

Family Support and Education

Lou Ann Goldstein, PT, MS, PCS

Physical Therapy Department, University of Illinois at Chicago, Chicago, IL, USA

ABSTRACT. Family involvement is essential to the developmental outcome of infants born into Neonatal Intensive Care Unit (NICU). In this article, evidence has been presented on the parent's perspective of having an infant in the NICU and the context of family. Key points to an educational assessment are also reviewed. Throughout, the parent's concerns and the educational needs of the family are shared, and strategies are given to help therapists enhance their teaching skills and ways to partner with parents. This article also introduces the NICU Discharge Path for parents "Preparing for Your Baby to Come Home". The Path educates parents on the steps towards home and encourages their participation in the process.

KEYWORDS. Birth defects, family functioning, high-risk newborn, infant development

The purpose of this article is to present a review of literature on families in the NICU (neonatal intensive care unit) and methods to assess and support their educational needs. One of the key elements to this article is the introduction of the NICU Discharge Path (Figure 1) as a teaching tool for parents. The NICU Care Path (Campbell, 2013, Figure 2.1) presents a timeline to guide assessment, intervention, caregiver support, and team collaboration. Articles by Byrne and Garber (2013), and Garber (2013), describe the interventions used by physical therapists in the NICU, most of which are taught to parents as part of family-centered care. The NICU Care Path (Campbell, 2013, Figure 2.1) contains a section titled Family Support and Education in which the therapist documents the most important aspects of care as they are taught to families. These include (a) recognizing and responding to infant behavioral cues; (b) handling for social interaction, sensory stimulation, and exercise; (c) feeding; and (d) guidance for the transition to home such as accessing community resources and facilitating development progress with home exercise programs. As with other aspects of the NICU Care Path, activities are sequenced across time based on the infant's age and competencies. The purpose of this article is to share with physical and occupational therapists the research from the parent's perspective on having a fragile infant in the NICU and to reinforce to therapists the

Address correspondence to: Lou Ann Goldstein, PT, MS, PCS, 1843 West Barry, Chicago, IL 60657, USA (Email: louanngouker@yahoo.com).

(Received 26 August 2011; accepted 27 November 2012)



NICU Discharge Path *Preparing for Your Baby to Come Home*

PARENT NAME(S): _____
 FOR BABY: _____ DATE OF BIRTH: _____

This sheet has been designed as a guide to educate families on the necessary steps that occur prior to your baby going home. You may use this tool to track your baby's progress by crossing out the square when you have completed that activity. All activities may not apply to every baby. Cross out only the activities that apply to your baby. If you have any questions regarding the above steps, please contact your primary nurse. Thank you.

	At Admission <i>Your Baby Weighs: _____</i>	When Your Baby Weighs: 1500-1600 g (3 - 3 ½ lbs)	When Your Baby Weighs: 1600-1800 grams (3 ½ - 4 lbs)	Two Weeks Before Discharge: <i>Your Baby Weighs: > 4 lbs</i>	One Week Before Discharge: <i>Your Baby Weighs: > 4 lbs</i>
Nutrition 	<input type="checkbox"/> Intro to feeding: breast, nipple, tube, or IV nutrition (assessed by a dietitian) <input type="checkbox"/> Meet with lactation consultant <input type="checkbox"/> Learn how to build your milk supply	<input type="checkbox"/> Begin feeding your baby (breast, nipple, tube, or IV nutrition)	Your baby is gaining weight <input type="checkbox"/> Review breast feeding or pumping with lactation consultant	<input type="checkbox"/> Learn how to mix formula (if applies) <input type="checkbox"/> Get shots (for babies 2 months old) <input type="checkbox"/> Demonstrate baby care competence with nurse	Your baby is eating every 3-4 hours <input type="checkbox"/> Gaining weight <input type="checkbox"/> Purchase formula <input type="checkbox"/> Order & pick up special formula (if needed)
Baby Care 	<input type="checkbox"/> Learn about skin-to-skin contact: How can it benefit my baby?	<input type="checkbox"/> Learn baby care: _____, taking temperature, _____, changing diapers, etc.	<input type="checkbox"/> Learn how to bathe your baby	<input type="checkbox"/> Decide on circumcision <input type="checkbox"/> Demonstrate baby care competence with nurse	<input type="checkbox"/> Ask your nurse or doctor any questions about how to care for your baby at home
Medications & Equipment 	<input type="checkbox"/> Learn what your baby's monitors can tell you	<input type="checkbox"/> Watch and learn about your baby's medications	<input type="checkbox"/> Demonstrate giving medications to your baby	<input type="checkbox"/> Learn about changes to your baby's medications	<input type="checkbox"/> Fill prescriptions at the pharmacy <input type="checkbox"/> Bring medications to the hospital <input type="checkbox"/> Have equipment delivered to your home <input type="checkbox"/> Receive your baby's immunization card
Your Health Care Team 	Meet your: <input type="checkbox"/> Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Case Manager <input type="checkbox"/> Social Services	<input type="checkbox"/> Attend several "Parent Nights" to learn more about team member roles and meet other parents <input type="checkbox"/> Be an advocate for your baby <input type="checkbox"/> Clarify your questions with your Health Care Team	<input type="checkbox"/> Meet with the appropriate therapist (PT, OT, SLP) to learn about your baby's development	<input type="checkbox"/> Follow up with case manager and social services to establish discharge plan	<input type="checkbox"/> Learn how to contact your health care team once your baby goes home
Tests 	Your baby will have multiple tests while in the hospital. If you have any questions, please ask your nurse or doctor.	<input type="checkbox"/> Eye exam (6 weeks of age) (for babies born <32wks PMA) <input type="checkbox"/> Developmental assessment by the appropriate therapists (PT, OT, SLP) (if needed)	<input type="checkbox"/> Hearing screening by the audiologist <input type="checkbox"/> Feeding assessment by the appropriate therapist (PT, OT, SLP) (if needed)	<input type="checkbox"/> Get baby's test results Please ask the appropriate staff to clarify the results if you have any questions.	<input type="checkbox"/> Car Seat Screen (for babies born at <37 wks PMA) <input type="checkbox"/> Get your baby's foot prints
Education 	<input type="checkbox"/> Begin journaling about your baby's NICU journey <input type="checkbox"/> Learn about your baby's diagnoses	Learn about: <input type="checkbox"/> Baby's needs <input type="checkbox"/> Baby's "signals"	<input type="checkbox"/> Get a car seat for your baby and attend a car seat class <input type="checkbox"/> Watch CPR video	<input type="checkbox"/> Attend CPR class <input type="checkbox"/> Return demonstration of CPR techniques with RN <input type="checkbox"/> Update and provide expanded explanation of diagnoses and/or problems that need follow up	<input type="checkbox"/> Learn about "do's and don'ts" <input type="checkbox"/> Get WIC form from your case manager
Discharge Planning 	Begin planning: <input type="checkbox"/> Add your baby to your insurance plan <input type="checkbox"/> Update personal information (i.e., phone number and address)	<input type="checkbox"/> Choose your pediatrician; your case manager can help.	<input type="checkbox"/> Get your baby's space ready at home (toys, bottles, clothes) <input type="checkbox"/> Get helpful hints from your nurse <input type="checkbox"/> Establish support system at home	<input type="checkbox"/> Learn about equipment needed for home (if applies) (apnea monitor, oxygen use, tube feedings) <input type="checkbox"/> Arrange an extended visit or overnight stay with your nurse to learn about home care	<input type="checkbox"/> Return demonstration of Tummy Time to Therapist <input type="checkbox"/> Learn sleep positions "Back to Sleep Program" <input type="checkbox"/> Receive your multidisciplinary discharge summary

Copyright © 2011 by Lou Ann Goldstein. All rights reserved. Sharing this information is prohibited without permission from IMPSS, LLC, and the author.

FIGURE 1. NICU Discharge Path.

importance of the parent to the developmental outcome of the infant. Throughout the article, the parent's concerns and educational needs are shared, and strategies are given to help therapists enhance their teaching skills and develop collaborative teaching approaches with the parent.

