
Parent and Occupational Therapist Collaboration in the Neonatal Intensive Care Unit

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Medical care of infants in the neonatal intensive care unit (NICU) is so complex that professionals have been almost exclusively responsible for providing care to the infants and information to their families. Although federal law now mandates early intervention programs and service providers to include families in decision making and treatment implementation for their children, family-centered care has generally not been implemented in the NICU. This article offers suggestions for occupational therapists from members of the Parent Connection, an NICU parent support group. They state that a therapist can have the greatest effect on an infant's development by helping the parents develop skills to nurture their infant the way that they choose.

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Medical care of preterm and critically ill newborn infants has become more and more complex. This complexity, along with the very nature of the hospital environment, creates situations in which professionals may undermine the family's relationship with its newest member (Shelton, Jeppson, & Johnson, 1987). Decision making and intervention have traditionally been within the realm of the health care professionals working in the critical care setting of the neonatal intensive care unit (NICU). These professionals have been almost exclusively responsible for providing care and controlling the flow of information to families (Rushton, 1990). Historically, medical and developmental services in the NICU have been child-centered (Brown, Pearl, & Carrasco, 1991).

In the past, early intervention also has been child-centered. However, since the mid to late 1980s there has been a philosophic shift from child-centered to family-centered provision of services. This change in philosophy now has been codified by Part H of the Individuals with Disabilities Education Act (Public Law 102-119). This federal law mandates early intervention programs and service providers to include families, to the extent that they desire, in collaborative decision making, goal setting, and treatment implementation for their children.

Essentially, family-centered care is a philosophy of care that recognizes and respects the important role that families play in the lives of children with special health and development needs. It involves parents and professionals in equal partnership collaborating to identify the family's concerns, priorities, and resources and to then match family-identified strengths and needs with supportive intervention strategies. A major goal of family-centered care is to support families in their natural caregiving roles (Association for the Care of Children's Health [ACCH], 1990; Brown et al., 1991; Shelton et al., 1987). Family-centered approaches generally have not been incorporated into neonatal intensive care services; many parents are still asked to leave their infant's bedside during medical rounds, for example (Thurman, 1991).

Occupational therapists traditionally have worked with the parents of the children whom they serve. Occupational therapy publications since the mid-1980s have documented the profession's shift in emphasis from working with parent-as-therapist (i.e., teaching the parent to carry out therapy programs) to establishing partnerships with parents in which all members together determine their roles and priorities for the child (Anderson & Hinojosa, 1984; Bazyk, 1989; Dunn, 1989; Hanft, 1988). However, the literature specifically addressing occupational therapy services in the NICU has not shown this change (Anderson, 1986; Case-Smith, Cooper, & Scala, 1989; Holloway, 1990; Vergara, 1992). It is now time for a shift in emphasis to the relationship between parent and therapist in the NICU.

The following suggestions derived from the litera-

ture regarding parent-professional collaboration may serve as useful guidelines to the occupational therapist who is beginning to reevaluate his or her practice with parents of infants in the NICU. Knowledge concerning parental stress and coping and parent-professional relations during the NICU experience are reported to be based primarily on the professionals' anecdotal and clinical observations; there may be other aspects of the collaborative process specific to the NICU that have not been addressed. Most importantly, there are few reports of the parents' perspective on collaboration with professionals during their child's NICU hospitalization (Hughes & McCollum, 1993). Because mutual communication is inherent in collaboration, future investigation into this area is essential.

Four members of the Parent Connection, an NICU parent-to-parent support group, were asked to share their perspectives on collaboration by writing down their thoughts for an occupational therapy audience. All of these parents had extremely preterm infants who had been hospitalized in an NICU and who had received occupational therapy intervention. Although they do represent a range of ethnic and socioeconomic backgrounds, their comments are not to be interpreted as qualitative research nor as representative of all parents of preterm infants. Rather, their comments exemplify the suggested guidelines and demonstrate to the practicing neonatal occupational therapist that the place to begin engaging in collaboration with parents is with the individual parents encountered in each NICU.

Guidelines for Parent-Therapist Collaboration

Create opportunities for a two-way dialogue between parent and therapist. Ask for the parent's perception of his or her infant (Cardone & Gilkerson, 1989; Kalmanson & Seligman, 1992). Parent Connection comments demonstrate this.

I wanted him viewed as a baby rather than a set of symptoms, medical diagnoses or statistical correlations.

Please ask parents how *they* feel their baby is progressing. Find out what *their* concerns are. Give them feedback in simple, clear language and offer to explain any terminology you may use.

