



Care of the Family of an Infant With a Congenital Heart Defect During the NICU Hospitalization

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ABSTRACT

The family of an infant born with a congenital heart defect is challenged by both the short- and long-term implications of the diagnosis and the neonatal intensive care unit (NICU) hospitalization. Nurses are in a key position to support these families as they deal with the psychological, emotional, and financial impact of the NICU experience. Understanding how families perceive the NICU environment and their grief in losing the desired healthy baby provides the NICU nurse with the knowledge to engage in self-reflection on her or his interpersonal style and caregiving attitudes. Utilizing the concepts and principles of family-centered care and relationship-based practice, nurses can work together with the families to determine how to best meet the families' needs and to find the resources to support them. Families and colleagues appreciate nurses who demonstrate expertise in this approach to family-centered care. This appreciation leads to greater job satisfaction and decreased job-related stress.

Key Words: congenital heart defect, family-centered care, relationship-based care

Becoming a parent is challenging with a healthy, full-term infant. The transition to parenthood is filled with intense emotions of seeing oneself as a mother or father and learning

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to put another's needs before one's own.^{1,2} For families whose infants are born with a congenital heart defect (CHD) who requires neonatal intensive care unit (NICU) hospitalization, parents face many additional challenges—psychologically, emotionally, and financially—that impact their lives.³ Of all of the NICU staff, families spend the most time with NICU nurses and develop the strongest relationship with them during the NICU hospitalization. The NICU nurse is, therefore, the key team member to care for the families through their NICU journey.²

The current article discusses how families with an infant born with CHD perceive the NICU and caregiving practices. As professional NICU team members, it is incumbent upon staff to care for the entire family, not only the infant.⁴ Such an approach often requires self-reflection and awareness as well as changes in our attitudes, values, and behavior. This process is challenging and often frightening. Working together as a team in a supportive and caring manner enables the NICU professional to integrate best practices into his or her care.⁴

THE NICU ENVIRONMENT

The NICU is an unfamiliar environment and is overwhelming for the vast majority of families. The physical environment seems bizarre and contributes to their anxiety and fear. While the NICU professional care team may feel very comfortable in this environment, families find it to be frightening. A NICU environment that is quiet and calm is essential for the infant, families, and staff. Dim or home-like lighting and day-night cycling facilitate circadian rhythm development in the infant and contribute to reduced anxiety in families and staff.⁵ Practicing developmentally supportive, neuroprotective care is the evidence-based standard of care in the United States.^{4,6} The NICU team, especially the

infant's nurse, can support families in becoming familiar with the equipment, the sounds, and the language. Just as important, the nurse facilitates the families' understanding of their infant's behavioral cues, how to hold and position their infant, and how to feed their infant.^{4,6}

FAMILY EMOTIONS

At admission, families are grieving the loss of the desired healthy baby. Whether the diagnosis of CHD has been made prenatally or postnatally, the grief of not having a healthy child can impact the families' attachment to their infant and their relationship with the NICU team.^{3,7} Initially, they are in a state of shock and denial. The families are dealing with a traumatic situation and may have difficulty processing the information that the NICU team provides them. Families often need the same information repeated to them over the first weeks of hospitalization and will ask the same questions more than once. A patient, caring response with each interaction will facilitate the development of a positive and healthy relationship between the nurse and the family.^{3,7} As the hospitalization proceeds, families will demonstrate the emotions of anger, frustration, happiness, and joy, often all in the same day. The NICU team can support families by validating that their emotions are accepted and understood. Team members who understand that these emotions are directed at the situation and the family's inability to control it, rather than taking those emotions personally, are able to scaffold the family members to confidence in their ability to parent a child with CHD.^{4,7,8}

Families come from many cultures, educational backgrounds, and interpersonal styles.³ The NICU team must take the time to learn about each family's unique needs and how the family functions. Appreciation for the uniqueness of the family and its members provides the nurse and other NICU team members with the information to develop individualized care plans for the family as well as the infant. The NICU team can then interact with a family and its individual members on the basis of their needs and resources.^{5,9}

STAFF REFLECTION

Being a NICU nurse can be challenging and at times stressful. Professional satisfaction and appreciation of one's work is an individual journey.^{7,8} Often, professionals become complacent about their career. All NICU professional team members, including nurses, must engage in self-reflection regarding their interpersonal style and professional practice. Self-reflection on one's professional attitudes, values, and behaviors requires being honest with oneself. This can be challenging and daunting, so providing NICU mental health professionals to coach staff in self-reflective process can be advantageous.