The pictorial NICU Discharge Path "Preparing for Your Baby to Come Home" (introduced in this special issue as Figure 2.2, Campbell, 2013) was designed specifically to educate parents in the steps toward an infant's discharge from the NICU. Literature explains that parents need step-by-step instructions and ways to become more involved in their infant's care (Bruns & Klein, 2005). Parents want their care to be individualized (Cleveland, 2008). Menghini (2005) recommended that educational materials invite readers to interact. Materials should focus on specifics that the parents can do rather than on facts or principles (Menghini, 2005). The NICU Discharge Path (Figure 1) was designed specifically to meet the parent's educational preferences. When therapists use this tool, they can individualize their teaching methods to achieve each step according to the parent's and infant's needs; parents need to be told that not every step might apply to their baby, and individual institutions vary slightly in when they introduce the various topics. Each step on the NICU Discharge Path (Figure 1) has approximate time frames so that parents can anticipate task achievement and see how each step builds upon the next. Teaching parents the expectations for discharge and how the steps build upon one

another helps parents to identify their role and encourages their participation. The NICU Discharge Path (Figure 1) for parents provides opportunities for them to check off completed tasks and encourages the parent's participation as their infant progresses through care path activities toward discharge home. Further methods on how to support parents in the NICU, such as using the NICU Discharge Path (Figure 1) as a teaching tool, will be described in more detail in this article.

Therapists play an important role in supporting parents in the NICU and influencing positive outcomes for infants and their families. This article has been divided into four sections: (a) Family Context, (2) Education Assessment, (3) Methods for Teaching, and (4) Topics for Teaching. This article summarizes literature on adult learners and family education, and provides suggestions to therapists on how to effectively work with culturally diverse families in the NICU. Evidence-based strategies and content areas for therapists to focus on during their teaching sessions are provided. The ultimate goal for therapists is to provide parents with the knowledge and skills to positively impact their infant's development and lifelong learning.

Each discipline has established advanced knowledge and skill guidelines that should be established prior to a therapist beginning to work in the NICU. Both the *Practice Guidelines for the Physical Therapist in the NICU* (Sweeney, Heriza, & Blanchard, 2010; Sweeney, Heriza, Blanchard, & Dusing, 2009) and the *Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit* (Vergara et al., 2006) recommend that therapists have an understanding in specific knowledge areas. Specific to parent/caregiver education, therapists must possess knowledge in family-centered care, parent–infant attachment, and infant development, and use intervention strategies and create discharge plans in collaboration with the family. Family-centered care requires the therapist to recognize the infant as part of a family system (Shelton & Stepanek, 1994). Once therapists have the recommended knowledge and skills to work in the NICU, they can then begin to adjust their skills to meet the needs of the family.

FAMILY CONTEXT

Stressors

The birth of a healthy term infant leads to many parental stressors, including adjusting to caregiving, coping with physical demands such as breast feeding and altered sleep routines, and living with the ongoing financial obligations of having an additional family member. When the birth is of a premature infant, the family takes on additional parental stressors including maternal recovery from a high-risk pregnancy, uncertainty about the infant's survival and outcome, the constant worry during the NICU experience, and the challenges of assuming care giving responsibilities for a recovering infant at home (Jackson, 2003).

Stress has been identified in the literature as one of the most common barriers to effective parenting and yet one of the most important predictors of the developmental outcome of the infant (Micelli et al., 2000). Parents often have difficulty developing their parenting roles sometimes leading to acute stress disorder, a sign of posttraumatic stress disorder (Shaw et al., 2006). Parents should be closely monitored for signs of depression and appropriate referrals should be made accordingly.

Parents report their stress being related to their inability to help, hold, and care for their infant (Shaw et al., 2006). Mothers and fathers appear to be equally stressed by having an infant born prematurely, but the stress manifests differently with mothers reporting higher levels of anxiety while their infants are in the NICU (Shields-Poe & Pinelli, 1997). Research suggests that much of the father's stress is "invisible to healthcare workers" because the root causes lie outside of the NICU and the father sees his primary role as returning to work after the baby is born to provide for the family (Pohlman, 2005). The suggestion in the NICU Discharge Path (Figure 1) that parents begin a journal to document their baby's NICU journey might be one helpful way for parents to manage stress, particularly if they use the journal to express their own feelings and reactions to the experience.

Fragile Babies

The anxiety level of the parent may also impair the parent's ability to provide effective caregiving. Anxiety about the child's present condition and future life course as well as the personal, family, and work-life disruptions and financial concerns related to the medical care costs or parental work demands may affect parents' ability to learn how to care for their recovering child and their readiness to assume care responsibilities at home (Suderman, Deatrck, Johnson, & Sawatzky-Dickson, 2000). Eventually, the infant is ready for discharge and this time would typically be a joyous and exciting event for the parents. But the discharge, too, can be a stressful, anxiety-provoking experience for parents (Melnyk, 2000). The anxiety is often the result of the perceived lack of preparedness and doubts about their own competency to manage their infant at home. Parents judge their infant's readiness to come home based on their feelings and ability to care for their infant, confidence, and desire for the transition to home (Bissell & Long, 2003). Unlike parents, physicians judge an infant safe for discharge according to the length of the hospitalization or the infant's clinical readiness. Now, the American Academy of Pediatrics recommends that physicians base their discharge decisions for hospitalized high-risk infants on the evaluation of four dimensions of readiness for discharge: neonatal readiness, home care plan readiness, family and environment readiness, and community and health systems readiness (American Academy of Pediatrics/American College of Obstetricians and Gynecologists, 2002).

Socioeconomical Stressors

Parent education begins the first day the baby arrives into the NICU and builds throughout the hospitalization with consistent visitation and participation by the parents/caregivers. Parents become more confident about their skills and prepared to take their infant home. However, along with the stress of having an infant born prematurely and hospitalized for a long length of time, several socioeconomic factors such as diminished family support and limited financial resources may affect the parent's/caregiver's ability to visit their infant in the NICU. According to the United States Census Bureau, that nation's poverty rate rose to 15.1% (46.2 million) in 2010, up from 14.3% (43.6 million) in 2009 and to its highest level since 1993 (United States Census Bureau, 2010, <http://factfinder2.census.gov>). Research has also shown that premature infants are more likely to be born among families living in poverty. Fifty-seven percent of the extremely low birth weight infants were

living in a household with an annual income of less than \$20,000 (Vohr et al., 2000). Socioeconomic factors ultimately affect the parents'/caregivers' ability to visit and participate in the infant's care, and their ability to meet with specialists such as the physical therapists and occupational therapists who help to teach parents about infant development. The suggestion in the NICU Discharge Path (Figure 1) that parents meet with social services personnel can help parents identify factors that may be influencing their ability to visit their infant. Social workers may be able to provide short-term resources and solutions, and may help parents determine ways to visit more frequently so that they have more opportunities to learn their infant's care. Throughout this article, strategies are suggested to enhance a therapist's ability to work more effectively with the diverse families in the NICU.

EDUCATION ASSESSMENT

Parent education begins with an assessment of the educational needs. Physical therapists can refer to *The Guide to Physical Therapy Practice* as a document that describes physical therapy practice in general and recommends that physical therapists gather information regarding cultural beliefs and behaviors, family and caregiver resources, and social interactions, activities, and support systems (American Physical Therapy Association, 2001). The data can be obtained through patient/caregiver interview, through review of the patient health care record, or from other sources.

Identifying the Family

The first part of the educational assessment begins with identifying who the family is and/or who will be involved in the care of the infant. Oftentimes this may involve extended family and/or friends. Gathering information from the health care record will include maternal history, family, and living situation, and the most effective technique is a direct interview with parent/caregiver. Again, collaborating with the social worker is helpful. Assessments by the social worker lend valuable input on the family, external support, employment, visitation, and family stressors. Therapists should work in collaboration with the parent/caregiver and the social worker to optimize teaching and learning experiences. Studies have examined the influences of psychosocial factors including the quality of the marital relationship, maternal education (Gerner, 1999), maternal stress, depression (Coyle, Roggman, & Newland, 2002), and social support on mother–infant interactions (Feiring, Fox, Jaskir, & Lewis, 1987). Both research and theory suggest that these factors are inter-related and together influence maternal behaviors and responsiveness to their infant. Taking these factors into consideration will help guide the therapist's plan of care and decision-making process. Therapists may also want to use the Decision Tree for Family Education and Support (Figure 2) as a guide to the process.

