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# Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins, Advances, Impact

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Family-centered care (FCC) has been increasingly emphasized as an important and necessary element of neonatal intensive care. FCC is conceptualized as a philosophy with a set of guiding principles, as well as a cohort of programs, services, and practices that many hospitals have embraced. Several factors drive the pressing need for family-centered care and support of families of infants in NICUs, including the increase in the number of infants in NICUs; growth in diversity of the population and their concurrent needs; identification of parental and familial stress and lack of parenting confidence; and gaps in support for families, as identified by parents and NICU staff. We explore the origins of and advances in FCC in the NICU and identify various delivery methods and aspects of FCC and family support in the NICU. We examine the research and available evidence supporting FCC in the NICU and offer recommendations for increased dissemination and for future study. *Semin Perinatol* 35:20-28 © 2011 Elsevier Inc. All rights reserved.

**KEYWORDS** family-centered care, FCC, NICU, family support

Family-centered care (FCC) is an approach to medical care rooted in the belief that optimal health outcomes are achieved when patients' family members play an active role in providing emotional, social, and developmental support (Fig. 1).<sup>1</sup> In the neonatal intensive care unit (NICU), FCC shifts the attention from the disease alone to the patient in the context of his or her family and community.<sup>2</sup> Family members, especially parents, are natural advocates for the neonatal patient for whom the emotional, social, and developmental needs are serious and urgent. Family support activities

and programs are operated with the intention of helping families cope with the stress of having an infant in intensive care and supporting the family as they join in the care of their infant. In the FCC model, family members are most effective as contributors to the medical decision-making and healing processes when they are engaged in open and honest communication with care providers, and when care is tailored to the patient and family's cultural and ethical beliefs, family structure, and traditions.<sup>3</sup>

## Origins of Neonatal FCC

Through the 1800s, the birth and care of infants born in the United States encompassed FCC naturally although the term had not yet been coined. Most infants were born at home with little involvement of physicians, and care was provided almost exclusively by the mother and extended—usually female—family members. During the course of the 19th century, infant deaths were accepted as a normal part of life, a “reflection of the natural order in which the strong outlived the weak.”<sup>4</sup>

From the later third of the 19th century to the early third of the 20th, the American public was awed by technological

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## Principles of Pediatric Family-Centered Care

1. **Respecting** each child and his or her family
2. **Honoring racial, ethnic, cultural, and socioeconomic diversity** and its effect on the family's experience and perception of care
3. **Recognizing and building on the strengths** of each child and family, even in difficult and challenging situations
4. **Supporting and facilitating choice** for the child and family about approaches to care and support
5. **Ensuring 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. **Sharing honest and unbiased information** with families on an ongoing basis and in ways they find useful and affirming
7. **Providing and/or ensuring formal and informal support** (e.g., family to family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. **Collaborating** with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
9. **Empowering** each child and family to discover their own strengths, build confidence, and make choices and decisions about their health

**Figure 1** From AAP policy statement: family-centered care and the pediatrician's role.<sup>1</sup>

advances of the industrial age, including the advent of incubators and intensive hospital-based care for the sick neonate. In the early 1900s, Dr. Martin Couney demonstrated a combination of shocking showmanship and medical advances, publicizing the newly invented incubator by putting premature infants on display for public viewing in carnival exhibitions, during which time their mothers were not permitted to care for them.<sup>5,6</sup> This era marked the beginning of the separation of neonatal care from the family.

The separation continued into the 1930s, as labor and delivery moved from the home environment to the hospital setting, where infection control and medical interventions increasingly led to improved health outcomes in perinatal care. Once the shift began, it was rapid. Out-of-hospital births in the United States decreased from 44% in 1940 to 1% in 1969 and have remained approximately 1% for several decades.<sup>7</sup>

Care for the mother and infant shifted dramatically from in-home, patient-, and family-focused to the hospital. There, for infection control and ease of medical care, the mother was separated first from her husband and family and, after child-

birth, from her infant, often for her entire recuperation of 10 days. Concern about infection and sterility, along with advances in technology, led to an increase in artificial nutrition and stricter hospital regulations regarding family presence and participation in the infant's care.<sup>8</sup> The roles of physicians, nurses, and parents ran a parallel course with physician as authoritarian, nurses as gatekeeper to the infant, and families as bystanders.

