Relationships Between Preterm Infants and Their Parents:

Disruption and Development

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Brynne was born unexpectedly at 24 weeks' gestation. Weighing 1 pound, 7 ounces and measuring only 11 inches long, she was born before the baby shower, before parental leave was scheduled, and before she was ready. Brynne spent more than 9 weeks on a ventilator, received blood transfusions and medications, was treated with steroids for chronic lung disease, and ate through a tube in her nose. Long before they could hold her, Brynne's parents cultivated an intimate relationship with her. They sat by her incubator for hours each day, touching her, talking softly to her, and offering her their familiar sounds, smells, and touch. They got to know her nurses, doctors, and therapists and communicated with them regularly. After 4 months, Brynne was discharged from the neonatal intensive care unit (NICU)—at approximately the time she would have been born if her mother's pregnancy had gone to term. She was home for the first time after having spent one third of her first year of life in the hospital.

Alfonso's family came to take care of him every afternoon during the 6 months he spent in the NICU. His mother had to wait for her husband to come home from work before she could go to the hospital because the family had only one car. Alfonso's siblings, both under 4 years of age, came with their parents and wanted to play with their very sick brother. It was hard for them to understand why they couldn't touch or hold him and why they had to come to the hospital instead of taking Alfonso home. Although NICU staff members wanted the parents to be with Alfonso, some were concerned about the presence at his bedside of two boisterous preschoolers. However, the family did not have alternative child care nor did they want to be apart from their children. Because Alfonso's father spoke only Spanish, he often had to rely on his wife to communicate with hospital staff.

After more than 6 months in the NICU, Alfonso died suddenly of respiratory complications. When he died, Alfonso's primary nurse alerted other members of his primary care team. A social worker who had worked closely with Alfonso's family came to the NICU on the weekend to be with the family as they said good-bye to their baby. She comforted the family, helped them make footprints and handprints as keepsakes, and facilitated funeral arrangements. The social worker and a psychologist organized a bereavement session so that Alfonso's primary team and other professionals could communicate their grief, reflect on his life, and ask questions about the cause of his death. Professionals also learned about culturally appropriate ways to support the family during their time of grief.

Photo: Barbara Young

When a baby is born prematurely, serious, ongoing medical and physical complications may require hospitalization in the NICU for days and sometimes months. Regardless of the reason for the early birth or the hospital course, disruption of the typical relationship between parents and their newborn may adversely affect the emerging parent–child relationship. As a consequence, the baby's mental health and overall development may be affected. Additionally, effects on the NICU professionals and the system of care are affected, regardless of the infant's outcome. Fortunately, infant–family professionals have learned how to enhance the well-being of babies, their caregivers, and medical staff in the NICU. Psychoeducational interventions with families, mental health services in the NICU, staff training, and developmentally supportive and family-centered practices all serve to strengthen the parent–infant relationship. So do appropriate discharge planning and ongoing monitoring and assessment of preterm babies and the developing patterns of interaction between babies and their parents. Attention to relationships can support the emotional well-being of family members and NICU staff even if the baby does not survive.

This article will describe supportive parent–infant relationships and identify factors during pregnancy, delivery, and hospitalization that may disrupt the emerging parent–infant relationship. This article also will review what we know about how relationship disruptions affect interactions between preterm infants and their parents. Finally, the article will recommend strategies to promote mental health in the context of the NICU.

Parent–Infant Relationships

Supportive, nurturing relationships between babies and their parents provide the foundation for the development of self-confidence, security, emotional stability, readiness to learn, and social competence. Well-timed interactions with

at a glance

- Characteristics of parents, infant factors, and factors in the hospital and NICU environments—in addition to the circumstances surrounding preterm birth—may disrupt parent–infant relationships.
- Parents make extraordinary efforts to maintain relationships with their hospitalized premature babies; fathers of preemies may be more involved in their care than fathers of full-term babies.
- The task-oriented NICU environment sometimes overlooks relationship development.
- Infant–family professionals can promote the mental health of preterm babies and their families through psychoeducational interventions with families, mental health services in the NICU, and training and support for NICU staff.

familiar caregivers help regulate babies' physiological responses (e.g., heart rate, breathing rate, body temperature), social and emotional responses (e.g., reactions to distress), and nutritional needs (Hofer, 1994). Parent–infant relationships also provide the foundation for the emergence of self-regulation capacities (Sameroff & Fiese, 2000).