Identifying the Primary Language

The next step in the educational assessment process is identifying the primary language spoken by the parent/caregiver. In Level III NICUs in which the hospital serves a large geographical area, therapists often meet diverse patient populations. According to the 2009 United States Census Bureau, Spanish is the second most

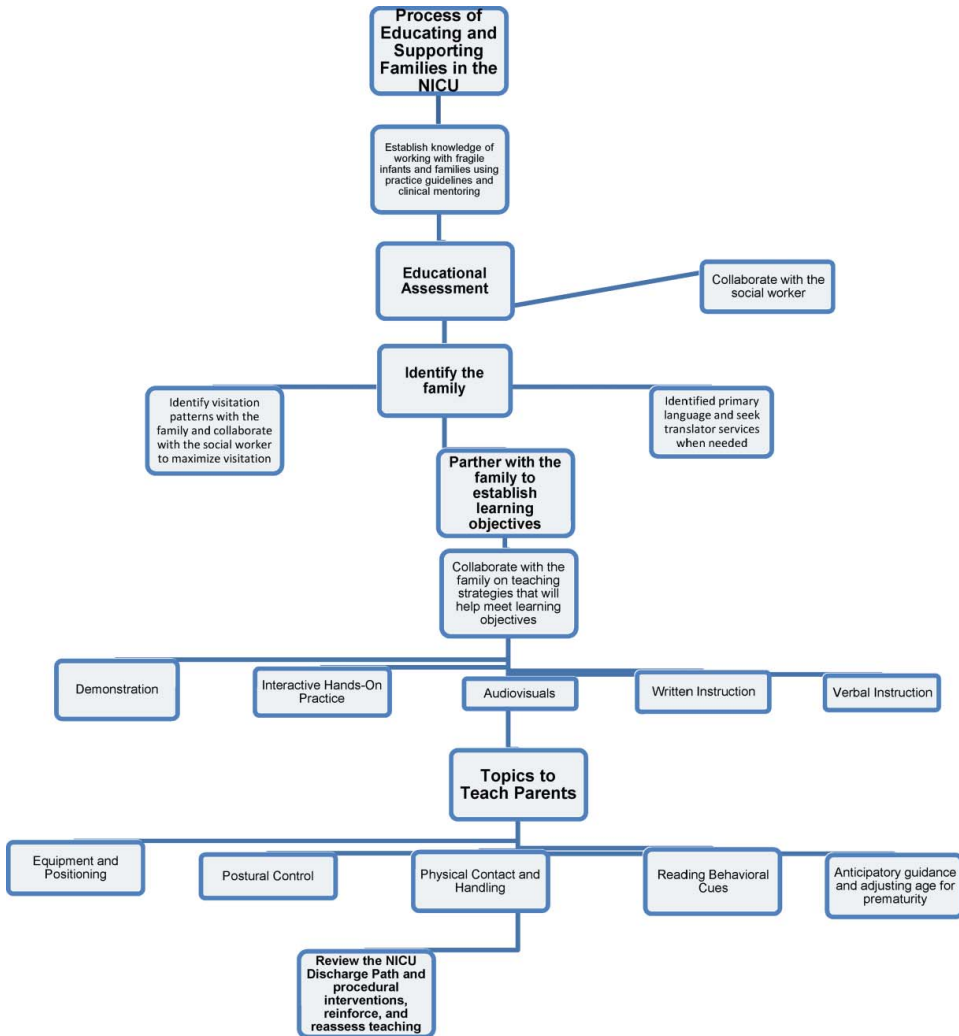


FIGURE 2. Decision Tree for Family Education and Support.

common language and spoken by over 12% of the United States (United States Census Bureau, 2009, <http://factfinder2.census.gov>). Twenty-eight million people over the age of 5 years old speak Spanish according to the 2000 report of the United States Census Bureau. If a parent/caregiver uses another language besides English, therapists, parents, or caregivers can request translator services to make communication more effective. Sometimes the parent/caregiver may decline services. If the therapist is concerned about the parent's/caregiver's comprehension or suspects a language barrier may exist, the therapist can insist on the presence of an interpreter to ensure that the information is communicated to the family in the appropriate manner. Therapists should again work closely with social workers regarding the need for translator services and other resources. There are statutory and regulatory requirements that hospitals provide interpreter services for patient/families. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and

state departments of public health are regulatory organizations that require hospitals to have translator services available to parents/caregivers. Therapists may work directly with translators or through phone services that provide language translation. Each parent/caregiver should be treated individually, without judgment, and the therapist should work in collaboration with the health care team, including the social worker, to identify the most effective strategies to teach a diverse population.

Partner with the Family

Once the primary language is established, the next step is determining what the parents want to learn and how they learn best. After the therapist has introduced themselves and explained their role in the treatment of their infant in the NICU, therapists can then begin to inquire about what the parent/caregiver currently understands about their infant. Patricia Lawler (1991) described several principles to facilitate adult learning. She described that adult learners are different from child learners in that adults are usually prompted by a transitional event in their lives in which they seek out education versus a child in which their education is compulsory. She emphasized how important it is for teachers to respect what adults already know and to use their knowledge and experiences to build a collaborative teaching experience. “Adult students are not empty vessels that teachers fill with facts and information. That attitude is not very successful.”

For example, therapists may start by inquiring about the parent’s/caregiver’s family, previous children, and experience with infants. From that discussion, one can build on what may be the same and different now that the family has an infant born prematurely. Building on what the parent/caregiver already knows and understands will build their confidence and their caregiving capability. Effective health care relies on the ability to communicate reciprocally with parents/caregivers. Research recognizes that limited patient/caregiver literacy is a challenge to medical diagnosis and treatment (Kripalani, Paasche-Orlow, Parker, & Saha, 2006) and is associated with poor health outcomes (Winslow, 2001). Interventions to assist individuals with lower literacy have been shown to benefit and be acceptable to those with adequate literacy (Sudore et al., 2006). Therapists can assess the parents’/caregivers’ understanding by asking questions about their infant’s medical condition, problems, and diagnoses, which will guide future educational sessions with the parent/caregiver. Confirmatory or “teach back” strategies to see whether parents/caregivers understand instructions are useful. Asking an open-ended question to parents/caregivers, e.g., “tell me what an intraventricular hemorrhage means to you?” or in simpler terms, “what does the bleed in your baby’s brain mean to you?” or “tell me how you know that your baby is having a good day or is feeling stressed or uncomfortable.” Open-ended questions typically allow parents/caregivers an opportunity to reflect on their understanding. Open-ended questions show the parent/caregiver that you are genuinely interested in their understanding of their infant and it hands the control of the conversation over to the parent/caregiver. Closed-ended questions can help to start a conversation or summarize the parent’s understanding and be used to redirect the conversation in a different direction if needed. Using strategies like these during your assessment of educational needs can help therapists build the parent’s/caregiver’s confidence in caregiving as well as help the therapists identify

areas for further explanation or teaching, or may encourage parents/caregivers to identify areas in which they would like to learn more.

Although therapists may have their own feelings about what parents need to know or what they should be told, therapists should recognize that effective parent/caregiver education begins with addressing what the parents feel is most important to them. Family-centered care is based on developing partnerships with families that support attachment and role development in the NICU (Lawhon, 2002). By encouraging the family to participate in goal setting and identifying areas for teaching will help make the teaching sessions more valuable to the family and ultimately more helpful to the infant. The therapist must be flexible and willing to adjust, and possibly separate what they feel the infant/parent needs from what is important to the family. Parents want to be given accurate information and be included in the infant's care (Cleveland, 2008). To be responsive, therapists must skillfully communicate their clinical impression and recommendations clearly and honestly about the infant's development while tempering the conversation with hope and sensitivity for a positive future so as not to interrupt the development of a strong parent–infant relationship.

Parent Empowerment

The JCAHO highlights the need for education to be specific and meet the individual needs of the patient or caregiver. Several studies have been conducted to examine the educational needs of parents in the NICU. A review article by Cleveland (2008) has identified six common needs of parents as they relate to infant care and daily assessment. The parents expect the hospital staff to collaborate with them and assist them in meeting their parenting needs by providing them with emotional support, parent empowerment, and parent education while having an opportunity to practice new skills through guided participation (Cleveland, 2008). Oftentimes infants are critically ill for weeks or months interrupting the typical parent/infant bonding process. Once the infant is more stable, parents express the need to be more involved in their infant's care and regain the position of being a significant person in the infant's life (Fegran, Helseth, & Solveig-Fagermoen, 2008). Therapists have a unique role in identifying importance aspects in the developmental care of premature infants and then coaching the parents on identifying what aspects are important to them as parents and how they can play an active role in caring for their babies. The NICU Discharge Path (Figure 1) meets this goal by providing a breakdown of steps the parents take to gradually assume responsibility for their infant.

Parents are Adult Learners

Once the learning objectives are established, the next step is to determine how best the parent/caregiver learns. Lawler (1991), in her work on adult learning, emphasized that adults learn best when giving opportunities to participate and receive feedback on their performance. Literature reports that parents/caregivers of infants in the NICU have similar learning needs. Parents want to be given more opportunities for hands-on practice and ask for more standardized procedures for learning basic and complex caregiving tasks (Gerner, 1999), and they want to be part of the discharge process (Anthony & Hudson-Barr, 2004). Some parents may

actually feel a sense of comfort and release of stress by participating in their infant's care (Shaw et al., 2006). Parents report that having the opportunity to practice new skills with assistance from medical staff is important to their learning (Cleveland, 2008). Parents want more standardized procedures for learning basic and medical caregiving, such as written instructions and step-by-step demonstrations (Bruns & Klein, 2005). In three critical areas of care, the NICU Discharge Path (Figure 1) suggests that the parents demonstrate skill: giving medications, cardiopulmonary resuscitation (CPR), and returning a demonstration of the physical therapy home program.

