Partnering with Parents: Establishing Effective Long-Term Relationships with Parents in the NICU

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ABSTRACT

Advances in health care have led to unprecedented innovation in the care provided to critically ill newborns. One outcome of this new reality is that newborn intensive care units have become "homes" for fragile infants who require long-term hospitalization. Clearly, NICUs were never so envisioned; thus, this reality has resulted in challenges for families and health professionals alike. As the duration of hospitalization increases, relationships between families and health care professionals become increasingly important. Parents of hospitalized newborns face fear, anxiety, and frustration as they struggle to cope with an ill child while developing their parental role. The quality of relationships established between families and health care professionals is crucial to their coping and adaptation. This article addresses challenges faced by families whose infants experience extended hospitalization, applies a model to help health care professionals understand parent perspectives, and proposes strategies to promote effective partnerships and alliances with families.

THE EXPERIENCE OF HAVING A BABY ADMITTED TO THE NICU can be overwhelming for families. Stress and anxiety quickly replace any anticipatory excitement and exhilaration surrounding the birth. Families find themselves attempting to cope with the uncertainty of the outcome of their infant's illness in a highly stressful and foreign environment. These families did not envision such an outcome and are not prepared for the experience.[1] Once they move through the initial shock, they must deal with the unique circumstances that an NICU presents, including a multitude of different health care professionals, imposed physical distance from their child, and the reality that the NICU will be their second home for an extended period of time. This is often the case for families of infants born extremely prematurely or with complex physiologic problems that require surgical intervention and prolonged convalescence. One mother whose infant was hospitalized for 12 weeks summarized her feelings about her infant's hospitalization many years later:

> "When I recall the time my daughter and I spent in the NICU, waves of emotion pour over me, and it is often difficult to sort the many conflicting feelings. Although I was grateful for the technology that supported the life of my tiny little one, I resented the cold intrusive shadow that it cast on her existence. The environment of the NICU seemed to dehumanize her birth and to distance me, in many ways, from my role as a parent." (p. 68)[2]

Many factors influence a family's adjustment and adaptation to stress when an infant is admitted to the NICU. Some families cope with the illness of their infant and are able to mobilize supports and resources as needed. Countless others, however, experience a high level of stress that can hinder their ability to cope with the situation. Similarly, many nurses caring for critically ill newborns and their families experience their own stressors in the work environment and find it difficult to accurately assess families'

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responses to the illness of their infant and to address their ongoing needs.

RELATIONSHIPS IN THE NICU

The experience of a baby's long-term hospitalization can have a profound emotional impact on a family that may last well past the time of discharge.[2–4] One early study indicates that parents do not always report parent and NICU staff relationships as a source of stress.[5] But a more recent study suggests that mothers clearly remember stresses associated with staff relationships. Mothers interviewed by Wereszczak and colleagues cited difficulty obtaining accurate and consistent information and negative feelings concerning the care their infants received as examples of environmental stressors.[4] In another study exploring mothers' remembrances after their baby's discharge from the NICU, mothers describe more painful memories if their infant had been sicker and if they had experienced a breakdown in staff-parent alliance.[6]

Satisfaction with care provided in NICUs has been studied extensively. Analyses of parental responses on satisfaction questionnaires reveal common themes, including needs for assurance, caring, communication, consistent information, education, attention to the environment, follow-up care, pain management, participation, proximity, and support.[7] Fully comprehending the issues related to parent satisfaction requires a realistic understanding of parental needs and expectations of neonatal care.[7–9]

To meet parental needs and those of their infant, health care professionals must acknowledge parental perspectives.[10] They must also seriously consider how to minimize stress and intrusiveness while providing care. A trusting relationship between parents and health care professionals is essential to reduce the stress associated with an infant's hospitalization and to have families become involved in the care of their infant. Partnerships can help build confidence in parents and can potentially optimize their role in the care of their sick newborn. Strong, trusting relationships are important for all parents, including those who have infants requiring NICU care for a prolonged period and who may experience chronic stress.