Effective interactions make demands on both babies and their parents. Infants and parents need to be able to provide a range of clear cues, respond to each other, and experience environmental support for the interaction (Goldberg, 1977; Kelly & Barnard, 2000). This means that babies must show a repertoire of behaviors (e.g., seeing, hearing, responding to handling, smiling) to provide the parent or other caregiver with feedback during interactions and to initiate interactions when necessary.

Caregivers promote optimal relationship development and infant mental health by being available—physically, psychologically, and emotionally—to their babies. Caregivers also foster mental health when they are aware of and sensitive to infants' patterns, cues, behaviors, states, emotions, and communication efforts, as well as to the effect of the environment on the infant (Browne, MacLeod, & Smith-Sharp, 1996). Based on their awareness, caregivers respond appropriately and structure the environment to match their infants' needs. In doing so, they facilitate relationships, development, and mental health. Finally, depending on feedback from their infants, caregivers flexibly adapt their behaviors to optimize their infants' responses, engaging in coregulation that leads to optimal mental health and self-regulation skills.

Relationship Disruptions

Disruptions to the relationship between preterm infants and their parents can emerge during pregnancy, delivery, and hospitalization:

- *Prenatal and postnatal* factors include events such as diagnosis of a congenital anomaly during pregnancy, medical complications, preterm delivery, and long-term hospitalization.
- *Parental* factors, such as maternal depression, grief, traumatic experiences, family violence, and language barriers, may disrupt the parent–infant relationship.
- *Infant* factors that may disrupt relationships include exhibiting disorganized behaviors and behaviors that are hard to read, having difficulty calming and quieting, and being sleepy or unable to socially engage.
- Factors in the *hospital and NICU environments* that may affect the parent–infant relationship include hospital policies, relationships with professional caregivers, and access to resources (e.g., money, transportation, privacy, comfortable chairs).

Prenatal and Postnatal Factors

A preterm birth violates parental expectations about pregnancy, childbirth, parenting, and development (Macey, Harmon, & Easterbrooks, 1987). Because pregnancy ends early and sometimes abruptly, parents of preterm infants experience disruptions in the normative biological, physical, and psychological changes associated with pregnancy. They also miss out on traditional rituals, such as baby showers, naming ceremonies, and the baby's first bath, that mark the transition to parenthood.

Fertility history and previous birth experiences influence parents' expectations of childbirth and parenting. A preterm birth may have a different meaning for parents who have struggled for years to conceive a child than it does for parents with a history of perinatal loss. Parents who have had fertility problems may feel great joy at the birth, along with concern for the baby's well-being and the NICU environment. Parents with a history of perinatal loss, on the other hand, may experience tremendous fear and anxiety about this baby's survival, coupled with rekindled grief.

The circumstances surrounding a preterm birth are likely to disrupt the relationship that parents developed during pregnancy with their imagined baby, and may derail their relationship with the newborn. Babies born prematurely through emergency deliveries enter the world under drastically different circumstances than infants who are born when they are due. Preemies may, for example, experience resuscitation and transfer to a NICU before they are ever held by their parents.

Parental Factors

Despite professionals' efforts to provide family-centered care and developmentally supportive practices that promote parental involvement with their preterm babies (Davis, Mohay, & Edwards, 2003), parents of preemies often experience guilt, anxiety, and depression (Gennaro, 1988; Maloni, Kane, Suen, & Wang, 2002); elevated symptoms of post-traumatic stress disorder (DeMier et al., 2000); and anger, helplessness, hopelessness, terror, and ambivalence about the baby's survival (Easterbrooks, 1988; Hynan, 2001; Tracey, 2000). Although research suggests that mothers' anxiety and depression decrease during the months after their babies are discharged from the NICU (Brooten et al., 1988), mothers of high-risk, very low birth weight children report high levels of emotional distress even 2 years after the child's birth (Singer et al., 1999).

Fathers of preterm babies may be more involved in their infants' care than are fathers of full-term babies. They may be the first to see and touch them, particularly if mothers are still recovering from the delivery. Fathers also may serve as a link between recovering mothers and hospitalized infants. However, the relationship between fathers' participation in infant care and preterm birth is complex; research suggests that father participation is highest in cases of moderately challenging circumstances but lower under typical or extreme circumstances (Parke & Anderson, 1987).

Supportive relationships within and beyond the family bolster parents' well-being during the crisis of a preterm birth, facilitate parent–infant interactions, and promote

infant development (Miceli et al., 2000). Unfortunately, potentially supportive people may be uncertain about how to provide support to parents or how to react to the birth of a preterm infant. One parent-support listserve uses the acronym DHAC ("doesn't have a clue") to refer to people who want to help but have limited insight into what it means to care for a preemie.