While mothers tend to focus on infant interaction and handling, fathers appear to focus more on interpreting the NICU experience by understanding monitors and technology, with less interacting or building emotional attachment with their infant (Nargoski-Johnson, 2008). Teaching should be individualized and recognize that mothers and fathers may have different learning needs. Therapist may use different teaching strategies for the fathers without changing the goal that is to improve parent–infant attachment. There are similarities between the literature on adult learning and what families in the NICU want to learn that should be considered. More information on adult learning can be found at the National Center for the Study of Adult Learning and Literacy (<http://www.ncsall.net/>) or the American Association for Adult and Continuing Education (<http://www.aace.org/>).

TEACHING METHODS

Several studies have examined the methods used to educate parents/caregivers in the NICU (Dusing, Murray, & Stern, 2008; Dusing, Van Drew, & Brown, 2012; Kripalani et al., 2006; Sudore et al., 2006; Widemayer & Field, 1981). Therapists use a variety of teaching methods such as verbal instruction, demonstration, and interactive hands-on practice, written instruction, and/or audiovisual materials. Once the therapist has established the parent's/caregiver's learning style, the therapist can then choose the educational method that best meets the parent's/caregiver's need and has the strongest potential influence on parenting and infant outcomes. Therapists may choose a particular method based on the effects it has on parents or they may choose a method based on the effects it may have on infant outcomes. Therapists should carefully collaborate with the parent/caregiver to identify what best meets their needs.

The NICU Discharge Path (Figure 1) is one tool and was designed for the infant and parent. The information on the clinical path is organized according to standards of care for the infant in the NICU. The design of the clinical path is used to communicate those standards to the parent and prepare the parents for discharge. Pictures, short phrases, and a checklist are used to give the path meaning to parents and encourage the parent's involvement in their infant's progress during the hospitalization. Communicating clear expectations to parents so that they can anticipate the next step can help reduce the anxiety that often develops around planning the infant's discharge (Melnyk, 2000). Parent–infant interaction improved after parents were empowered to help care in the NICU for their infant born preterm (Melnyk et al., 2006). Once the parents' needs have been identified, therapists can offer to

use the NICU Discharge Path (Figure 1) as a tool to involve parent participation and guide teaching.

Parent Preferences

Research has focused on involving parents in the examination process (Dusing, Murray, & Stern, 2008; Kripalani et al., 2006; Sudore et al., 2006). Parents prefer a combination of educational formats when learning more about a physical therapist's examination and recommendations on infant motor development (Dusing, Murray, & Stern, 2008). A majority of parents preferred observing an infant's motor assessment on the Test of Infant Motor Performance (TIMP) while a physical therapist described the assessment and made recommendations about play activities as simulated in a video (Dusing, Murray, & Stern, 2008). The parents had improved knowledge of motor development and were able to describe ways that they would play with their infant. Knowing the parent's learning preference and the benefits to parents in learning about infant development, therapists should make every effort to coordinate their assessments and interventions around the parent's/caregiver's visitation.

Parent Benefits

Parents not only prefer to observe their infant's motor assessment, but research also shows that it can be beneficial to the parents. Interventions focused on involving the parents in the examination process facilitate development of parent–infant relationships and teach parents about infant motor development. As previously mentioned in the Assessment Article, the Newborn Behavioral Observation (NBO) System (Nugent, Keefer, Minear, Johnson, & Blanchard, 2007) is an off shoot of the BNBAS (Brazelton Neonatal Behavioral Assessment Scale, Brazelton, 1973; Brazelton & Nugent, 1995), which has been designed to engage parents with their infants while the clinician helps them to understand their baby's development. The NBO has been used to help build relationships between the parent and their infant and is more practical for clinical use than the full BNBAS. Goldstein and Campbell (2008) found that the TIMP (Campbell, Kolobe, Osten, Lenke, & Girolami, 1995) is an effective tool for educating mothers with low socioeconomic status (SES) about infant motor development. Mothers were able to gain and retain knowledge of premature infant motor development after observing their infant's performance on the TIMP.

Written parent education materials such as booklets, brochures, and information sheets can be useful if parents can read and understand the material given, but this method was the least recommended by parents (Dusing, Murray, & Stern, 2008). Therapists should make a careful assessment of the parent's/caregiver's level of understanding and choose the most appropriate materials specific to their learning needs (Menghini, 2005). Therapists can complement their verbal and hands-on teaching with written material to reinforce learning. According to the National Center for Education Statistics, educational materials should be written at a 6th–8th grade reading level in order to communicate effectively with a general audience in the United States (<http://nces.ed.gov/>). Menghini (2005) provided several recommendations for developing educational materials for parents/caregivers in the NICU. She recommended aiming for a 6th-grade reading level or lower without

sacrificing content. Computer programs such as Microsoft Word automatically calculate the reading level of written passages. Avoid using medical terminology but when necessary define terms in simple, nontechnical language. Focus the written material on specifics that the parents should do rather than on facts or principles. For example: Place your baby on his stomach daily for play to help develop arm strength. Not: The therapist wants you to place your baby on his stomach daily for play to help develop arm strength. Provide parents with a list of easy-to-access, more in-depth resources so that those so motivated can choose to read more about the topic. Use photographs, drawings, or videos that help clarify concepts and use captions to emphasize importance. Checking in with the parents to assess the level of completion of items on the NICU Discharge Path (Figure 1) can be useful for spotting difficulty with documentation because of literacy issues or lack of understanding.

The neonatal individualized developmental care and assessment plan (NIDCAP) is an approach to care in which the infant is systematically observed during caregiving and handling, and suggestions for modifications that reduce infant stress are developed (Als et al., 2003). Individualized developmental care plans have been shown to reduce family stress and enhance parent appreciation of the infant (Als et al., 2003). With this model, parents are encouraged to participate in the infant's care. Parents are taught techniques that modify the NICU environment such as decreasing sensory stimulation, aiding infants in self-regulation, and providing supportive positioning to the infant. Parent–infant interactions and subsequent infant development improved using the NIDCAP model of care (Blauw-Hospers & Hadders-Algra, 2005). Using this method provides benefits to the parent and infant.

As infants mature and become more physiologically robust, physical therapists and occupational therapists often give instructions to parents/caregivers on specific activities or exercises to perform with their infant. A picture of the activity and a short description is easier for parents to understand than verbose explanations of the facts and principles behind the action. Jennings and colleagues found that scheduled “tummy time” increased with parent education, and parents provided more “tummy time” when a pictured brochure was given (Jennings, Sarbaugh, & Payne, 2005). Parents also preferred the pictorial version of the TIMP (Campbell et al., 1995) in a study that determined the TIMP to be an effective tool for parent education (Goldstein & Campbell, 2008). Along with a video of the TIMP, the audiovisual materials available to accompany the chapter on The Child's Development of Functional Movement in the 4th edition of *Physical Therapy for Children* include an instructional video demonstrating tummy time activities with a 2-month-old infant that can be used for parent instruction (Campbell, 2013).

Parents are more confident about the infant's discharge with hands-on learning (American Physical Therapy Association, 2001; Coyl et al., 2002; Feiring, et al., 1987; Gerner, 1999). Therapists often provide specific exercises or activities for parents to do with their infant. The activities are first demonstrated and later practiced with the therapist's feedback until the parent/caregiver performs them correctly. Often therapists ask the patients to demonstrate the exercises to ensure correct performance. Rastall and colleagues found that patients were able to remember their physical therapy exercises better when the teaching involved the patient's

motor performance of the exercises (Rastall, 1999). Explicit teaching and experiential learning builds confidence in the parent's ability to draw on the information needed to care for the infant once they are at home (Weiss et al., 2008). The opportunity to engage parents in providing care to their infant prior to discharge is a successful strategy for building confidence and competence (Costello & Chapman, 1998). The NICU Discharge Path (Figure 1) provides parents with a means for documenting their preparation in seven areas: Nutrition, Baby Care, Medications and Equipment, Your Health Care Team, Tests, Education, and Discharge Planning. Therapists can engage parents in discussing their feelings about having their infant come home by using the NICU Discharge Path (Figure 1). Therapists can help parents reflect back on what they have accomplished and their infant's readiness to come home. Therapists can also coach parents to review their journals about what their infant has faced and accomplished during their hospitalization. Lekskulchai and Cole (2001) found a hands-on teaching approach to be effective for instructing parents as well as improving infant motor outcomes. Parents/caregivers were given a session to practice the activities on the infant under the supervision of the physical therapist. At a follow-up session, caregivers were given another opportunity to practice the activities again to ensure the parent's/caregiver's understanding and compliance with the program. Infants were excluded from the study if parents/caregivers could not demonstrate the previous month's activities correctly for 2 consecutive months. The authors reported that there were no parents/caregivers who demonstrated the activities inappropriately so the hands-on approach to teaching would appear effective. Using a hands-on approach is common to physical therapy practice and appears to be more beneficial to the parent/caregiver than verbal instruction alone.

