After a Child's Death* by Sandy Fox
- *Stars in the Deepest Night: After the Death of a Child* by Genesse Gentry
- *The Bereaved Parent* by Harriet Schiff
- *You are Special* by Max Lucado

Key Concepts

- Children with special health care needs are those who have, or are at risk for, a chronic physical, developmental, behavioral, or emotional condition that generally requires more intensive and diverse health services, as well as coordination of those services, than do typical children.
- Most children with chronic illnesses or who are dependent on technology progress through stages of growth and development just as typical children do, though possibly at a slower pace, and desire to be treated as normal children.
- Parents of special needs children experience a multitude of emotions and changes in their lives, often carrying a heavy caregiving burden. They become the experts on their child's care and should be empowered and supported in their efforts.
- Children with special health care needs are at increased risk for the development of vulnerable child syndrome, which may have psychologically harmful effects on the child and parents for many years.
- Home is the most developmentally appropriate environment for children with special health care needs and those who are technology dependent. Children display an improved physical, emotional, psychological, and social status when they are cared for at home.
- Family-centered care provides the optimal framework for caring for children and families with special needs. Empowering the family strengthens them. A medical home or permanent relationship with the health care provider benefits the family, as care coordination and advocacy are provided.
- Use adjusted (or corrected) age when assessing growth and development of the infant or child who was born prematurely. Provide early screening and intervention for issues related to development to maximize the former preemie's potential for growth and development.
- Become familiar with the risks and benefits of adjuvant therapies used by some families of children with special health care needs.

- Screen children with special health care needs for failure to thrive or a feeding disorder.
- Screening helps to identify children with unmet health needs early so that intervention may begin.
- The child and family with special needs may require additional support during times of transition, such as at initial diagnosis or change in prognosis, when symptoms increase, when the child moves to new setting (hospital, school), during periods of developmental change, or during a parent's absence.
- Early discharge planning and ongoing inclusion and education of the family facilitate continuity of care. During mid-adolescence, initiate a written plan to help the special needs child make the transition to adult care.
- Early intervention provides care coordination (developmental services and special education), as well as an individualized family service plan for qualifying children and their families.
- Each special needs student is entitled to an individualized education program (IEP), which is a written plan that is designed to meet the preschool, primary, or secondary school student's needs.
- Younger children who are dying generally need for their families to be close and to trust their needs will be provided for. Older children require honest explanations given at a level appropriate for the child's age or developmental stage.
- Support the dying child and the family throughout the end-of-life decision-making process, providing facts as desired about palliative care, hospice, and organ donation.

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Building the Legacy: IDEA 2004: http://idea.ed.gov/

End-of-life Nursing Education Consortium: www.aacn.nche.edu/elnec

American Academy of Pediatrics: www.aap.org

American Hippotherapy Association: www.americanhippotherapyassociation.org

National Center on Birth Defects and Developmental Disabilities, promoting optimal fetal, infant, and child development; preventing birth defects and developmental disabilities; enhancing quality of life for those with disabilities: www.cdc.gov/ncbddd

Articles and resources for families of children with disabilities: www.childrensdisabilities.info/

Children's Hospice International: www.chionline.org

Division of Early Childhood, promoting support of families and optimal development of young children with or at risk for developmental delays and disabilities: www.dec-sped.org/

Voice for health care consumers, dedicated to achieving high-quality, affordable health care for all Americans: www.familiesusa.org

Institute for Family-Centered Care: www.familycenteredcare.org/

A national clearinghouse for information and education related to the health care of children with special health needs: www.familyvoices.org

Federation for Children with Special Needs: www.fcsn.org

Federation of Families for Children's Mental Health: www.ffcmh.org

Kids as Self-Advocates: www.fvkasa.org/

National Center for Hearing Assessment and Management: www.infanthearing.org

Initiative for Pediatric Palliative Care: www.ippcweb.org

Internet Resource for Special Children: www.irsc.org

American Academy of Pediatrics, National Center of Medical Home Initiatives for Children with Special Needs: www.medicalhomeinfo.org/