Contextual Factors

Many contextual factors affect the relationship between parents and their preterm baby. These include: (a) the financial burden on parents; (b) the ease or difficulty of travel to the NICU; (c) the needs of siblings; (d) the quality of the marital relationship; and (e) family history. Typically, a number of these contextual factors interact, creating an even more complex picture of family functioning.

Cultural differences, including language barriers, affect the interaction between parents and their preterm babies (McCollum & McBride, 1997). Feelings of isolation and loneliness may be intensified for families who do not speak English and cannot readily communicate with NICU professionals. Lack of communication, in turn, may lead to fewer opportunities for parents to interact with and care for their preterm infants in the NICU. Cultural differences also may emerge around issues of authority figures (e.g., medical professionals), family roles (e.g., cultures in which women must be accompanied by men when traveling), parenting responsibilities (e.g., what parents do with their infants), and communication styles (e.g., demonstrations of affect, including anger and frustration).

Infant Factors

The preterm baby's condition powerfully affects what he or she can bring to the parent–infant relationship. Neurological immaturity and medical complications make preterm babies capable of less physiological, motor, and behavioral organization and modulation (Als, 1982) than infants who are born full term. Thus a preterm infant may be fussy and irritable but cannot be soothed by a feeding because it may hurt when he eats. The baby whose underdeveloped lungs require high-frequency ventilation may not be able to be held. The infant who does not have the energy to wake up and look at his parents even for brief periods misses the most basic early relationship-building opportunities.

Pain is a fact of life for babies in the NICU. Preterm infants may experience pain because of their conditions or illnesses. They also are likely to experience pain from medical procedures, ranging from heel-sticks to major surgery. Babies' cries and motor responses signal their immediate reactions to pain. Research also suggests that cumulative or repeated painful experiences can alter brain development and future responsiveness to pain (Anand & Scalzo, 2000). Babies who experience painful procedures repeatedly may not trust adults who have the potential to inflict pain, and thus reduce their availability for social interaction.

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The infant factors discussed above may affect relationships well after the baby's discharge from the NICU. Preterm infants may experience ongoing health, academic, and emotional difficulties that create chronic stress for their families (Blackburn, 1995). Even when difficulties are not "diagnosable," they may present challenges. Sensory overload, difficulties with transitions, and laborious efforts to complete schoolwork emerge repeatedly in parents' descriptions of life with prematurely born children.

Hospital and NICU Factors

The NICU environment often presents significant—and paradoxical—challenges to developing parent–infant relationships.

- Parents need support in order to develop a loving relationship with their baby, but in the NICU, the primacy of medical interventions creates a task-oriented environment that sometimes overlooks relationship development. In a task-oriented environment, for example, professionals clothe babies during routine caregiving. In a relationship-centered environment,

staff tell parents when their baby will be dressed for the first time; parents are present and dress the baby or at least select the outfit and have a picture taken if they are unable to be present.
- To feel like parents, mothers and fathers need to become experts in interacting with their baby, but in the NICU early interactions occur almost exclusively in the presence of professional caregivers. As a result, development of the parent role may be limited by feelings of helplessness, lack of access to their infants, and negative communication with staff (Fenwick, Barclay, & Schmied, 2001).
- Parents of fragile infants need accurate information and clear, open communication with hospital staff. But parents often receive conflicting messages, face inconsistent approaches to treatment, experience the effect of high staff changes, and report misunderstandings and conflict with professionals.

Mothers in the NICU spend most of their time touching, holding, and playing with their babies. Preemies sleep and smile more with their parents than with nurses.

In the face of these challenges, parents make extraordinary efforts to maintain relationships with their hospitalized babies. Already exhausted by the care of a fragile infant, these parents experience the additional burden of parenting in the NICU environment (Fenwick, et al., 2001; Hurst, 2001; Lasby et al., 1994). They must negotiate with health care providers, choose the right time to challenge institutional authority, and build supportive relationships with other parents of preemies as well as within their own networks of family and friends (Hurst, 2001).