It is difficult to exclusively provide intervention to only the parent or infant. In nearly all cases, the therapist is providing intervention to both. If there is a benefit to the parent such as improving the parents' understanding of development, and increasing skill and confidence in handling their fragile infant, most likely there will be a benefit for the infant. Maternal stress and social support were the most important predictors of developmental outcome and not the infant's medical complications at birth (Micelli et al., 2000). Helping parents to understand their infant's behavioral styles and responsiveness are important in supporting maternal confidence in caregiving (Pridham, Lin, & Brown, 2001).

Teaching Delivery

In an article on nursing care in the NICU, the delivery of discharge teaching was a predictor of parental readiness for hospital discharge (Weiss et al., 2008). The amount of information provided to the parent was not a predictor. The higher the parents rated the nurse's skill in delivering educational material, the more ready parents felt to take their child home. The effective qualities included listening, sensitivity, understandability, timing and consistency, promoting confidence, and reducing anxiety (Weiss et al., 2008). Therapists, like nurses, should continuously evaluate their own teaching effectiveness and determine whether the focus, content, and delivery of teaching materials is meeting the family's or caregiver's needs (Bailey & Caldwell, 1997). Therapists can invite other skilled therapists to observe their teaching sessions to evaluate the delivery of material (Bailey & Caldwell, 1997).

Therapists could also assess their effectiveness as teachers by surveying parents after discharge as to the usefulness of the material provided in the hospital and how the information was provided.

The number of teaching intervention sessions with the parent/caregiver may vary depending on several factors including the complexity of the infant, learning needs of the parent/caregiver, and social factors such as visitation and availability. Parent instruction sessions focused on infant development activities and parental involvement that were given on a frequent basis throughout the NICU hospitalization and after discharge had a greater impact on the infant's cognitive skills than a remedial model of intervention (Resnick, Armstrong, & Carter, 1988). It would appear that repetition reinforces the parent's understanding and improves their confidence and competency in caregiving, which ultimately affects the infant's development.

Coordinating Teaching with Visitation

It is important to identify when and how often parents visit so that therapists provide the correct amount of teaching sessions to allow parents to feel confident about their caregiving. Family-centered care is providing care that meets the needs of the parents/caregivers (Maternal and Child Health Bureau, 2005). Parents and caregivers may not always visit during the therapist's scheduled work hours. Flexibility in the therapist's schedule is important by offering times that are convenient to the parent/caregiver. Therapists can utilize nursing staff to coordinate a meeting time by leaving a note at the bedside with a contact number. Nurses can then contact the therapist when the parent arrives. Several studies report that parents prefer to learn about their infant's development by participating in the infant's care rather than solely relying on skilled professionals to provide all health and developmental services (Als et al., 2003; Jackson, 2003; Shaw et al., 2006; Widmayer & Field, 1981). Therefore, therapists should make every effort to meet with every family in the NICU. The more frequent the visitation, the more opportunities to reinforce the parent's understanding and the more confident the parent becomes at handling their infant and recognizing their baby's cues. Ultimately, the more confident the parent becomes, the stronger the infant will become.

Infant Benefits

Research has shown that parent education fosters infant development (Blauw-Hospers & Hadders-Algra, 2005; Jennings, Sarbaugh, & Payne, 2005). Regular assessments of the infant's development with modeled activities for the parents to do with their infants and attention given to the next stage of development improved infant cognitive skills at 12 months of age (Resnick et al., 1988). Interventions focused on motor development programs taught and supervised by a physical therapist but implemented on a regular basis at home by the caregiver resulted in significantly greater improvement in infant motor performance than a monthly consultation alone (Lekskulchai & Cole, 2001). Follow-up programs have proven more advantageous developmentally to the child when the therapist works directly with the parents rather than exclusively with the infants (Barrera, Rosenbaum, & Cunningham, 1986).

Several teaching methods have been described with the key element of collaborating with the family to identify what is most important to them. The NICU Discharge Path (Figure 1) was developed and is suggested as a tool to encourage parent participation and ultimately build their confidence as parents. The next section provides physical and occupational therapists with suggested topics to cover during teaching sessions with parents.

TOPICS FOR TEACHING

Physical therapists and occupational therapists practicing in the NICU have a unique opportunity to educate parents on their infant's current and anticipated development. In addition, therapists have an obligation to educate and provide parents/caregivers with evidence-based interventions, play activities, and strategies to maximize their infant's development, and to formally assess those infants at highest risk for delays because infants born prematurely and, in particular, those born extremely premature are at very high risks for developmental delays (Byrne & Campbell, 2013; Byrne & Garber, 2013; DeGroot et al., 2007; Garber, 2013). Therapists are also responsible for creating linkages for families to community resources and follow-up programs. The next section discusses the evidence as it relates to some of the most critical content taught to parents because of their benefits to parent–infant interactions and infant development. A positive relationship exists between a mother's ability to use effective coping strategies that strengthen mother–infant interactions that later indirectly affect an infant's development (Davis, Edwards, & Mohay, 2003).

Physical Contact/Handling

The parent's physical contact with their infant is disrupted by a premature birth. Facilitating the parent's physical contact with their infant is one intervention that can be used to improve the parent–infant bonding. Skin-to-skin care (SSC, also called kangaroo care) is included as an intervention on both the NICU Care Path (Campbell, 2013, Figure 2.1) and the NICU Discharge Path (Figure 1) because of its relationship-building potential. Mothers and fathers may react differently to having their infant born prematurely. They may describe the attachment process differently and they may cope with the birth in different ways (Shields-Poe & Pinelli, 1997). Fathers tend to understand monitors and technology more easily (Nargoski-Johnson, 2008). Considering this characteristic about fathers, therapists could coach fathers to use their eyes and hands to observe their infant's behavior and to use the recordings off telemetry to verify their understanding of their baby. This could help fathers build confidence in their handling and observation skills, and a closer attachment with their infant. Research has also shown that fathers who were able to have early skin-to-skin contact with their infant described this as a very positive experience (Shields-Poe & Pinelli, 1997). Physical contact with their infant helped them transform the infant from something impersonal to becoming a child with whom they emotionally and physically identified (Shields-Poe & Pinelli, 1997). Fathers' early involvement seemed to be strengthened by their positive SSC experiences and by the mothers' encouraging them to be important contributors to the child's care (Fegran, Helseth, & Solveig-Fagermoen, 2008).

Interventions like massage and kangaroo care that involve skin-to-skin contact can be taught to parents. Mothers who provided SSC had a more positive mood, more touch, and could better adapt to their infants' cues while the infants showed greater alertness and less gaze aversion (Feldman, Eidelman, Sirota, & Weller, 2002). Infant massage increases maternal confidence in caregiving (White-Traut & Nelson, 1988). Although massage and SSC have not been shown to improve the infant's motor outcomes, these interventions can have indirect benefits when included on a therapist's plan of care. Interventions that improve the mother's caregiving and responsiveness to their infant's behavior will assist with the mother's confidence in handling her fragile infant during therapeutic activities recommended by a therapist.

Reading Cues

While providing SSC, parents need to recognize whether the intervention is being tolerated well by the infant. Therapists can teach parents how to recognize their infant's stress signals and behavioral cues and should document their teaching on the NICU Care Path (Campbell, 2013, Figure 2.1). The written handout by Brenda Hussey-Gardner titled "Understanding my signals: help for parents of premature infants" www.vort.com (VORT Corporation 1-650-327-0747 sales@vort.com) is an essential handout that complements teaching parents about behavioral cues. The handout comes in both English and Spanish, and provides parents with short captions and pictures of infants demonstrating approach and avoidance signals commonly seen in fragile infants. The parents can use the NICU Discharge Path (Figure 1) to record their ability to read their infant's cues. Research has shown that the parent's ability to recognize the infant's cues benefits the infant and reduces parent stress thereby facilitating positive parent-infant interactions (Dudek-Shriber, 2004).