The Importance of Nurse-Patient Relationships

Nursing scholars have long described the unique nature of the nurse-patient relationship.[10,11] They have also emphasized the importance of that relationship in the provision of effective nursing care. In fact, Robinson states that "relationships are not central to care, they *are* care" (p. 153).[10] Establishing strong, trusting, therapeutic relationships is essential if nurses are to provide effective family-centered care (FCC) to infants and their families. Family-centered care is defined as an approach to health care that acknowledges the vital role that families play in ensuring the health and well-being of all members of a family. Family-centered practitioners assume that all families bring important strengths to their health care experiences.[12]

Fostering trust between family members and care providers is fundamental if parents are to feel welcome and valuable as parents. Owen suggests that a trusting relationship with a few health care professionals can develop over time and is helpful to parents who are learning about their child and growing in their role as parents. Owen believes that there must be "an ongoing commitment to form trusting and informative relationships between families and nurses" (p. 69) so that parents will become increasingly confident in themselves as parents and actively provide care to their child.[2]

Relationships emerged as a major theme in an investigaion of the perspectives of mothers, nurses, and neonatologists on FCC. Bruns and McCollum describe two interrelated themes that emerged from this qualitative study: (1) the need of mothers for care and concern and (2) the development of a relationship between mothers and professionals. Underlying these themes were the mothers' need for trust, support, and individualized attention calibrated to their emotional and psychological state at the time. Frequency and duration of contact between parent and professional seemed to play a significant role in the development of relationships in the NICU. Mothers developed more significant relationships with nurses than with other health care professionals, probably because nurses spend more quality time with mothers at their infants' bedsides.[13]

The Concept of Guarded Alliance

Thorne and Robinson proposed a model to explain the development of relationships between families and health care professionals over the course of long-term illness. They studied how patients and families experience chronic illness and established that satisfaction with health care depends upon a good working relationship between provider and recipient of care. Their qualitative study was one of the first to describe health care relationships from the patient and family perspective rather than from that of only health care professionals.

Thorne and Robinson's model includes three phases, or stages, in the dynamics of relationships from the perspective of patients and families: naïve trusting, disenchantment, and guarded alliance. Although infants hospitalized in the NICU are not traditionally viewed as "chronically ill," these three phases apply to the NICU setting, where parents spend an intensive and extended period of time interacting with care providers for their infants. Much of this article applies Thorne and Robinson's concept to families experiencing the lengthy hospitalization of their newborns. Vignettes from the authors' clinical practices illustrate the phases of the relationship.[14–16]

Naïve Trusting. The first phase of the family relationship with health care providers occurs early in a patient's experience with chronic illness. Families enter into relationships trusting that health care professionals will act in the best interest of their ill family member. The assumption, according to Thorne and Robinson, is that "family members'

involvement as primary health care providers on a day to day basis would be acknowledged and respected, and that care would be collaborative and cooperative with decisions being mutually negotiated" (pp. 296–297).[14] Families new to the NICU are still recovering from the shock of their baby's illness and adjusting to the NICU environment. High expectations of tertiary care may foster various elements of naïve trusting for family members. They may assume that their baby will recover quickly after transfer to a tertiary care hospital. Many infants admitted to tertiary care NICUs have or develop highly critical and complex medical, surgical, and nutritional problems that require many months of hospitalization, however.

After a while, families recognize that their trust in health care professionals and the health care system is based on naïve expectations and not on the reality of health care. Discrepancies arise between the views of family members and those of professionals as to the best interests of the infant. The mismatch in expectations between health care professionals (especially nurses) and mothers is a significant concern for mothers.[17–19] It can lead to the decline of naïve trusting. The phase of naïve trusting can also end when differences emerge in expectations of outcomes between parents and health care professionals.[14,16] Some families pass from the stage of naïve trusting to disenchantment when their infant moves from acute to chronic illness. This transition may be particularly difficult when the acute illness unexpectedly becomes chronic.

