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Family-Centered Care in the NICU

In this Issue...

Family-centered care (FCC), an established approach in pediatrics for more than 3 decades, came into use in neonatal intensive care units (NICUs) in the mid-1990s. Recently, FCC has emerged as standard care in NICUs across the United States, and is considered best practice by many. FCC involves a fundamental change from a view that parents are NICU visitors to one that recognizes, values, and enhances the key role parents play in the lives of their infants during their NICU stay. It is a comprehensive approach that empowers parents with the information and opportunities necessary to become active caregivers and decision-makers for their infants.

In this issue, we present the most recent literature on FCC in the NICU, with the goal of educating clinicians about how to best implement it to improve outcomes for neonates and their families.



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Course Directors

Edward E. Lawson, MD
Professor
Department of Pediatrics
Division of Neonatology
The Johns Hopkins University
School of Medicine

Christoph U. Lehmann, MD
Associate Professor
Department of Pediatrics
Division of Neonatology
The Johns Hopkins University
School of Medicine

Lawrence M. Noguee, MD
Professor
Department of Pediatrics
Division of Neonatology
The Johns Hopkins University
School of Medicine

Mary Terhaar, DNSc, RN
Assistant Professor
Undergraduate Instruction
The Johns Hopkins University
School of Nursing

GUEST AUTHOR OF THE MONTH



Commentary & Reviews:
Brenda Hussey-Gardner, PhD, MPH
Assistant Professor
University of Maryland School of Medicine
Department of Pediatrics,
Division of Neonatology
Baltimore, Maryland

Guest Faculty Disclosure

Dr. Hussey-Gardner has no relevant financial relationships to disclose.

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LEARNING OBJECTIVES

At the conclusion of this activity, participants should be able to:

- Contrast nurses' and parents' perceptions of family-centered care (FCC) in the neonatal intensive care unit (NICU)
- Describe to colleagues the benefits of FCC for parents with infants in the NICU
- Discuss with colleagues several different approaches for improving FCC in the NICU

COMMENTARY

The high-tech environment of the NICU, the infant's reliance on technology for life support, the distance of the hospital from home,¹ and the newborn's behavior and appearance² frequently leave parents of premature infants feeling helpless, as if they have no role in the care of their child. It has been well documented that parents of NICU patients are stressed by alterations in their parental roles.¹⁻⁵ Parents have the inherent right to provide for,

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nurture, and protect their child¹ and evidence points to improved childhood outcomes when professionals positively support the parent-child relationship in the NICU.⁶ FCC has been shown, in several instances, to reduce length of stays in NICUs and to improve condition of the infant at discharge. NICU parents want to learn how to care for their infants,⁷ and evidence supports the value of incorporating family members in this care.⁸ For these reasons, FCC has become standard practice in many NICUs across the nation.⁹

In 2003, the American Academy of Pediatrics established several core principles of FCC, all of which apply directly to the care of infants and families in the NICU¹⁰:

1. Respect each child and his/her family;
2. Honor racial, ethnic, cultural, and socioeconomic diversity, and its effect on the family's experience and perception of care;
3. Recognize and build on the strengths of each child and family;
4. Support and facilitate choice for the child and family about approaches to care and support;
5. Ensure flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family;
6. Share honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming;
7. Provide and/or ensure formal and informal support for the child and his/her parent (s);
8. Collaborate with families at all levels of health care, in the care of each individual child, and in professional education, policy-making, and program development;
9. Empower each child and family to discover their own strengths, build confidence, and make choices and decisions about their health.

Although the philosophy of FCC is easy to adopt, effective implementation may be more difficult. One cannot assume that all concepts will be equally embraced, and researchers need to investigate the perspectives of key stakeholders to gain a clear understanding of how to progress toward optimal implementation. As FCC may have the greatest impact on the role played by nurses, it is important to approach implementation from their perspective. Petersen and colleagues provide such guidance in an investigation of nurses' perceptions and experience with key elements of FCC. Since families are the beneficiaries of FCC, it is imperative to recognize their perspectives as well, an insight that is provided by Berns and associates in a study of parental perceptions on 4 specific FCC topics. FCC is a multifaceted approach that requires more than implementation of a single intervention, as well as ongoing evaluation to ensure a positive impact on the lives of infants and their families. To this end, Cooper et al. and Johnston et al. have evaluated 2 different approaches to implementing FCC, via NICU Family Support[®] and the FCC map.

It is our goal that, through a review of the research presented in this issue, clinicians will be aided in understanding, implementing and evaluating FCC in their individual units.