Premature infant cues tend to be disorganized and of lower intensity as compared to full-term infants and are therefore more difficult for parents to respond adequately (Sajaniemi et al., 2001). Parents will need to work harder to interact with their premature infants. In a study by Harrison, mothers needed to work harder to initiate and maintain interactions as compared with mothers of full-term infants and, in return, received fewer positive responses from their infant (Harrison, 1990). Mothers need to emphasize their maternal behaviors in order to compensate for limitations in their preterm infant's social abilities (Miles & Holditch-Davis, 1995). Therapists have the unique opportunity of providing consistent care to their patients and families, developing close relationships with their clients, and learning an infant's individual characteristics. Therapists play an important role in helping parents learn more about their infant's communication skills.

Interventions on behavioral cues and how to respond to these cues in soothing interactions with their infant have been found to be important in reducing parental stress and anxiety, and to improve confidence in caregiving (Loo, Espinosa, Tyler, & Howard, 2003). Parents of premature infants had an increased sense of security and fewer readmissions to the hospital when taught to observe and understand the infant's expressions and movements as well as any signs of stress (Broedsgaard & Wagner, 2005). Interventions designed to educate parents about the appearance and behaviors of preterm infants are effective at improving parent-infant

interactions, building maternal confidence (Pridham et al., 2001), as well as shortening the length of the NICU hospitalization (Melnyk, 2000). Interventions that focus on teaching caregivers about infant behaviors and how to appropriately modify caregiving has further shown to enhance the mother's ability to understand their infants' developmental needs allowing them to fashion a home environment that is better suited to address their infant's needs (Parker, Zahr, Cole, & Brecht, 1992).

Anticipatory Guidance/Adjusting Age for Prematurity

Because of the risk of developmental delays in infants born prematurely, parents/caregivers should be given the tools to provide ongoing monitoring of their infant's development. This begins with first teaching parents about realistic expectations, providing developmental assessment results, and instruction on how to correct the infant's age for prematurity with teaching recorded on the NICU Care Path (Campbell, 2013, Figure 2.1). There is currently no consensus among professionals regarding how long to correct a child's age for prematurity when evaluating test results. The majority of professionals who work with infants correct the infant's age through age 2 years. Once parents/caregivers understand the appropriate age expectations, interventions can focus on what to expect in the future. Interventions that focus on providing anticipatory guidance about premature infant development and infant behaviors improved the parent's responsiveness and facilitated involvement and confidence in the mothers (Melnyk, Feinstein, & Fairbanks, 2002). Research also supports that parents are accurate detectors of developmental delay. Parental report of their infant's current skills has been shown to be predictive of developmental delay and parents can clearly identify when developmental problems exist (Diamond, 1993). The written handout by the Pathways Awareness Foundation titled "Is my baby ok?" is an essential handout for providing anticipatory guidance (<http://www.pathwaysawareness.org/>). The handout provides parents with short captions and pictures of infants demonstrating typical and atypical development from birth to 15 months of age. The Infant and Toddler Connection of Virginia's Early Intervention Prematurity Workgroup created a brochure, titled *After the NICU: Promoting Your Premature Baby's Development at Home* (<http://www.infantva.org/documents/Pr-PA-NICU.pdf>). The brochure provides parents with information on the value of play, ways to support developmentally appropriate play, and developmental red flags. Teaching parents the importance of anticipatory guidance also encourages the parents to take the lead in seeking support from the medical community when they have a concern. Although premature infants of the same postmenstrual age may have similar motor outcomes (Campbell, 2006), they are different in behavioral responsiveness (Eckerman & Oehler, 1992). Infants born prematurely may be harder to console, less adaptable to change, and more likely to cry, and be considered to be fussier babies (Gennaro, Medoff-Cooper, & Lotas, 1992). It is essential that therapists provide parents with realistic information so that they can be appropriately prepared to seek intervention when needed. Providing anticipatory guidance and offering suggestions on how to respond to their infants' behaviors as they grow and develop such as appropriate use of equipment, knowing when to step away, and when to look to others for support are common practices.

Equipment/Positioning Recommendations

As part of the infant's discharge from the NICU, physical therapists provide recommendations for follow-up services and equipment needs. Infant cognitive and behavioral development is strongly associated with the home environment and parent–infant interaction (Donovan, Leavitt, Taylor, & Broder, 2007). As a result, therapists should work with parents to create an environment at home that promotes learning and infant development. Parents have a variety of positioning and equipment options available, but little is known about the influence the devices have on later development. The use of equipment might enhance early motor development or the equipment might impede optimal motor development. The American Academy of Pediatrics recommends supine sleeping positions to reduce the incidence of sudden infant death syndrome, but infants who sleep in supine and spend little time in the prone position have early motor delays (Davis, Moon, Sachs, & Ottolini, 1998). Dudek-Shriber and Zelazny (2007) found a significant difference in the gross motor scores on the Alberta Infant Motor Scale (AIMS) if 4-month-old infants spent less than 81 total min of time in prone per day. It appears that infants are at risk for motor delays if active prone time is not encouraged by parents. Therapists should reinforce to parents that supine time is required for sleep but that the prone position should be used for play to promote optimal development. Handouts describing tummy time activities in six languages are available from Children's Healthcare of Atlanta at <http://www.choa.org/childrens-hospital-services/orthopaedics/programs-services/orthotics-and-prosthetics/tummy-time-tools>.

Another controversial topic is the use of infant walkers. Infants who used an infant walker showed delays in gross-motor development (Siegel & Burton, 1999). Bartlett and Kneale-Fanning (2003) found that parents of premature infants spent on average 2 hr per day carrying their infant with a range up to 10 hr per day. They found a negative relationship between the amount of carrying and the sit subscale on the AIMS, meaning that the more infants were carried, the less sitting ability the infants had. Common play equipment reported by parents included infant seats, swings, and infant walkers. Although no other statistically significant negative association was found, therapists should explain to parents the potential long-term effects of prolonged use of carrying and play equipment, and educate parents on the advantages of providing infants with a variety of play positions that present different challenges to the infant's postural control as well as how to adapt equipment to support the infant's needs.

Postural Control

Once parents/caregivers can consistently read their infant's stress signals and behavioral cues, therapists should feel comfortable teaching the parents activities that challenge their infant's motor and sensory skills. Impaired postural control and decreased endurance are two common impairments of infants in the NICU that often limit the infant's ability to interact with their parents and demonstrate typical age-appropriate motor skills and behaviors. The therapist guides activities that challenge the infant's postural control and endurance and gives the parents/caregivers opportunities to practice. The therapist encourages the parent/caregiver to reassess

the infant's tolerance for these activities and to recognize when it is appropriate to continue or discontinue an activity.

Interventions focused on infant developmental activities and parental involvement that were given on a frequent basis throughout the NICU hospitalization and after discharge had a greater impact on cognitive skills than a remedial model of intervention (Resnick et al., 1988). Regular assessments of the infant's development with modeled activities for the parents to do with their infants and attention given to the next stage of development improved the infant's cognitive skills at 12 months (Resnick et al., 1988). Interventions focused on motor development programs taught and supervised by a physical therapist but implemented on a regular basis at home by the caregiver showed significantly greater improvement in motor performance than a monthly consultation alone (Leksukulchai & Cole, 2001).

Parent education is important to infant development because it has been shown to encourage parent–infant relationships, help parents learn typical developmental trends, and help parents identify when delays may be present. Research has documented that parent involvement in the examination process facilitates parent–infant relationships. Widmayer and others demonstrated that the BNBAS is an effective method of fostering the mother's responsiveness to her infant's behavior (Widmayer & Field, 1981). Unanue (2002) compared two types of parent education programs (family-centered parent education versus general education on infant development) and although she did not find a significant difference between the programs in terms of infant outcomes, she reported that both programs increased the parent's confidence levels in caregiving and slightly improved caregiving abilities. Melnyk and others investigated the effects on infant development of their educational-behavioral intervention program for mothers of low birth weight premature infants (Melnyk et al., 2001). Infants in the intervention group scored significantly higher on the Mental Developmental Index (MDI) of the Bayley Scales of Infant Development (BSID) at 3 months and 6 months corrected age (CA) as compared with the control infants (Melnyk et al., 2001). Brazelton and Nugent used the BNBAS to acquaint parents with their newborn's behavior and improve their knowledge and awareness of their infant's abilities (Nugent et al., 2007).

Parent education has also been shown to improve the parent's ability to provide a stimulating environment for infants. Parker and colleagues examined the efficacy of developmental intervention in the NICU for mothers of preterm infants with low SES (Parker et al., 1992). The intervention sessions were held weekly with the mothers. Follow-up home visits at 4 and 8 months of age showed that the experimental group scored significantly higher on the MDI of the BSID at both ages and significantly higher on the Motor Scale, but only at 4 months of age. The authors suggested that their results supported the benefits of educating parents in infant development.