Disenchantment. During the phase of disenchantment, families become frustrated, fearful, angry, and dissatisfied with the care the patient is receiving.[14,16] Family members identify a lack of adequate information as a major stimulus for evolving feelings of anger and disenchantment. In their attempts to influence the experience of illness for their infant, parents may become assertive, confrontational, and adversarial in their interactions with health care professionals. Or they may fear the possibility of reduced quality of care for their infant and remain quiet. Health care teams often describe disenchanted families of infants in the NICU as demanding, difficult, or manipulative and perceive them as occupying tremendous amounts of time. Following is the criticism of one disenchanted family member.

> Vignette #1: The nurse isn't suctioning him the way he likes. He got 42 milliliters instead of 44 milliliters for his last feed, and the fortified formula didn't come up from the formula room this morning. I am sick of these things happening!

This quotation illustrates the frustration and anger that parents may feel and subsequently express during the phase of disenchantment.

Parents in this phase may feel conflicted if they remain passive and do not express their concerns; then their infant may suffer harm. But if they seek active involvement, pushing their own agendas, their infant may suffer as a result of reduced goodwill on the part of health care professionals. This is a significant and stressful dilemma for patients and families and results in generalized discomfort and anxiety. Adversarial encounters usually end, however, when the long-term nature of the illness serves as a catalyst to move families into the final phase described by Thorne and Robinson: guarded alliance.[14–16]

Guarded Alliance. This phase requires a reconstruction of trust based on obtaining accurate information rather than on naïveté. In this type of relationship, family and the health team cooperate, and both perspectives are accommodated in care for the infant. Parents actively seek information to make decisions, understand the difference in perspectives, express their own expectations more clearly, and negotiate mutually satisfactory goals for care. Parents continue to experience frustration and disappointment, but they learn to handle these situations more positively and to prioritize concerns. When alliance replaces the initial naïve trust and subsequent conflict of disenchantment, activities become more purposeful and goal directed.[14]

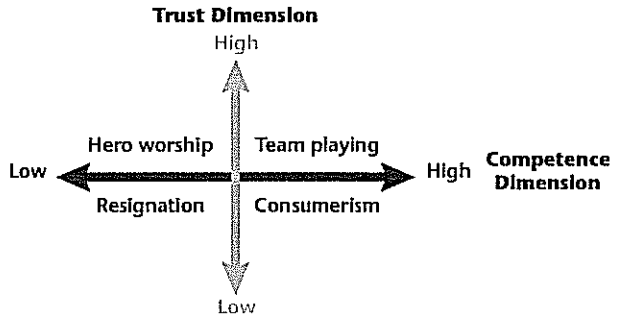
It is important to acknowledge that the behaviors of guarded alliance do not necessarily indicate patient/family satisfaction with all care or comfort in all relationships. Instead, the concept helps us to understand that parents often attempt to use strategies to humanize their relationships with health care professionals. For example, they might enquire as to the well-being of professionals and acknowledge the challenges inherent in caring for sick people.[14]

Thorne and Robinson indicate that trust is key to developing a successful health care relationship. Families of infants in the NICU strive to have their opinions respected, and many wish to be treated as equals, especially if they have established a partnership through the ups and downs of an infant's long-term hospitalization. Reciprocal trust can be challenged and disenchantment reoccur when the infant experiences a complication.[14] In the following example, parents of a preterm, postoperative infant experienced this fluctuation between phases when they became upset about a complication that developed secondary to a perceived miscommunication between the surgical and medical teams.

> Vignette #2: The father of the baby said, "Everybody is trying to tell us a different story about what happened, but we know what happened, and we know why it happened. We were here, and no one will listen to us. We aren't trying to blame anyone. We just want to be clear about the facts and make sure this doesn't happen again."