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FAMILY-CENTERED CARE: PERCEPTIONS AND PRACTICES OF NURSES

Petersen M, Cohen J, Parsons V. **Family-centered care: Do we practice what we preach?** *J Obstet Gynecol Neonatal Nurs*. 2004;33(4):421-427.

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The authors investigated nurses' perceptions and practices of FCC using the Family-Centered Care Questionnaire (FCCQ), which consists of 45, five-point Likert-type items across 9 subscales: family constancy, parent-professional collaboration, recognition of family individuality, sharing information, recognition of developmental needs, parent-to-parent support, emotional-financial support, design of the health care system, and emotional support of staff. Nurses ranked FCC components according to necessity and practice implementation.

Sixty-two surveys (54.3% of those sent) were returned; 37 from NICU nurses and 25 from pediatric or pediatric intensive care unit (PICU) nurses. Nurses concurred that all 9 components were necessary for FCC; mean scores ranged from 3.69 (parent-professional collaboration) to 4.53 (recognition of family individuality). Scores representing current FCC practice were significantly lower than necessity scores ($P=.000$); mean scores ranged from 3.06 (recognition of developmental needs) to 3.88 (recognition of family individuality). The greatest discrepancies existed in emotional support of staff (-1.059), design of the health care system (-1.034), and recognition of developmental needs (-0.996).

Compared to nurses with >10 years experience ($P=.02$ and $P=.017$, respectively), nurses with ≤ 10 years experience rated FCC elements as more important and reported using them more consistently. In addition, NICU nurses rated FCC as less necessary than pediatric and PICU nurses ($P=.013$); however, the groups did not differ in ratings of current practices.

There was a discrepancy between how nurses valued FCC and how far the implementation progressed in their NICUs, with the greatest differences found in organizational barriers of the health care system and lack of emotional support of staff. The authors note that simply embracing the philosophy of FCC is insufficient – organizations must also dedicate the resources necessary to achieve successful implementation.

The authors further note that the higher necessity and implementation scores of less experienced nurses may reflect current trends to include FCC in nursing education, and offer 3 explanations for the lower necessity scores of NICU nurses: 1) FCC is relatively new in the NICU, 2) NICU nurses care for babies prior to assimilation into their families, and 3) the high-tech NICU environment with its intimidating effects on parents may further negatively impact FCC. They recommend continued FCC education opportunities for nurses and families working together to develop practical FCC standards.

The authors suggest that future research into this area include sampling multidisciplinary team members and families from geographically varied institutions, modifying surveys to address cultural sensitivity, and implementing a pre-post survey design to study the effectiveness of interventions devised to enhance FCC.

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FAMILY-CENTERED CARE: PERCEPTIONS OF PARENTS

Berns SD, Boyle MD, Popper B, Gooding JS, the Premie Health Coalition. **Results of the Premature Birth National Need-Gap Study.** *J Perinatol.* 2007;27:S38-S44.

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This study, designed to assess parents' perceptions of caring for their premature infant in the NICU, used a 30-minute survey covering 4 FCC topics (NICU involvement, communication, information, and discharge preparation) and was conducted by USA/DIRECT, Inc. with a national sample of online household panel members. To broaden its reach to parents of preterm infants, the sample was supplemented by 5% telephone interviewing. Parents had to be ≥ 18 years and have > 1 child who was ≤ 30 months of age, born at ≤ 36 weeks' gestation, and hospitalized in a NICU. Of the 502 participants, 89% were female and 76% were White/Caucasian; 71.9% of the infants were born at > 32 weeks gestation, with mean overall length of stay at 2.88 weeks.

NICU Involvement: Eighty percent of parents described their initial reaction to the NICU as "worried/scared," and 70% as "nervous/overwhelmed." Eighty-five percent of participants reported being encouraged to become involved in their infant's care (eg, holding, changing diapers), 78% were satisfied with their level of involvement, and 22% would have liked to have been more involved. Parents cited resistance of nurses and limited visiting hours as primary reasons for their lack of involvement.

Communication: Eighty percent of families reported talking with their infant's nurses and physicians as often as they wanted, 69% were very comfortable asking questions, 68.5% felt that nurses and physicians listened to their concerns, and 60% were very satisfied with their level of involvement in decision-making. When asked what they would change about communication with nurses and physicians, 43% reported that they would not change anything, while others wanted more communication or better and quicker communication.

Information: Parents reported receiving information from a variety of sources (professionals, brochures, handouts); 89% stated they understood all or most of the information received; and 74.9% rated the amount of information received as appropriate. When asked what they would change about the information they received, 26% requested more information in general; when asked about areas of information to help them with their infant at home, parents requested information regarding development (31%) and venues for support (25%).

