FAMILY SUPPORT PROGRAM
UNC School of Social Work

Topical Briefs: Family Support & Family-Centered Care in the NICU

Having an infant in the Neonatal Intensive Care Unit (NICU) can bring an understandable amount of stress and anxiety on any parent as they begin to adjust to the new emotional, social, and developmental needs of their child. Family-Centered Care is an approach to health care based on the premise that stronger health outcomes can be achieved when a patient's family plays an active role in providing patient support (Goodwin et al., 2011). The American Academy of Pediatrics and the Institute of Medicine have identified family centered care as a vital component to serving the needs of the child. Our Family Support Network™ of North Carolina looks to aid families in the navigation of this support process, and answers common questions about the basis of Family-Centered Care below.

- The most common factors for the need of implementing family centered care is found in the increase in the number of infants in the NICU, growth in the current population's diversity, the realization of parental and family related stressors, lack of parenting confidence, and a gap in the continuum of care for parents of babies in the NICU (Gooding et al., 2011).
- Research has come to find that parents who engage in the FCC model are more effective in contributing to medical decision making, as well as health related care and keeping of their child, when the care is tailored to the patient and family's structure. This is often evident through open and honest communication with care providers and other staff (Gooding et al., 2011).
- Through the use of support groups, parent-to-parent, online & technology based support, as well as parent education and participation in care-giving, the FCC model provides supportive spaces for families and caregivers alike (Gooding et al., 2011).

Background of Neonatal FCC:

1. **Historical Context.** Although FCC has been present since the early 1800's, it was not until the 1970's that a campaign for patient and family centered care was put into effect. This push was a result of family needs for proximity in the hospital setting, as well as patients looking to gain proper control of patient care, access, and decision-making. This movement was led by Helen Harrison, who first pioneered the installment of FCC in 1993, along with Beverley Johnson, who later founded the Institute for Family Centered Care (now located in Bethesda, Maryland) (Gooding et al., 2011).

2. **A push for FCC in the NICU.** With more and more parents advocating to be involved in decisions about meeting their child's health needs, a push for FCC in hospital settings began. Although there is a higher demand for consumer participation within health care, we see there is still a lack of family centered care taking place in NICU's. There is significant encouragement for parents and infants to have constant interaction, however, this philosophy is not always consistent among NICU's. It is for this reason that FCC is imperative, allowing the parents to be able to participate more fully in caring for and making decisions for their child while in the NICU (Gooding, et al., 2011).

3. **Principles of Pediatric Family-Centered Care.** The foundations of pediatric family centered care were developed by the American Academy of Pediatrics in 2003, to guide the course of intended care. FCC upholds the respect of each child and family, honors racial and ethnic diversity, builds on the strengths of the child and family, supports parent choices for the child about proper care and support, allows for flexibility in policies and procedures that cater to the child, provides a safe place for sharing honest information with families, guarantees both informal and formal support for families, works in a collaborative way with families to meet the health care needs of the child, and empowers the family to succeed (AAP, 2003).

What FCC looks like in the NICU:

1. **Staff Participation.** All staff members are able to participate in FCC related care, even if they are not working with the child. These staff can provide adequate care by working to keep the culture and functioning of the NICU in alignment with the FCC principles, as well as making the environment welcoming for all family members. The more collaboration with parents, the more empowered and involved parents will feel in their ability to directly influence decision making (Gooding et al., 2011).

2. **Families who have been through the NICU experience.** Often times, families who have already been through a NICU related experience can offer support and encouragement within a NICU setting. This can be through teaching, home visits, discussion groups, role playing, and sharing supportive stories. Also, studies have found that contact with volunteer mentor parents allows for a stress-buffering influence to occur (Kerr & McIntosh, 2000). This collaboration is very valuable to parents who might be experiencing and navigating their child's health care decisions (Gooding et al., 2011).

3. **Creating a supportive space**. NICU design is imperative in lowering the stress level of a parent and supportive family members as they cope with the health of their child. The physical space itself needs to be conducive to family centered care, as well as responsive to the changing developmental, educational, emotional, and social needs of the family. This set up allows for families to feel comfortable and mimics a space for open and honest communication to effectively take place (Gooding et al., 2011).

4. **Parent-to-Parent support and Technology resources.** Being matched up with another parent who has already had an infant in the NICU can be a great foundation for providing family-centered care in hospital settings. By connecting with someone else who has had a similar experience, support is given in a unique way that not all medical providers can relay. It is through parent-to-parent support where NICU parents can feel relief and have the opportunity to share their feelings in a non-threatening environment. Parents may also benefit from online technology resources, as another option towards gaining support in a flexible medium. The March of Dimes provides electronic parent resources for NICU and infant health conditions (Gooding et al., 2011).

   Please see http://www.marchofdimes.org/baby/common-conditions-treated-in-the-nicu.aspx for more information regarding March of Dimes online NICU resources that are available to parents as they learn the health-related care and keeping of their child.

Benefits of FCC in the NICU:

5. **Improves parents' self-efficacy and confidence in the care & keeping of the child.** Family centered care instills the appropriate amount of confidence in the parents of NICU babies and is central in efforts to achieving the goals of family-centered care. FCC has shown parents ability to feel more comfortable in caring for their child, as well as the proper ways to engage with the infant. This self-efficacy reduces stress levels, anxiety levels, depressive symptoms, and increases competence in parenting techniques required for their infant (Gooding et al., 2011).

6. **Creates parent to parent support and relationships.** Caregivers who are matched with volunteer mentor parents have higher patient satisfaction, and parent to parent education helps effectively meet discharge needs and eases the transition to home, which can otherwise be overwhelming. Overall, families who engage in FCC have stronger relationships with their infant's physician and have an overall higher satisfaction rate during their time in the NICU (Gooding et al., 2011).

7. **Increases competency of the emotional, social, and developmental needs of the child.** FCC promotes bonding and attachment among patient and caregiver, as it strongly promotes skin to skin contact. This contact helps the body to adapt to a mother and gain appropriate bonding that is essential for social needs of the child. This is also beneficial for parents who are experiencing post-partum depression and depression related symptoms. During hospitalization, FCC strongly encourages for mothers and babies to be bonding, and promotes parent-child interactions to help in the development of the child (Gooding, et al., 2011).

References

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