Collaboration and discussion of ideas can take place between the parent and occupational therapist. You (the therapist) are now actually making the parents part of the team, something they of course in theory have always been, but truly haven't felt.

Respond to the parent's concerns in addition to the occupational therapy concerns. Keep in mind that parent concerns may change and that each parent may have a different area of focus (McGrath & Meyer, 1992). Three parents recalled three different areas of concern.

Since our baby was so small, we were very concerned that her head would be flat on one side from laying down all the time. The occupational therapist got us a gel pillow for her head. When I worked with the staff [members], it helped my baby.

Even though we were concerned about our child in the NICU, we had to consider our whole family's needs. It was difficult for our son to believe that he had a new sister. The staff [members] helped when they put her near a window or sent little notes from her to him. I really appreciated the staff [members] who considered him.

We were most interested in breastfeeding our baby. Often, attention was focused on the mechanical and medical aspects . . . measuring the precise quantity of breast milk consumed . . . [we wanted] attention paid to the quality of the nurturing experience embodied in the nursing relationship.

Select methods of sharing information that value and respect the parent as a person. Acknowledge that the parent has the infant's best interests at heart (ACCH, 1990; Krefting, 1991). An experienced support parent wrote that

being nonjudgmental of the parents in the NICU is probably the hardest concept for many staff members. You (staff members) have to have confidence that the parents care about their baby, even though their approach may differ from your own. This is especially true for parents with other challenges such as teen moms, parents who are substance abusers, and homeless families.

Value individual differences not only in infants' development and temperament but in parents' views of their role and involvement (Kalmanson & Seligman, 1992; Rushton, 1990). Parents may want to be very active or seemingly passive:

As parents, our role in the nursery as well in the outside world should include nurturing, advocacy, participation whenever possible, and planning for the infant's future. We need to be recognized as the ultimate caregivers and that as our child gets stronger we may want to take on more of his care. However, we also need the staff [members] to recognize that we have other responsibilities outside of the hospital and may not always be available in the way that we or the staff [members] may want.

Help parents find resources. Videotapes, books or classes provide information and power. It is knowledge that helps parents to make difficult decisions for their infant in the NICU.

I just wanted to sit and look at my baby.

Observe and follow the infant's behavior together. Discuss both the parent's and your interpretations, then engage in mutual problem solving (Kalmanson & Seligman, 1992). These parents discussed feeding and developmental issues as they reflected on their parenting roles:

The feeding of the high-risk infant is an especially nerve-wracking time for parents. The push is on for weight gain, every ounce is precious and the focus on the weight chart becomes everyone's obsession. Can you imagine feeding an infant comfortably in such an environment? It is very difficult, and breastfeeding is even more of a challenge. The [occupational therapist] has invaluable skills and ideas to share with the parents around feeding issues. These ideas need to be presented and discussed with the parents in such a way that the agreed-upon approach has been achieved with parents sharing their insight as well. The parents then feel that the feeding plan is doable, that their role as baby's parent was respected and that the information they have to share about how baby feeds has been given some validity.

The occupational therapist can work with the baby in the most unthreatening way. By this I mean that the [occupational thera-

pist] is guiding and working closely with the parents in those areas of most importance to them: be it developing ways to help the baby be more calm, feeding the baby, or helping them to feel comfortable holding their baby. No matter how involved the baby's care may be, when the [occupational therapist] is able to work with the baby, she or he can begin a cooperative relationship with the parents, and so begin to help parents maximize their parenting role in the NICU.

Acknowledge parent skills and successes (Cardone & Gilkerson, 1989; DeGangi, Royeen, & Wietlisbach, 1992). Parent Connection comments reflect this point.

When you (the parent) can begin to see your baby as a unique person with unique abilities that you can help develop, you can begin to be a parent.

Remind parents of the special things that only they can give their babies, such as their breast milk, their special touch, the sound of their voice.

Watch for and respond to parent reactions to occupational therapy interventions. Watch for parent reactions in addition to monitoring infant physiologic and behavioral responses (Kalmanson & Seligman, 1992). Parents may tell the therapist how they are feeling in a variety of ways.

Having a baby in the hospital for 10 or 15 weeks is the hardest experience our family has ever had. Getting involved with our baby's care from the very beginning helped me believe I was really a mother, gave me a chance to begin to know my wonderful baby, and made me start to take responsibility for a precious little person.

Parenting in the fishbowl of the NICU is very difficult.