Self-reflection takes time, a safe environment, and administrative endorsement. Reflecting on the rewards as well as the challenges of the work is critical. Understanding one's interpersonal approach to life (ie, introvert or extrovert) assists in thinking about interactions with families and coworkers. As one reflects, it is vital to remember that the work is family-centered and relationship-based as the gold standard of NICU care.⁹ Self-reflection is an ongoing process that can be gratifying and enriches professional development.⁷ The NICU mental health professional can maintain the reflective process as an expected ability in professional practice. Opportunities for staff to engage in reflection as a group are vital. As a team, reflecting on the unit's values, attitudes, and cultural expectations supports ongoing communication that sustains staff in their daily practice.⁷

CAREGIVING STYLES

Caregiving styles affect how parents perceive NICU team members.^{7,8,9} Mothers report that they feel most comfortable with NICU team members who respect their role as the mother and the mother-infant bond. Nurses who facilitate the mother being physically close to her infant and interacting with her infant provide the mother with some sense of control and importance in her infant's care and life.^{7,9} Nurses who act as though they are the expert on the infant's needs and caregiving make mothers feel alienated from their infant and the nurse. These mothers often express feelings of frustration, anger, and bitterness because they do not feel respected as the infant's mother and primary caregiver.^{7,10} This authoritative approach is a barrier to a positive parent-nurse relationship. When family members express their dissatisfaction with this approach to care, they are often labeled as "challenging or difficult." A NICU team member with an authoritative approach often leads to conflict and poor communication with the family. Not only does the family feel stressed but all of the staff feel additional stress and challenges in these situations.⁷ Working together as a NICU team to engage in caregiving styles that acknowledge the parent as the primary caregiver and decision maker decreases parental stress, facilitates positive parent-staff relationships, and increases professional satisfaction.¹¹

FAMILY-CENTERED, RELATIONSHIP-BASED CARE

Family-centered, relationship-based care is founded on the principles of respect, communication, collaboration, and building on the family's strengths.^{5,9} It is not a separate practice but is integrated into all aspects of caregiving in the NICU. This type of care puts the infant *and the family* at the center of the work. At its core is

the belief that families are part of the NICU team and are not visitors. Families are the stable caregivers in the NICU and after discharge. They are the ultimate decision makers in the care of their child.⁹

Another key component of family-centered, relationship-based care is the knowledge and expertise to understand the difference in mothers' and fathers' responses to the birth of a child.

Mothers tend to be more concerned about the condition of their infant and less concerned about their own medical needs and health.^{5,7,10} While mothers are most concerned about their infants, fathers are more concerned about the health and care of the mothers immediately after birth.^{2,8,12} They want to be involved in the infant's care but often feel that they need to protect and care for the mother as their first priority.¹² Fathers report feeling like "bystanders" in the NICU, with their needs and concerns often being overlooked. Caring for the father of the infant with CHD is just as important as caring for the mother. Fathers also need to be encouraged to ask questions and be part of the decision making in the infant's care.¹²

Each member of the NICU team has a specific role in caring for the infant. The NICU professional understands what each role provides to the infant and the family, and respect for each role is critical to care provision. Professional team members educate families regarding their role in the infant's care as part of their practice. The NICU professional team's acknowledgement and respect of families as primary members of the NICU team results in optimal development of the parent-infant relationship and optimal neurodevelopment outcomes of the infant.^{5,9} Family-centered, relationship-based care provides the families with the ability to develop a strong relationship with the rest of the NICU team and to feel more confident in their ability to parent a child with CHD.^{4,5,9,11}

As NICU team members, nurses can support families dealing with the care of their infant with CHD by respecting their concerns and emotions and by actively listening to them and encouraging them to ask questions. The nurse encouraging parents to be at the bedside talking and touching their infant validates the parents' role as the most important people in their child's life.⁹ Parents should be actively involved in caregiving for the infant. Activities such as skin-to-skin contact, feeding, diapering, and comforting the infant after procedures enable the parent to gain confidence in their parenting before discharge. Demonstrating to parents that their child knows them (often seen with the infant having more stable vital signs and decreased movement in the presence of the parent) enhances the parents' view of themselves as a parent and the attachment process' success.^{4,5,9}