The parents of this infant wanted their opinion taken seriously, and they were upset that it required so much effort for them to be heard. Through a subsequent open, honest discussion of the event, coupled with recognition of their accurate understanding, the trusting relationship survived (although the parents remained guarded with certain health care professionals). If this discussion had not occurred, the

FIGURE 1 ■ Reconstructed trust in guarded alliance.



From: Thorne S, and Robinson C. 1989. Guarded alliance: Health care relationships in chronic illness. *Image: The Journal of Nursing Scholarship* 21(3): 156. Reprinted by permission.

parents might have remained in the phase of disenchantment. Continuation of disenchantment increases the risk for more frequent confrontational situations with health care professionals and for resultant parental dissatisfaction.

Reconstruction of trust during guarded alliance is manifested in a variety of ways and involves two dimensions: (1) patient/family trust in their own competence and (2) patient/family trust of health care professionals (Figure 1). When these dimensions intersect, four types of relationships emerge: hero worship, resignation, consumerism, and team playing. During guarded alliance, patients/families may reconstruct trust based on any or all of these relationship types with health care professionals.

Hero Worship. Patient/family identification and designation of a single health care professional as distinct from all others characterize hero worship. With this type of relationship, the family has great trust in one health care professional, but little sense of personal competence within the health care context. With such relationships, trusting alliances can be established while flaws in the system are acknowledged. The parents in the following vignette experienced this type of relationship.

> Vignette #3: A premature infant was waiting for transfer for surgery when the parents entered the tertiary care NICU clearly in a stage of disenchantment. They were extremely anxious, worried, and angry and had unrealistic expectations; they were adversarial and distrustful of everyone. The parents identified a hero, however—a person who spent a great deal of time with them, listened to their concerns, was honest and forthright, and took a personal interest in them and their baby. Through this relationship, much of their anger was defused and their anxiety reduced.

The most positive aspect of this hero worship relationship was that the parents, although particularly guarded, were able to communicate their needs effectively not only to their "hero," but also to other health care professionals. As their baby's condition improved, their confidence in their own ability to parent grew, and they continued to have the security of complete trust in at least one person. Although such trust and dependence can be challenging for the hero as well as for other health care professionals, the scenario illustrates how an identified hero can help to facilitate the transition from disenchantment to guarded alliance that can benefit both families and health care professionals.

Resignation. A second relationship type, resignation, results from a low degree of trust both in self and in the competence of health care professionals. Patient/family withdrawal from the health care environment for a period of time characterizes this type of relationship. Parents may express minimal or no expectations of health care professionals and are resigned to whatever happens. Many NICU families experience temporary periods of resignation, especially following a phase of disenchantment. Thorne and Robinson identify despair, hopelessness, and a perceived need for time away from intense health care relationships as common feelings in this type of relationship.[16] Resignation can be recognized in the responses of parents of hospitalized infants.

> Vignette #4: An infant was hospitalized for a number of problems. While awaiting the results of genetic testing, the family expressed hope that the test would be "normal" and that their infant's problems would be unrelated to a genetic diagnosis. When the test result confirmed a genetic abnormality, the parents were told the result and the clinical implications. Immediately afterward, the nurse reported, "Since they received the diagnosis, they have hardly come in. It is so unlike them; they're always here. I hope they're all right."

Families may feel powerless and unable to manage the information and situation. Both the NICU environment and ongoing interactions and discussions can be so intense and overwhelming for families that they need time away to process information and try to gain some perspective on the situation. Families rarely remain in a phase of primary resignation but generally transition to another form of guarded alliance, with expectations that health care professionals can make their situation better.

Consumerism. A third relationship type occurs when a patient or family members have high trust in their own competence as health care consumers, but low trust in health care professionals. The family's purpose in this type of relationship is solely to obtain what they deem as essential services for their ill family member. They acknowledge that their "real" needs are not usually addressed, but they are determined to ensure that health care professionals address important care issues.