Relationship Development for Preterm Infants

All the factors described above affect interactions between preterm infants and their parents. A number of studies of preterm infants report links between sensitive and responsive interactions with mothers and improved cognitive outcomes (Magill-Evans & Harrison, 1999; Moore, Saylor, & Boyce, 1998; Zahr, 2001). But according to Goldberg's (1979) model of preterm parent–infant interaction, preterm infants tend to: (a) provide more diffuse cues, decreasing their "readability"; (b) respond less consistently, decreasing their predictability; and (c) exhibit a more limited repertoire of responsiveness than full-term babies. Goldberg proposes that these factors make it difficult for parents to determine how to respond to their baby, which decreases the infant's experiences of sensitive and appropriate caregiving and ultimately creates a cycle in which parents feel less effective and the infant experiences fewer contingent interactions. Consistent with this model, Poehlmann and Fiese (2001) found that preterm infants with more substantial medical complications (e.g., lower birth weight, longer hospitalization) had more problematic interactions with their mothers at 6 months than did infants with fewer medical complications. In the model tested, problematic interactions between mothers and their infants accounted for infants' lower cognitive scores at 12 months.

Researchers have studied the connections among maternal depression, parent–infant interaction in the NICU, and later development. Lower levels of maternal depression and higher quality interactions are correlated with better mental and psychomotor development when preterm babies are 6 months old (Feldman, Eidelman, Sirota, & Weller, 2002). Preterm infants whose mothers reported lower levels of depression and stress also experienced fewer internalizing and externalizing behavior problems at age 3 (Miceli et al., 2000).

Although prematurity, illness, and immaturity affect the interactions between preterm infants and their parents, most studies do not find global differences in the attachment relationships of preterm and full-term infants in the first 2 years of life (Goldberg & DiVitto, 1995). However, researchers have documented subtle differences in relationship characteristics. In one study, for example, preterm infants explored a new environment less and showed more interest in their mothers than did full-term infants (Macey, Harmon, & Easterbrooks, 1987). Additional studies have found that mothers of preterm infants tend to initiate more interactions than do mothers of full-term infants, and that both mothers and fathers are less physical with preterm infants than with full-term babies (Parke & Anderson, 1987).

Although most research on interactions between preterm babies and their parents explores interactive patterns when babies are 6 months of age or older, studies that have examined the development of parent–infant relationships in the NICU suggest that babies' relationships with their parents differ from relationships with professional caregivers. Miller and Holditch-Davis (1992) observed that preterm infants responded differently to nurses, who engaged in routine caregiving, than to their mothers, who spent most of their time in the NICU touching, holding, and playing with their babies. Infants slept and smiled more with parents. With nurses, infants transitioned from asleep to awake more frequently, and exhibited more jittery behaviors and large body movements.

Promoting Mental Health in the NICU

Disruptions in the relationship between preterm infants and their parents occur for many reasons and may be associated with infant outcomes across a broad range of developmental domains. From 20–50% of infants born preterm meet the criteria for a physical, emotional, or cognitive disability

(Lorenz, Wooliever, Jetton, & Paneth, 1998; Wood, Marlow, Costeloe, Gibson, & Wilkinson, 2000). Family stress places children born prematurely at high risk for maltreatment; the risk of maltreatment among children with disabilities is more than 3 times greater than among typically developing children (Sullivan & Knutson, 2000).

For early interventionists, nurturing and cultivating the parent–infant relationship during the perinatal period is critical. The parent–infant relationship can protect the preterm baby from risk and foster healthy long-term development. Infant–family professionals in the NICU can promote the mental health of preterm babies and their families in a number of ways.

In some hospitals, memorial services celebrate the lives and commemorate the deaths of babies. Families may attend these services for many years.

Using Existing Psychoeducational Interventions

Psychoeducational programs in NICUs vary in duration, content area, and mode of delivery (Achenbach, Howell, Aoki, & Rauh, 1993; Cardone & Gilkerson, 1990; Pridham et al., 1998). They typically aim to: (a) enhance parents' abilities to read their infants' cues and respond appropriately; (b) validate parents as advocates for their babies; and (c) provide forums for communication and emotional support.

Providing Mental Health Services in the NICU

Social workers, psychologists, and psychiatrists, on staff or in consultation with NICU staff, help families: (a) access resources and negotiate conflicts between parents and staff; (b) provide therapy to infants and families; (c) conduct neurobehavioral and developmental examinations; and (d) participate in psychosocial conferences attended by nurses, mental health professionals, physicians, public health coordinators, and allied health professionals (Harmon, 2002). Mental health professionals also design policies and procedures to help NICU staff deal with and monitor the cumulative stress of working in an environment in which babies' lives are in peril. Several identifiable interventions by mental health professionals in a NICU include support for both families and staff.