Discharge preparation: Thirty-seven percent of families stated they received discharge preparation throughout their infant's NICU stay, with 86% reporting that nurses provided this information. When asked what they would change about their discharge preparation, 13% desired more information, more hands-on experience, and additional practice and preparation time. Most parents (80%) reported being "happy/excited" about bringing their infant home.

The authors note several study limitations: the respondents were all English-speaking and most were female primary caregivers, and that the retrospective nature of the study was subject to recall bias. With these acknowledgments, the results suggest that most parents were satisfied with access to, and the attention and information received from, nurses and physicians. However, approximately one-fourth of parents were only moderately satisfied and nearly 10% were mostly or completely dissatisfied. The authors conclude that there is room to improve parental experiences in the NICU, and recommend that staff be sensitive to parents' fears and uncertainties, encourage parents to become more involved in decision-making and caregiving, help parents feel more comfortable asking questions, listen more carefully to parental concerns, provide parents with more information regarding their infant's progress and development, and begin discharge preparation earlier. They also suggest that professionals offer parents more information on premature infant development and outside support resources.

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FAMILY-CENTERED CARE: IMPACT OF NICU FAMILY SUPPORT®

Cooper LG, Gooding JS, Gallagher J, Sternesky L, Ledsky R, Berns SD. **Impact of a family-centered care initiative on NICU care, staff and families.** *J Perinatol.* 2007; 27:S32-37.

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The objective of this study was to evaluate the impact of the March of Dimes Foundation initiative, NICU Family Support® (NFS). NFS is comprised of a battery of interventions, which commonly include baby photos, scrapbooks, parent-to-parent support, parent education hours, and sibling education groups. The investigators used a quasi-experimental, post-only design to examine 8 of the 23 NFS sites previously evaluated by Health Systems Research Inc. in their 2005 national evaluation. Selected case sites (4 fully implemented sites) were non-randomly matched to comparison sites (3 partially implemented sites and 1 site that had not yet implemented NFS). Sites selection was based on average census, annual admission rates, and patient demographics. Data were obtained from telephone interviews with NICU administrators, and written surveys from NICU staff and families.

Administrators: NICU administrators identified the NFS Family Support Specialist as beneficial, noting that this individual focused on families while nurses concentrated on infants. Administrators also saw the NFS specialist as promoting hospital reputation and as a staff recruitment tool. However, they identified the primary benefits as NICU culture changes and additional support to families.

NICU Staff: Five-hundred-two NICU staff members responded to the survey (48% response rate), with 50% from fully implemented sites, 42% from partially implemented sites, and 8% from the not-yet-implemented site. Most respondents (66%) identified themselves as registered nurses. Of the respondents from fully implemented sites, 68% stated that NFS enhanced the quality of NICU care, citing more informed parents (81%), decreased parental stress (80%), increased parental confidence at discharge (75%), and enhanced parent-infant bonding (74%) as anticipated or actual positive effects. Staff perception of the importance of FCC in the NICU increased significantly following implementation of NFS ($P \leq .001$).

Families: Of the 216 families who responded to the survey (13% response rate), 30% were NICU graduates, and 70% were current NICU families. Eighty-three percent of the respondents from fully implemented sites indicated that talking with the NFS specialist reduced stress and increased confidence. When asked about preparation for discharge, families regarded the NFS specialist as the most helpful member of the health care team. Families from fully implemented sites were more comfortable giving care in the NICU. Additionally, they felt more knowledgeable regarding their infant's medical condition, growth, and development, and expressed a higher comfort level installing a child safety seat. Many families from fully and partially implemented sites reported making caregiving decisions "often" or "a lot" (56% and 60%, respectively), whereas those from the not-yet-implemented site reported a lower level of involvement (44%). Finally, 80% of families from fully implemented sites reported that their opinions were taken seriously "often" or "a lot" as compared to 71% of families from partially implemented sites and 50% of families from the not-yet-implemented site.

NFS had a positive impact on the stress, comfort, and parental confidence of families, and enhanced the receptivity of staff to FCC. The authors offer 2 explanations for the positive change: staff exposure to FCC tenets during NFS professional development, and staff opportunity to participate on the local March of Dimes NFS Parent-Staff Action Committee. The authors state that more research is needed to identify what interventions are most comforting to families, how and why changes in FCC occur, and short- and long-term outcomes of FCC.

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FAMILY-CENTERED CARE: IMPACT OF THE FAMILY-CENTERED CARE MAP

Johnston AM, Bullock CE, Graham JE, Reilly MC, Rocha C, et. al. **Implementation and Case-Study Results of Potentially Better Practices for Family-Centered Care: The Family-Centered Care Map.** *Pediatrics.* 2006;118:S108-S114.