Well-informed families who reconstruct trust using a consumerlike relationship act as advocates for their baby and know how to maneuver the system to get needs met. Many families reconstruct trust in this manner by learning more

about their baby's condition, making sure they are present during rounds, and voicing their opinions strongly but not confrontationally. For some families, however, the persistent low trust in health care professionals, or consumerism, can be a negative experience.

> Vignette #5: A mother of an extremely premature infant believed that she was the only person who knew what her baby's medical needs were. She was convinced that treatments she had read about on the Internet could be tried with her baby. She put herself under tremendous pressure to figure out and advocate for specific and, at times, radical treatments. She had tremendous difficulty trusting the opinions of any health care professionals and could trust only her own opinions.

In this case, the infant's mother had significant trouble moving toward reconstructed trust and regularly returned to a phase of disenchantment. Health care professionals may label this type of behavior as manipulative and demanding, especially if families persist in behaving in ways that do not conform to specific norms.

Team Playing. A final relationship type results when the patient and family members have a high degree of trust in their own competence as well as in that of health care professionals. In this type of relationship, a reciprocal and negotiated alliance forms between the patient/family members and health care professionals. Both parties acknowledge the limitations of mainstream health care and systems issues.

> Vignette #6: An infant, born at term, was diagnosed with esophageal atresia and tracheal esophageal fistula. The esophagus was too short to be repaired initially, and the plan was to wait until the baby grew and reassess. During this time, the parents enthusiastically learned suctioning techniques and actively cared for their baby. Nurses supported them, and their relationship with most health care professionals was strong. Upon reassessment, the esophagus was still too short for repair. The second waiting period, when the baby experienced an episode of pneumonia, was difficult for the parents. They became notably agitated when they came into the hospital to spend time with their infant and unhappy about the situation. Minor issues upset them, and they voiced feelings of hopelessness about ever taking their baby home. After a while, the infant's esophagus was assessed and, again, was too short for repair. A decision was made to wait a longer period of time and then perform a definitive procedure. The parents, while disappointed and troubled by this news, expressed a desire to take their baby home while they waited. Although a few health care professionals initially met this request with apprehension, the parents and health care professionals were able to work together to determine the specific needs of the infant and family and to organize the care, equipment, and support needed for them to be discharged home.

A high degree of trust in health care professionals as well a high degree of trust in their own abilities is evident in this vignette. The team-playing nature of the relationship was essential to make the goal of taking the baby home a reality.

As illustrated in the preceding vignettes, Thorne and Robinson's model of health care relationships offers NICU health care professionals a useful framework and context within which to understand family perspectives on relationships with health care professionals during their infants' lengthy hospitalization.[14–16] It is important to recognize that, over the long term, families and health care professionals can experience many different types of relationships. Movement toward reconstructing trust after the inevitable phases of naïve trust and disenchantment is key. With this trust comes guarded alliance, an effective partnership between the family and health care professionals.

STRATEGIES FOR DEVELOPING A GUARDED ALLIANCE

The guarded alliance model provides a framework that promotes understanding of health care relationships in the context of chronic illness. The framework helps in understanding experiences of families of infants hospitalized for lengthy periods of time in the NICU and provides a foundation for developing strategies to assist families through these specific stages during hospitalization. A primary goal for health care professionals is to facilitate a smooth and efficient transition for families through the early phases of naïve trusting and disenchantment, minimizing the duration and severity of disenchantment and encouraging progress toward a guarded alliance. With the establishment of a guarded alliance come effective and collaborative relationships among family members and health care professionals.[14–16] Goals and practical strategies may help health care professionals and families to achieve such relationships. Table 1 lists possible strategies for attaining the following goals as well as brief discussions of some of the scenarios in the vignettes presented in this article.