It was a long time before I felt ready to touch my babies without supervision. I watched others. I slowly started to get to know my children. I knew that our son liked to have the side of his face stroked and that his sister liked to be stroked on the top of her little head.

Be sensitive to possible bidden messages in parent-professional communications. Carefully monitor formal and casual conversations as well as actions (McGrath & Meyer, 1992). NICU procedures to safeguard infants may send unintended messages to parents.

One of the frustrating, but necessary parts of hospitals is all the rules. The difficult part for us was the staff [members]'s varying interpretation of the rules. I had been told that I could hold my baby any time I wanted once she had reached a specific weight and could maintain her own body heat. However, at times I felt that I had to fight to hold her. One of the nurses was concerned that I would hold her so much that I would hurt her. I had always shown that I loved my baby enough to respect *her* needs, not mine, and by that time I knew her signals better than anyone, so it was hard for me not to hold her.

A focus on his individuality and normalcy helped us to transition to the warm and natural parent-infant relations that are often precluded by the atmosphere of the NICU.

Facilitate the parent's expertise. Encourage the parent to be the person to communicate therapeutic strategies to other family and staff members (Fenichel & Eggbeer, 1991). Parent comments support the importance of this.

It wasn't very long before my husband and I knew our children better than anyone else. Still, I felt that some staff [members] disregarded my parental knowledge. Of all the people who cared for my children, my husband and I were the only ones who saw them every day. And we sometimes saw things that might have been overlooked otherwise.

The occupational therapist gave me exercises to do with my baby when she wasn't there. She taught me to read his cues. She respected me and assumed that I was a loving, responsible parent who wanted the best for her child. She believed I was capable of following directions and exercising my baby correctly. When I did his exercises I felt I was making a real difference in his development.

Seeing others following through on our suggestions . . . bolstered our confidence in our parenting skills, knowledge of our baby and ability to develop a closeness with him.

Support the importance of parent-infant nurturing activities as activities of daily living and facilitate the NICU environment so that parents feel welcomed to engage in them (AOTA, 1993). Parents reported that establishing a relationship with their child is of utmost importance to them.

Provide time for moms and dads just to hold and coo with their babies without the demands of teaching well baby care or therapy techniques. They need this "mommy/daddy/baby time." As an [occupational therapist], you can appreciate the importance of this for the entire family and can share the value of this special time between baby and parent with other staff members who may be tempted to use it as a time to "teach" dad something or to evaluate mom's caregiving skills.

In a world of medical staff [members], terminology and technology, the occupational therapist is sometimes the only one who can promote the normalcy of the baby to the parent. No matter how sick or involved the baby may be, the [occupational therapist] can find something positive or special about that baby . . . and support each parent's personal style, teaching along the way . . . with a gentle touch . . . not how to be a parent, but how to parent in the NICU.

Conclusion

Neonatal intensive care is a field that continues to change rapidly. It serves a heterogeneous population of infants and families. NICU services often appear inherently child-centered due to the nature of the infant's medical problems (Krehbiel, Munsick-Bruno, & Lowe, 1991). The manner in which medical and nursing care is given often sets up barriers to providing family-centered care. Examples of barriers are

- A lack of clear-cut parental role within the NICU. This at times places parents in an enforced role of passivity.
- Mixed messages sent from staff members to parents regarding parent competencies (e.g., a parent is encouraged to feed her baby, is unable to get the infant to take the entire amount of formula, and then watches as the occupational therapist is successful).
- The NICU culture may expect a certain type of

parental behavior. Because there is a whole range of help-seeking behaviors, distinct ways in which parents go about finding help or support at particular times during their child's illness, parents may not always fit into their NICU's particular "cultural rulebook." (Krefting, 1991, p. 15)

Valuing parent-professional collaboration and incorporating it into neonatal intensive care services can assist professionals in meeting both infant and parent needs by removing some of these barriers (Krehbiel et al., 1991). Although an individual occupational therapist may not be able to influence hospital policies regarding provision of medical care, she or he can make establishing collaborative relationships with parents a primary focus of occupational therapy practice.

The comments of the Parent Connection volunteers as well as the literature document the importance of establishing parent-staff member partnerships. In addition, these parent statements reflect the contribution that occupational therapy can make to mediating the effects of the NICU high-tech medical model on the parent-infant relationship. Parents ask that the therapist view their child as just that, a baby, a person with strengths and potentialities as well as vulnerabilities. They suggest that by working as a partner with the parents, to assist them in developing confidence and skills for nurturing their infant in the way that they choose, an occupational therapist can have the greatest, most important effect on the child's development. ▲

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