Communication is vital to the parent-professional relationship. Greeting families when they are with their infant and asking how they are doing and feeling demonstrate that staff care about them as well as their infant.⁴ Siblings need to feel included and valued as part of the family as well during this time. Encouraging parents to bring siblings to the bedside for brief periods of time with the NICU nurse present facilitates sibling attachment to their new brother or sister. When NICU nurses help parents explain the infant's condition to siblings, the parent-nurse relationship is enriched.⁹

Communication tools such as white boards with the care team of the day and care plan goals encourage parent-professional discussion. White boards should have a place where families can write down their questions and observations to facilitate communication between them and the many caregivers they encounter. Including parents in nursing change of shift, medical rounds, and regular family meetings shows that the NICU staff respects, communicates, and collaborates with families and includes them as part of the NICU team.^{8,9,13}

The nurse spends more time with the family and the infant than any other member of the NICU team.^{8,9,13} The nurse-family relationship is the most important one in the journey from the NICU to home. Parents integrate this relationship into their lives forever. It is important that nurses understand the significant impact they have on parents and the parents' relationships with their children. It is an impact that very few other professionals in any of the human services have in the lives of families and their children.^{7,9} The parent-nurse relationship offers nurturance to the parent with the understanding that this is a difficult and traumatic experience for the mother and the father. Parents are struggling to understand what is happening and are often tired and overwhelmed. The nurse's presence at the bedside offers the opportunity to empathize and validate their feelings and emotions. A genuine interest in the families' needs emotionally, physically, and financially provides them with a foundation from which they can work with the professional NICU team to develop a plan of care for the infant and the families as a whole.^{5,8,9}

For some families, peer-to-peer support can be beneficial. Peer-to-peer support in the NICU helps parents to understand that they are not alone.^{8,13} Peer-to-peer support begins by recruiting caring and empathic parents of infants with CHD who have been discharged from the NICU.¹³ The NICU team, specifically the social worker or other NICU mental health professional, trains these parents on supporting other parents in the NICU. A staff member is dedicated to the group as the liaison and the facilitator. Peer-to-peer support parents work closely with the NICU team in caring for the

family. They provide specific assistance to parents that augments and enriches the professional NICU team's care.¹³ There are national support groups such as Hand to Hold (handtohold.org) and Kids With Hearts (kidswithhearts.org) the NICU professional team can access for materials and methods to implement a successful peer-to-peer support program for parents whose infants are born with CHD.

Online support groups for parents whose infants have CHD, such as www.conqueringchd.org and www.childrensheartfoundation.org, in addition to Kids With Hearts can provide resources, materials, and support for parents. These groups provide support past the NICU hospitalization that can be essential for families as their child grows and develops.

FAMILIES IN CRISIS

Nurses are often the first team member to note that a family is having significant difficulties requiring the assistance of allied health professionals.^{4,5,8,9} The neonatal social worker should be consulted at delivery as he/she is an important member of the NICU team in evaluating family needs and resources. The NICU social worker is the first point of contact if the nurse has concerns about family members and their functioning. It is critical to update the NICU social worker on information the nurse receives from the family and to describe nurse observations of the family's adjustment to the NICU.^{7,11}

The NICU team can utilize psychologists and psychiatrists support families who are dealing with mental health issues.³ Professionals from the hospital business office and case management can educate families on the costs associated with the hospitalization, including obtaining health insurance.⁸ There are many federal, state, and local agencies that provide resources for families in need. The NICU social worker engages with these agencies to obtain the needed resources. Collaboration with NICU team members and allied health professionals enables mothers and fathers with significant challenges to become competent and confident in parenting their children.

CONCLUSION

The birth of an infant with CHD is a traumatic and overwhelming experience for parents and the entire family. The NICU team, most importantly the NICU nurse, provides a comforting and supportive milieu for the families to understand and care for their infant. Neonatal intensive care unit nurses who engage in self-reflection on their interpersonal approach and caregiving styles facilitate the family-centered, relationship-based practice that is integrated into all aspects of care for the family and the infant with CHD.⁹

Nurses spend the most time with the infant and the family on a daily basis. Families remember the nurses who cared for their child for the rest of their lives.^{8,9} Families view their relationship with the NICU nurse as essential to their confidence in learning to take care of their infant with CHD. Peer-to-peer support is beneficial to parents, and the professional NICU team can facilitate the development of a group of graduate parents of infants with CHD. Nurses have a tremendous responsibility in caring for the infant with CHD and an opportunity for a lifelong impact on the infant and the family.

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