Create a Culture of Partnership

Partnership between consumers of health care and those who provide it is discussed regularly in the literature. Partnership remains a contentious issue, however. Some believe that patients can never be partners because they lack the requisite knowledge of illness and disease to fully participate in the health care process; others ask why the same process used to comparison-shop for other service providers, such as mechanics or interior designers, does not apply to seeking suitable health care resources. Autonomy is a core principle at work in this debate.[20] Autonomy also features prominently in the principles of FCC, a philosophy of health care in which families are encouraged to be independent and active in decision making and in which unique cultural and personal values and beliefs are respected.[12] Infants hospitalized for prolonged periods of time in NICUs require

TABLE 1 ■ Strategies for Developing a Guarded Alliance

Goals	Strategies	Making It Work
Create a culture of partnership.	• Complete a thorough family assessment.[29] • Model partnership; use inclusive language when interacting with parents (e.g., "You know your baby best...we're all working together."). • Include parents in daily rounds. • Regularly assess parents' desire to be involved in decision making. • Involve parents in treatment decisions. • Promote the development of trusting relationships.	• *Vignette #3:* The parents in this vignette did not initially feel a sense of partnership with the staff in the NICU. After they established a rapport with one individual (their hero), a partnership began between the parents and that individual. A broader and enhanced partnership could have been accomplished with (1) a thorough family assessment upon admission and (2) early and ongoing parent involvement in decision making. • *Vignette #4:* Part of the parents' resignation involved devastation in response to the genetic diagnosis, but also the uncertainty of their role as parents in future medical treatment decisions. An open dialogue discussing and supporting their role in decision making in the event of a diagnosis may have helped eliminate their stress.
Optimize continuity.	• Identify a core group of professionals to be consistently involved with the infant and family. • Design schedules to promote continuity of care and providers. • Establish interdisciplinary care plans as a permanent part of the health record.[22] • Integrate documentation from all disciplines into one plan of care.	• *Vignette #1:* This parent expressed a perspective that the health professionals caring for her infant did not know him well. Documentation may also have been lacking. The partnership may have been improved with (1) enhanced continuity (of person and process) and (2) collaboration with the family to gain a parent perspective before implementing strategies.
Optimize parental access to information.	• Facilitate continuity of care and providers. • Regularly assess family needs for information. • Provide access to information for families (e.g., through a family library or Internet access and recommended websites). • Consider conducting an annual review or assessment of resource needs of families. • On parent satisfaction questionnaires, include questions regarding communication.	• *Vignette #2:* When health care professionals do not provide accurate and timely information, especially when complications arise, distrust and conflict may result. In this scenario, consistency in information and immediate acknowledgment of parental concerns would have been helpful. Situations such as this occur when multiple health care providers are involved. Optimal communication is required among health care providers as well as with families.
Educate families to enhance competence.	• Discuss with parents the level of participation that they are interested in. • Develop mutual goals regarding discussion of information and decision making. • Offer a self-directed program for parents to enhance their abilities to participate as part of their infant's health care team.[25]	• *Vignette #5:* The mother in this scenario would have benefited from information to help her to advocate for her infant in a more effective manner. Providing alternative methods of communication and making expectations clear lead to a trustful, beneficial relationship.
Encourage development of the parental role.	• Acknowledge family strengths and abilities.[10,22] • Teach parents how to interact with their infant. • Assist parents in learning how to comfort their infant. • Encourage parents, and provide positive reinforcement and commendations for the care they provide.[10] • Demonstrate trust in parents' abilities to provide care. • Listen to and respect parents' perspectives.[22] • Share care responsibilities with parents. • Ensure consistency in what care parents are able to provide in the NICU. • Give parents space and privacy when they are with their infant. • Don't underestimate the small things parents can do to comfort and care for their infant (e.g., touch, mouth care, reading to their infant).	• *Vignette #6:* The parents and health care professionals in this situation demonstrated a team approach to meeting both parent and infant needs. If these strategies can be applied through each step of the process from admission to discharge, parents will feel more valued in their role and more confident as discharge approaches.

sophisticated health care intervention, and parents are aware of their need for information, reassurance, guidance, support, and individualized attention throughout this experience.[13,21] Parents also seek respect, acknowledgment of their expertise in caring for their infants, and a central role in the decision-making process.[21,22] The philosophy of FCC addresses these

FIGURE 2 ■ Principles of family-centered care.

1. Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
2. Patients and family members build on their strengths by participating in experiences that enhance control and independence.
3. Patients, family members, and providers collaborate in policy and program development and professional education, as well as in delivery of care.

Adapted from: Institute of Family-Centered Care. 2004. What is family-centered care? Retrieved December 15, 2004, from http://www.familycenteredcare.org/about-us-frame.html.

parental needs and promotes a culture of partnership in the NICU that is characterized by mutual decision making, trust, active engagement, and frequent communication addressing important information relevant to the infant's care (Figure 2). Fostering a culture of partnership can be challenging because it can require a changed concept of the role of families in health care practice. Table 1 suggests practical strategies for fostering partnership. For example, completing a thorough family assessment allows the health care team to gain an understanding of a family's structure, developmental stage, and functionality. With this knowledge, the team can begin to develop a partnership that addresses the individualized needs of the family.

Optimize Continuity

Continuity, a common term in health care literature, is noted to be of importance to patients and families. The term is used most often in relation to primary health care, however, and generally describes personal continuity, when one health care professional is responsible for the care of a patient.[23,24] In hospitals, patients require and receive care from a number of health care professionals. This fact stimulates us to think differently about continuity, conceptualizing it as a process, not simply as a person. Reframing continuity in this way allows us to consider how processes and systems can optimize continuity for infants and families in the NICU while still allowing them access to all the professionals and services they require.

Haggerty and colleagues discuss two core elements of continuity: care of an individual and care delivered over time. Continuity is not an attribute of a system or a health care professional, but is an experience of the integration and coordination of services by an individual infant and family. The second element described by Haggerty and colleagues, longitudinal continuity, refers to care provided over time and relates to how this care affects outcomes for the patient.[23]

Haggerty and colleagues suggest three forms of continuity: informational, management, and relational. *Informational continuity* reflects the importance of consistent information as a common thread among various care providers across health care events. *Management continuity* refers to the integration of multiple services and providers in the care of an infant with long-term, complex clinical issues. This form of continuity is intended to eliminate the potential for providers to work at cross-purposes without understanding or being aware of services provided by others. Finally, *relational continuity* refers to the opportunity for families to develop relationships with specific health care providers that will endure over time, across health care episodes.[23] Krogstad and colleagues call this *personal continuity.*[24] Several strategies may be used to help achieve these types of continuity (see Table 1).

Optimize Parental Access to Information

Researchers have identified access to timely, accurate, and consistent information on a regular basis as a significant contributor to parents' satisfaction with care.[13,14,17] Mothers in NICUs express their need for vast amounts of information in order to understand their infants' needs and actively parent them. Mothers describe themselves as "vigilantly watching over" their infants.[17] They are "guarding" their infants to ensure the safety and well-being of themselves and their infants despite "inhibitive actions" on the part of health care professionals.[21] Providing complete and unbiased information to families is also a core principle of FCC.[12] A variety of strategies can be used to ensure that families have all the information they need during their infant's hospitalization and beyond (see Table 1).