The communities in which the families of babies in the NICU may live can be very diverse. Along with the risks of having an infant born prematurely, the families may also have environmental and social risks such as poverty, limited police protection in the community, and limited education may increase both the health risks of the mother and the chance that the child will experience the effects of family stress, neglect, poor nutrition, and suboptimal parenting (Collins et al., 1998).

Parent education on infant development may be an effective method for improving overall parenting skills of these mothers. The NICU Discharge Path (Figure 1) includes many items intended to insure the infant's health and safety, such as those on car seats, CPR, sleeping positions, and tummy time play.

In summary, this article provided information on the importance of early parent/caregiver education and support, research on what parents/caregivers want to learn in the NICU and strategies on how to obtain that information, research on intervention and teaching strategies that can build infant–parent relationships and the usefulness of the NICU Discharge Path (Figure 1) for parents. Working in an NICU with a diverse patient population can be a very rich learning experience for the therapist. Therapists must respect the parents'/caregivers' knowledge and experience they have had with their infant, and understand who they are and what their needs are. Establishing a climate where the parents/caregivers feel comfortable sharing and learning can be the key to making it work. Emphasis on parent–therapist collaboration is the goal in helping family members develop positive relationships with their infant and gain confidence and skill in their ability to care for their infant. Parents/caregivers undoubtedly grow in the knowledge and skills from the services provided by physical therapists and occupational therapists, but the same can be true of the therapists. Therapists who listen closely to parents/caregivers and apply what they learn often broaden their repertoire as a teacher, facilitator, and coach, and improve their effectiveness as a therapist.

Declarations of interest: The author reports no conflict of interest. The author alone is responsible for the content and writing of this article.

ABOUT THE AUTHORS

Lou Ann Goldstein, PT, MS, PCS is board certified in pediatric physical therapy and owner of Lou Ann Goldstein, PT, LLC, Chicago, IL, USA.

REFERENCES

- Als, H., Gilkerson, L., Duffy, F., McAnulty, G., Buehler, D., Vandenberg, K., *et al.* (2003). A three center randomized controlled trial of individualized developmental care for very low birth weight preterm infants: Medical, neurodevelopmental, parenting, and care giving effects. *Journal of Developmental and Behavioral Pediatrics*, *24*, 399–408.
- American Academy of Pediatrics/American College of Obstetricians and Gynecologists. (2002). *Guidelines for perinatal care* (5th ed.). Elk Grove Village and Washington, DC: AAP & ACOG.
- Anthony, M., & Hudson-Barr, D. (2004). A patient-centered model of care for hospital discharge. *Clinical Nursing Research*, *13*, 117–136.
- Bailey, R., & Caldwell, C. (1997). Preparing parents for going home. *Pediatric Nursing*, *9*, 15–17.
- Barrera, M., Rosenbaum, P., & Cunningham, C. (1986). Early home intervention with low-birth weight infants and their parents. *Child Development*, *57*, 20–33.
- Bartlett, D., & Kneale-Fanning, J. (2003). Relationships of equipment use and play positions to motor development at eight months corrected age of infants born preterm. *Pediatric Physical Therapy*, *15*, 8–15.
- Bissell, G., & Long, T. (2003). From the neonatal unit to the home: How do parents adapt to life at home with their baby? *Journal of Neonatal Nursing*, *9*, 7–12.

- Blauw-Hospers, C. H., & Hadders-Algra, A. (2005). A systematic review of the effects of early intervention on motor development. *Developmental Medicine and Child Neurology*, *47*, 421–432.
- Brazelton, T. B. (1973). *Neonatal behavioral assessment scale*. London: Spastics International.
- Brazelton, T. B., & Nugent, J. K. (1995). *The neonatal behavioral assessment scale*. London: Mac Keith Press.
- Broedsgaard, A., & Wagner, L. (2005). How to facilitate parents and their premature infant for the transition home. *International Nursing Review*, *52*, 196–203.
- Bruns, D., & Klein, S. (2005). An evaluation of family-centered care in a Level III NICU. *Infants and Young Children*, *18*, 222–233.
- Byrne, E. M., & Campbell, S. K. (2013). Physical therapy observation and assessment in the neonatal intensive care unit. *Physical and Occupational Therapy in Pediatrics*, *3*, 39–74.
- Byrne, E. M., & Garber, J. B. (2013). Physical therapy intervention in the NICU. *Physical and Occupational Therapy in Pediatrics*, *3*, 75–110.
- Campbell, S. K. (2012). The child's development of functional movement. In S. K. Campbell, R. J. Palisano, & M. N. Orlin (Eds.), *Physical therapy for children*, (4th ed.). Philadelphia, PA: Elsevier.
- Campbell, S. K., Kolobe, T. H. A., Osten, E. T., Lenke, M., & Girolami, G. L. (1995). Construct validity of the test of infant motor performance. *Physical Therapy*, *75*, 585–596.
- Campbell, S. K., Levy, P., Zawacki, L., & Liao, P.-J. (2006). Population-based age standards for interpreting results on the test of infant motor performance. *Pediatric Physical Therapy*, *18*, 119–125.
- Cleveland, L. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, *37*, 666–691.
- Collins, J. W., David, R., Symons, R., Handler, A., Wall, S., & Andes, S. (1998). African-American mothers' perception of their residential environment, stressful life events, and very low birthweight. *Epidemiology*, *9*, 286–289.
- Costello, A., & Chapman, J. (1998). Mothers' perceptions of the care-by-parent program prior to hospital discharge of their preterm infants. *Neonatal Network*, *17*, 37–42.
- Coyl, D., Roggman, L., & Newland, L. (2002). Stress, maternal depression, and negative mother-infant interactions in relation to infant attachment. *Infant Mental Health Journal*, *23*, 145–163.
- Davis, B. E., Moon, R. Y., Sachs, H. C., & Ottolini, M. D. (1998). Effects of sleep position on infant motor development. *Pediatrics*, *102*, 1135–1140.
- Davis, L., Edwards, J., & Mohay, H. (2003). Mother-infant interaction in premature infants at 3 months after nursery discharge. *International Journal of Nursing Practice*, *9*, 374–381.
- DeGroote, I., Vanhaesebrouck, P., Bruneel, E., Dom, L., Durein, I., Hasaerts, D., et al. (2007). Outcome at 3 years of age in a population-based cohort of extremely premature infants. *Obstetrics and Gynecology*, *110*, 855–864.
- Diamond, K. (1993). The role of parents' observations and concerns in screening for development for developmental delays in young children. *Topic in Childhood Special Education*, *13*, 68–81.
- Donovan, W., Leavitt, L., Taylor, N., & Broder, J. (2007). Maternal sensory sensitivity, mother-infant 9-month interaction, infant attachment status: Predictors of mother-toddler interaction at 24 months. *Infant Behavior & Development*, *30*, 336–352.
- Dudek-Shriber, L. (2004). Parent stress in the NICU and the influence of the parent and infant characteristics. *American Journal of Occupational Therapy*, *58*, 509–520.
- Dudek-Shriber, L., & Zelazny, S. (2007). The effects of prone positioning on the quality and acquisition of developmental milestones in four month old infants. *Pediatric Physical Therapy*, *19*, 48–55.
- Dusing, S., Murray, T., & Stern, M. (2008). Parent preferences for motor developmental education in the neonatal intensive care unit. *Pediatric Physical Therapy*, *20*, 363–368.
- Dusing, S., Van Drew, C., & Brown, S. (2012). Instituting parent education practices in the NICU: An administrative case report of practice evaluation and statewide action. *Physical Therapy Journal*, *92*, 967–975.