March of Dimes Resource Center, addressing personal and complex problems related to pregnancy and birth defects: www.marchofdimes.com

North American Riding for the Handicapped Association: www.narha.org

National Early Childhood Technical Assistance Center: www.nectas.unc.edu

National Dissemination Center for Children with Disabilities: www.nichcy.org/

Parents of Premature Babies, Inc., a nonprofit foundation supporting parents of preterm infants: www.preemie-l.org

Preemies.Org; helps parents of premature infants find other parents using various Internet resources: www.preemies.org

Resources for parents and caregivers of children with special needs: www.specialchild.com

Social Security Administration: www.ssa.gov

Make-a-Wish Foundation: www.wish.org

Zero to Three, supporting healthy development and well-being of infants and toddlers and their families: www.zerotothree.org

CHAPTER WORKSHEET

MULTIPLE CHOICE QUESTIONS

1. The parents of a 5-year-old with special health care needs talk to the parents of a 10-year-old with a similar condition for quite a while each day. What is the nurse's interpretation of this behavior?
   a. The nurse has not provided enough emotional support for the parents.
   b. This relationship between the children's parents is potentially unhealthy.
   c. Support between parents of special children is extremely valuable.
   d. Confidentiality is a pressing issue in this particular situation.
2. The nurse is caring for a child who has received all possible medical care for cancer, yet continues to experience relapse and metastasis. It is time to make the transition from curative care attempts to palliative care. What is the most important nursing consideration at this time?
   a. The health care professionals should make the decision about the child's care.
   b. The family may lose a sense of hope, so cancer treatments should continue.
   c. Involve the family in the decision-making process about the shift to palliative care.
   d. Palliative care can take place only at home, so the child should be discharged.
3. The nurse is caring for a 3-year-old with a gastrostomy tube and tracheostomy who is on supplemental oxygen and multiple medications. The mother is rooming in during this hospitalization. What is the priority nursing action?
   a. Incorporate the mother's assistance in care when convenient.
   b. Recognize the mother as the expert on her child's needs and care.
   c. Recommend that the mother go home to get some rest.
   d. Provide family-centered care since the mother is there.
4. The nurse is caring for a child with a developmental disability who is starting kindergarten this year. The mother is tearful and doesn't want the child to go to school. What is the best response by the nurse?
   a. "Do you need some time alone to collect yourself?"
   b. "You've known for a while this time would come."
   c. "Can I call your husband or a friend for you?"
   d. "It is normal to feel stressed or sad at this time."
5. The parents of a child with a developmental disability ask the nurse for advice about disciplining their child. What is the best response by the nurse?
   a. "You should choose methods that are most congruent with your values about discipline."
   b. "Children like this really can't follow directions, so they may be very hard to discipline."
   c. "Punish your child only for socially unacceptable or offending behaviors."
   d. "Spanking works well for this type of child, as they really don't like pain."

CRITICAL THINKING EXERCISES

1. A 15-year-old boy is dying of cancer after all medical care options have been exhausted. Describe the plan of care for this child and his family. What strategies should the nurse use to support the child and his family through this difficult process?
2. A 5-month-old infant who was born at 24 weeks' gestation is ready to be discharged from the NICU. She will be going home on oxygen, gastrostomy tube feedings, and eight medications. Develop a teaching plan for the family.

STUDY ACTIVITIES

1. In the clinical setting, care for a child with a terminal illness. Reflect in your clinical journal about the feelings you had during the care of the child, as well as the feelings and behaviors that you noticed in the child, siblings, parents, and nursing staff.
2. Visit a preschool that provides care for developmentally delayed and typical children. Choose two same-age children, one with a disability or impairment and the other a typical healthy child. Perform a Denver developmental screening or development assessment on each of the two children. Compare and contrast your findings.
3. Spend the day with a home care nurse providing care for a technology-dependent child. What obstacles has the family overcome to have this child at home? What adjustments does the nurse make to provide family-centered care in the home (as compared to the hospital setting)?