Educate Families to Enhance Competence

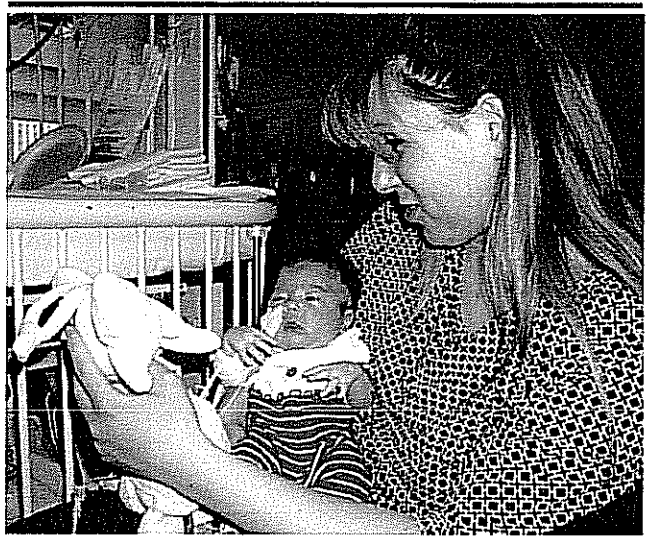
Many parents wish to participate actively as members of their baby's health care team and to be included in all decision making involving their infant. They may not have the knowledge or communication skills to participate at the level they desire, however. Durbach and Kerzner developed a self-directed program to help parents attain these skills. Using the findings from focus groups with parents, they identified competencies and skills parents needed to engage in a collaborative relationship with health care professionals. These include establishing a tone that facilitates trust and respect, receiving and providing quality information, making decisions confidently and jointly, negotiating differences, and managing emotions during health care interactions.[25] The program manual provides sample scenarios and offers responses that parents could use in specific situations. The program was successful when used by parents motivated to improve interactions with health care professionals.

For health care professionals, "parents as partners" on the health care team represents a cultural shift. Supporting and encouraging parents in their involvement as team members can improve competence and confidence of the parents, demonstrate respect for their ideas and concerns, and gradually lead to a reciprocal trusting relationship that is mutually satisfying for all. See Table 1 for strategies to educate families and help them increase their competence.

Encourage Development of the Parental Role

A common theme throughout the literature describing sources of parental stress is the change of parental role.[8,26,27]

FIGURE 3 ■ Acknowledging and encouraging the parental role.



Courtesy of The Hospital for Sick Children, Toronto, Ontario.

Parents describe feelings of inadequacy and helplessness. The philosophy of FCC focuses on their needs to parent their infant. Central concepts of FCC include recognizing and valuing family strengths and capabilities and encouraging family members to participate in assessment, planning, implementation, and evaluation of care to the degree that they wish.[28]

Although most health care professionals agree that these principles are important, it is often difficult to translate them into day-to-day practice because of barriers such as time constraints, severity and complexity of long-term illness, and increased workload in an intensive care setting. In addition, some nurses find the shift from the more traditional role of helper and caregiver to that of educator, coach, and consultant challenging. Efforts to develop a trusting, collaborative relationship with parents will establish a foundation for promoting parental involvement and improved confidence in ability to care for an infant. Parental feelings of competence and self-assurance will, in turn, reduce parental stress, ease transitions to community hospitals or home, and promote stronger parent-infant relationships.

Health care professionals should be aware that the needs of parents vary over time as they adapt to their role. An ongoing open and honest relationship will encourage the dialogue necessary to meet parents' unique needs as parents to their infant. Several strategies (see Table 1) can be employed to help them optimize their parental role (Figure 3).

CONCLUSION

The lengthy and often unanticipated hospitalization of infants in the NICU can induce significant stress and anxiety in parents. Reciprocal and trusting relationships with health care providers benefit both infants and their families. Thorne and Robinson's model of relationship development provides a framework that can advance health care professionals' understanding of both the evolution and patterns of health care relationships experienced by parents of long-term NICU patients.[14–16]

While acknowledging the inevitable stress of the NICU environment, all health care professionals can play a key role in establishing collaborative partnerships with parents. In addition, health care administrators can make available educational programs and resources to provide health care professionals opportunities to develop and enhance their skill in communicating effectively and partnering with families. The value of reciprocal trust in health care relationships must be recognized; trusting relationships serve to improve outcomes for the infants and families cared for in the NICU.

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