Connecting Families with Parent-to-Parent Support Groups

Parent support groups range from open forums that enable parents to discuss what they are thinking and feeling to psychoeducational and informational sessions with invited speakers or designated topics. Group leaders may be mental health professionals, other staff, or "graduate" parents. Parent-to-parent networks often pair experienced graduate parents with parents who currently have a preterm infant in the NICU. Family members and professionals can access an online support community through Web sites such as preemie-l (www.preemie-l.org).

Training Staff

Although NICU professionals are well trained and highly skilled, few of their training experiences focus specifically on supporting parent–infant relationships. An educational program under development at the University of Colorado Health Sciences Center is designed to train NICU professionals to appreciate and support the emerging relationship between preterm infants and their parents. The program includes seminars, practice guidelines, self-instructional units, and skills checklists to deepen staff understanding of parent– infant interaction and translate understanding into practice. Materials for parents are designed to help staff and families discuss how to promote the parent–infant relationship while babies are hospitalized (Talmi & Browne, 2003).

Modeling Developmentally Supportive Caregiving

An extensive literature documents the importance of family-centered, individualized, developmentally supportive care practices for enhancing the outcomes of preterm infants (Als et al., 1994; Fleisher et al., 1995; Westrup et al., 2002). When babies are in the NICU, professionals can collaborate to ensure that they receive appropriate support from the environment, pain management, safe and effective treatments, and all of the benefits of the parent–infant relationship (Harrison, 1993). When preterm and fragile infants and their families go home, a program such as the Family Infant Relationship Support Training (FIRST; Browne, MacLeod, & Smith-Sharp, 1996) guides community caregivers to support parents in adjusting the environment, pacing and timing interactions, providing continuity and predictability, and supporting the infants' ability to stay awake or asleep and transition between states. These strategies are essential components of supporting the infant's organization and development through relationships with their parents.

Creating Meaningful Moments

Helping parents and families experience and create meaningful moments with their babies in the NICU helps them develop positive relationships. Moments can be "firsts" (first picture, first breast-feeding, being dressed for the first time, first smile), special celebrations (holidays, birthdays), or everyday events that are highlighted and cherished. If a baby is dying, hospice programs in the NICU can support families by adding structure and meaning to the end of life (Whitfield et al., 1982). In some hospitals, memorial services celebrate the lives and commemorate the deaths of infants. Families may attend these services for many years after losing babies in the NICU.

Providing Ongoing Monitoring, Assessment, and Support

Services offered to families should demonstrate continuity and persist long beyond the date of discharge from the NICU. Comprehensive, multidisciplinary evaluation and intervention services are beginning to focus on parent–infant relationships (Perez, Peifer, & Newman, 2002). Ongoing groups can help parents access resources; groups also help to reduce emotional distress, enhance relationships with partners or others, alleviate fears associated with having subsequent children, and provide a safe place to voice concerns about the baby.

Support of NICU Staff

Families are not the only ones in need of ongoing support services. NICU professionals must cope with the critical care environment and all of the emotions it evokes (Zeanah & Canger, 1983). NICU professionals have reported higher levels of depression and psychosocial dysfunction than community samples (Lopez, 1983). High burnout and turnover rates are not surprising in the face of the harrowing events (Hutchinson, 1984) that professionals experience daily in the NICU. Mental health professionals can support staff by: (a) being available for case consultation, (b) leading ongoing support and bereavement groups, (c) facilitating open discussions of conflicts, (d) following up after critical incidents occur, (e) providing education and training, and (f) offering suggestions to enhance systems-level functioning in the NICU.

Summary

The birth and hospitalization of a preterm infant have powerful effects on the emerging parent–infant relationship. Disruptions in this relationship may occur as a result of prenatal and postnatal factors, parental factors, infant factors, or the hospital environment itself. Such disruptions have consequences for relationship development and may affect infant mental health and development.

NICU professionals can reduce the negative effect of relationship disruptions and promote the mental health of preterm infants and their families through psychoeducational interventions with families, mental health services in the NICU, staff training to support the parent–infant relationship, emotional support for staff, and developmentally supportive and family-centered practices. Interventions should include appropriate discharge planning and ongoing monitoring, assessment, and support of preterm infants and of the developing parent–infant relationship. It is important to note that family reorganization at the time of birth and during hospitalization profoundly affects how infants, parents, and couples function later. As such, the perinatal period offers opportunities for intervention efforts aimed at supporting the adaptive reorganization of families in the face of extremely challenging circumstances.

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