- Eckerman, C., & Oehler, J. (1992). Very low birth weight newborns and parents as early social partners. In S. L. Freidman & M. D. Sigman (Eds.), *The psychological development of low birth weight infants* (pp. 91–124). Norwood, NJ: Ablex.
- Fegran, L., Helseth, S., & Solveig-Fagermoen, M. (2008). A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit. *Journal of Clinical Nursing, 17*, 810–816.
- Feiring, C., Fox, N., Jaskir, J., & Lewis, M. (1987). The relation between social support, infant risk status and mother-infant interaction. *Developmental Psychology, 23*, 400–405.
- Feldman, R., Eidelman, A., Sirota, L., & Weller, A. (2002). Comparison of skin-to-skin (kangaroo) and traditional care: Parenting outcomes and preterm infant development. *Pediatrics, 110*, 16–26.
- Garber, J. B. (2013). Oral motor function and feeding intervention. *Physical and Occupational Therapy in Pediatrics, 3*, 111–138.
- Gennaro, S., Medoff-Cooper, B., & Lotas, M. (1992). Perinatal factors and infant temperament: A collaborative approach. *Nursing Research, 41*, 375–377.
- Gerner, E. (1999). Emotional interaction in a group of preterm infants at 3 and 6 months of corrected age. *Infant and Child Development, 8*, 117–128.
- Goldstein, L., & Campbell, S. K. (2008). Effectiveness of the test of infant motor performance as an educational tool for mothers. *Pediatric Physical Therapy, 20*, 152–159.
- Harrison, M. (1990). A comparison of parental interactions with term and preterm infants. *Research in Nursing and Health, 13*, 173–179.
- Jackson, K. (2003). From alienation to familiarity: Experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing, 43*, 120–129.
- Jennings, J. T., Sarbaugh, B. G., & Payne, N. S. (2005). Conveying the message optimal infant positions. *Physical and Occupational Therapy in Pediatrics, 25*, 3–18.
- Kripalani, S., Paasche-Orlow, M. K., Parker, R. M., & Saha, S. (2006). Advancing the field of health literacy. *Journal of General Internal Medicine, 21*, 804–805.
- Lawhon, G. (2002). Facilitation of parenting the premature infant within the newborn intensive care unit. *Journal of Perinatal Neonatal Nursing, 16*, 71–82.
- Lawler, P. (1991). *Keys to adult learning: Theory and practical strategies*. Philadelphia, PA: Research for Better Schools.
- Lekskulchai, R., & Cole, J. (2001). Effect of a developmental program on motor performance in infants born preterm. *Australian Journal of Physiotherapy, 47*, 169–176.
- Loo, K., Espinosa, M., Tyler, R., & Howard, J. (2003). Using knowledge to cope with stress in the NICU: How parents integrate learning to read the physiologic and behavioral cues of the infant. *Neonatal Network, 22*, 31–37.
- Maternal and Child Health Bureau. (2005). Definition and principles of family-centered care. Rockville, MD: Department of Health and Human Services. www.familyvoices.org/admin/work_family_centered/files/FCCare.rtf. Last Accessed: September 2012.
- Melnyk, B. (2000). Intervention studies involving parents of hospitalized young children: An analysis of the past and future recommendations. *Journal of Pediatric Nursing, 15*, 4–13.
- Melnyk, B., Alpert-Gillis, L., Fischbeck-Feinstein, N., Fairbanks, E., Schultz-Czarniak, J., Hust, D., et al. (2001). Improving cognitive development of low birth weight premature Infants with the COPE program: A pilot study of the benefit of early NICU intervention with mothers. *Research in Nursing & Health, 24*, 373–389.
- Melnyk, B. M., Feinstein, N. F., Alpert-Gillis, L., Fairbanks, E., Crean, H., Sinkin, R. A., et al. (2006). Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: A randomized, controlled trial. *Pediatrics, 118*, e1414–e1427.
- Melnyk, B. M., Feinstein, N. F., & Fairbanks, E. (2002). Effectiveness of information/behavioral interventions with parents of low birth weight premature infants: An evidence base to guide clinical practice. *Pediatric Nursing, 28*, 511–516.
- Menghini, K. (2005). Designing and evaluating parent educational materials. *Advances in Neonatal Care, 5*, 273–283.

- Micelli, P. J., Goeke-Morey, M. C., Whitman, T. L., Kolberg, K. S., Miller-Loncar, C., & White, R. D. (2000). Brief report: Birth status, medical complications, and social environment: Individual differences in development of preterm, very low birth weight infants. *Journal of Pediatric Psychology, 25*, 353–358.
- Miles, M., & Holditch-Davis, D. (1995). Compensatory parenting: How mothers describe parenting their 3-year-old, prematurely born children. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 10*, 243–253.
- Nargoski-Johnson, A. (2008). Engaging fathers in the NICU: Taking down the barriers to the baby. *Journal of Perinatal and Neonatal Nursing, 22*, 302–306.
- Nugent, J. K., Keefer, C. H., Minear, S., Johnson, L. C., & Blanchard, Y. (2007). *Understanding newborn behavior & early relationships: The newborn behavioral observations (NBO) systems handbook*. Baltimore, MD: Paul H. Brooks Publishing Co.
- Parker, S. J., Zahr, L., Cole, J. G., & Brecht, M. (1992). Outcomes after developmental intervention in the neonatal intensive care unit for mothers of preterm infants with low socioeconomic status. *Journal of Pediatrics, 120*, 780–785.
- Pohlman, S. (2005). The primacy of work and fathering preterm infants: Findings from an interpretive phenomenological study. *Advances in Neonatal Care, 5*, 204–216.
- Pridham, K., Lin, C., & Brown, R. (2001). Mothers' evaluation of their caregiving for premature and full term infants through the first year: Contributing factors. *Research in Nursing and Health, 24*, 157–169.
- Rastall, M., Brook, B., Klarenta, M., Moylan, N., McCloud, W., & Tracey, S. (1999). An investigation into younger and older adults' memory for physiotherapy exercises. *Physiotherapy, 85*, 122–128.
- Resnick, M., Armstrong, S., & Carter, R. (1988). Developmental intervention program for high risk premature infants: Effects on development and parent-infant interactions. *Journal of Developmental and Behavioral Pediatrics, 9*, 73–78.
- Sajaniemi, N., Makela, J., Salokorpi, T., von Wendt, L., Hamalainen, T., & Hakamies-Blomqvist, L. (2001). Cognitive performance and attachment patterns at four years of age in extremely low birth weight infants after early intervention. *Journal of Perinatal and Neonatal Nursing, 10*, 122–129.
- Shaw, R., Deblois, T., Ikuta, L., Ginzberg, K., Fleisher, B., & Koopman, D. (2006). Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics, 47*, 206–212.
- Shelton, T. L., & Stepanek, J. S. (1994). *Family-centered care for children needing specialized health and developmental services* (3rd ed.). Bethesda, MD: Association for the Care of Children's Health.
- Shields-Poe, D., & Pinelli, J. (1997). Variables associated with parental stress in neonatal intensive care units. *Neonatal Network, 16*, 29–37.
- Siegel, A., & Burton, R. (1999). Effects of baby walkers on motor and mental development in human infants. *Journal of Development and Behavior in Pediatrics, 20*, 355–361.
- Suderman, E. M., Deatrick, J. V., Johnson, L. S., & Sawatzky-Dickson, D. M. (2000). Action research sets the stage to improve discharge preparation. *Pediatric Nursing, 26*, 571–576.
- Sudore, R. L., Landefeld, C. S., Williams, B. A., Barnes, D. E., Lindquist, K., & Schillinger, M. D. (2006). Use of a modified informed consent process among vulnerable patients: A descriptive study. *Journal of General Internal Medicine, 21*, 867–873.
- Sweeney, J., Heriza, C., & Blanchard, Y. (2009). Neonatal physical therapy. Part I: Clinical competencies and neonatal training models. *Pediatric Physical Therapy, 21*, 296–307.
- Sweeney, J., Heriza, C., Blanchard, Y., & Dusing, S. (2010). Neonatal physical therapy. Part II: Practice frameworks and evidence-based practice guidelines. *Pediatric Physical Therapy, 22*, 2–16.
- American Physical Therapy Association. (2001). The guide to physical therapist practice. 2nd Ed. *Physical Therapy, 81*, 9–744.
- Unanue, R. (2002). *The effect of parent education on the motor performance of premature infants and parent care giving abilities*. PhD dissertation. Hahnemann University, Philadelphia, PA.

- United States Census Bureau. (2009). *Selected Social Characteristics in the United States: 2009*. Suitland, MD: United States Census Bureau.
- United States Census Bureau. (2010). *Poverty Status in the last 12 months: 2010*. Suitland, MD: United States Census Bureau.
- Vergara, E., Anzalone, M., Bigsby, R., Gorga, D., Holloway, E., Hunter, J., et al. (2006). Specialized knowledge and skills for occupational therapy practice in the neonatal intensive care unit. *American Journal of Occupational Therapy, 60*, 659–668.
- Vohr, B., Wright, L., Dusick, A., Mele, L., Verter, J., Steichen, J., et al. (2000). Neurodevelopmental and functional outcomes of extremely low birth weight infants in the National Institute of Child Health and Human Development Neonatal Research Network, 1993–1994. *Pediatrics, 105*; 1216–1226.
- Weiss, M., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008). Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing, 23*, 282–295.
- White-Traut, R., & Nelson, M. (1988). Maternally administered tactile, auditory, visual, and vestibular stimulation: Relationship to later interactions between mothers and premature infants. *Research in Nursing & Health, 11*, 31–39.
- Widmayer, S. M., & Field, T. M. (1981). Effects of Brazelton demonstrations for the mothers on the development of preterm infants. *Pediatrics, 67*, 711–714.
- Winslow, E. H. (2001). Parent education materials: Can patients read them or are they ending up in the trash. *American Journal of Nursing, 101*, 33–38.