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The “Family Matters” exploratory group of the Neonatal Intensive Care Quality Improvement Collaborative 2002 created the FCC map, which identifies 63 potential practice improvements. The map is web-based and designed for use by NICU staff and families. It parallels the clinical course of an infant and provides links to better practices, operational processes, and case studies. The authors of this study described 6 of these potentially better practices through 7 case studies at 3 different institutions (Sunnybrook and Women’s College Health Sciences Centre [SWC]; Vermont Children’s Hospital at Fletcher Allen Health Care [VCH]; and Joe DiMaggio Children’s Hospital [JDCH]):

1. A multimedia virtual tour to familiarize the family with the NICU environment, care philosophies, and health care team prior to admission;
2. Family visit by the NICU admission nurse to establish contact with the family prior to the birth of the infant;
3. Transport card and diary, to support the family’s initiative to envision and record their infant’s story;
4. “Family on Rounds” during weekly multidisciplinary rounds, to gain a better understanding of their newborn’s condition and an opportunity to be more involved in their infant’s care;
5. “Family on Rounds” during daily rounds, to gain a better understanding of their newborn’s condition and an opportunity to be more involved in their infant’s care;
6. A “Got Milk – Breast Milk is Best” program, to promote and support lactation, with components including education, guidelines on the handling/feeding of breast milk, information on the benefits of kangaroo care, and implementation of a weekly “Mother’s Milk Club”;
7. A “Watch Me Grow” program, to provide parental support through a weekly scrapbook/photograph album club.

Case studies of the virtual tour and family visits by the NICU admission nurse were conducted at SWC. A total of 25 staff members and 17 families completed a questionnaire after viewing the virtual tour, with all respondents indicating that the tour was helpful. Staff considered the medical terminology too complex, but families reported high levels of satisfaction with all aspects of the tour. Of the 10 families that received a visit from the NICU admission nurse, 9 reported the visit as helpful.

Case studies of the transport card and diary, and “Family on Rounds” during daily rounds were conducted at VCH. In response to “Family on Rounds,” the data demonstrated high family satisfaction even though communication on the existence of the rounds was poor and many parents never learned about the opportunity to participate. Measurement of family satisfaction revealed improvements in FCC. When asked about participation in planning their infant’s care and about how well they were helped to feel like a parent, ratings of very good and excellent increased from 76% to 93% and from 76% to 88%, respectively. In addition, hospital length of stay (LOS) for very low birth weight infants who were discharged home decreased from 73 to 60 days.

Case studies of “Family on Rounds” during weekly multidisciplinary rounds, “Got Milk – Breast Milk is Best,” and “Watch Me Grow” were conducted at JDCH. In response to “Family on Rounds,” families reported an improved understanding of their infant’s condition and greater opportunity to be involved in their infant’s care. While many of the fears that staff expressed prior to initiating “Family on Rounds” turned out to be unfounded, the disruption of moving family members in and out during rounds did pose some difficulty (this was addressed by permitting families to remain in the unit, with confidentiality protected by avoiding discussion of patients near other families). In response to “Got Milk – Breast Milk is Best,” families and staff reported satisfaction, and families expressed a sense of empowerment. With this program, the percentage of extremely low birth weight



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infants with discharge weights >50th percentile increased from 8.8% to 14.8%, and discharge head circumferences >50th percentile increased from 20.6% to 25.9%. The initial format of “Watch Me Grow” was a weekly scrapbook club: families took photographs of their infants weekly and brought them to the meeting where the events surrounding the photographs were discussed and put into a scrapbook. While funding was limited and the supplies ran out, the authors state that this format was successful. As such, the format changed to a weekly support group during which families were guided through a discussion of their infant while eating a light meal. Attendance fluctuated with unit census, with the highest attendance occurring when members recruited new NICU families. Twenty-four “Watch Me Grow” participants (light meal format) responded to a 10-item survey and reported an overall satisfaction rating of 95.3%.

The authors recognize that addressing FCC through a web-based tool is both rewarding and challenging for the participating institutions, with difficulties including measuring outcomes and staff attitudes maintaining patient confidentiality, and a lack of adequate family support spaces. Despite these issues, the authors report improvements in clinical outcomes (decrease in LOS at VCH) and family satisfaction, and conclude that there are predictable points during the NICU experience to apply potentially better FCC practices, and that use of the FCC map by NICU health care team members and others will help improve delivery of FCC.

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- Contrast nurses' and parents' perceptions of family-centered care (FCC) in the neonatal intensive care unit (NICU)
- Describe to colleagues the benefits of FCC for parents with infants in the NICU
- Discuss with colleagues several different approaches for improving FCC in the NICU

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