By the late 1940s, some recognition of the need to address family needs for proximity in the hospital setting began to emerge. A campaign for patient- and FCC followed in the 1970s and continues through today. It is strongly supported by the informed, involved, participatory American consumer, who values control of care and decision-making.

The social changes leading to the empowered and informed healthcare consumer have also led to greater inclusion of parents in the care of their hospitalized child.<sup>9</sup> According to *Crossing the Quality Chasm: A New Health System for the 21st century*: "These new health care consumers represent new opportunities for responding to patient needs and re-establishing the clinician-patient relationship that are at the heart of good health care."<sup>10</sup>

As the 20th century closed and the 21st dawned, the FCC movement in America rapidly accelerated. In addition to consumer demand, this movement was driven by strong advocates such as Helen Harrison, who introduced the principles of FCC in the NICU in 1993,<sup>11</sup> and Beverley Johnson, who founded the Institute for Family-Centered Care (now the Institute for Patient- and Family-Centered Care)<sup>2</sup> and developed and defined FCC in health care.<sup>12</sup> In Harrison's seminal work summarizing the principles of family-centered neonatal care, she notes that "all of us share the belief that parents should be able to participate more fully in caring for and making decisions for their hospitalized newborns. We also believe that consumers, working in collaboration with professionals, can exert a powerful positive influence on the provision of medical care."<sup>11</sup>

Despite the increasing demand for consumer (parent) participation and the developments encouraging hospitals to adopt FCC as a philosophy of care, FCC initiatives continue to be sporadically implemented in NICUs. Although NICU culture shifted somewhat to encourage parent-infant interactions,<sup>13</sup> it continues to be inconsistent within and among neonatal units. Many parents nationwide remain dissatisfied with opportunities for parent involvement, physician-parent communications, availability of information, and transition to home planning.<sup>14</sup> High rates of psychological distress among NICU parents<sup>15,16</sup> and lifelong medical and neurodevelopmental problems among many preterm and low birth weight infants<sup>17</sup> further demonstrate the need to continue to incorporate FCC into NICU policies, procedures, and culture.

## Mechanisms for FCC and Family Support in the NICU

### NICU Staff

Staff members in all roles—even those not directly involved in patient care—can contribute to FCC. Formal training for

physicians and nurses in how to explain medical concepts to families fully and compassionately has been shown to be important.<sup>8</sup> Other examples of integration of FCC into the culture and functioning of the NICU include participation by families who have been through the NICU experience in teaching FCC to medical students through home visits, discussion groups, role playing, and sharing stories. This method is effective in helping medical students understand families' opinions about health care and their experience of the health care system.<sup>18</sup>

When NICU staff collaborate with parents, families become more involved in decision-making and are empowered to influence the process of their infant's recovery<sup>19</sup> and may alternate or share leadership of the care plan with the physician.<sup>18</sup> Parents derive support from nurses and physicians, highlighting the importance of training health care providers to adopt family-centered approaches.<sup>20</sup> Many families indicate that the best information they receive is from nursing staff.<sup>21</sup> In addition, the presence of a designated family support person has also been shown to be highly effective. Parents report that this support person helped parents feel less stressed, more informed, confident, attached to their infant, and prepared for discharge.<sup>20</sup> Hospital administrators indicated that a dedicated family support person was beneficial to NICU staff and to the quality of NICU care.<sup>20</sup>

### NICU Design and Supportive Spaces

The design of the physical space of the NICU is an important mechanism for family support and FCC. The Recommended Standards for Newborn ICU Design call for NICU designs to take into account infants', families', and staff members' medical, developmental, educational, emotional, and social needs.<sup>22</sup> The importance of supportive spaces is fully addressed and discussed in "The NICU Environment of Care: How We got Here, Where We're Headed, and Why" by Robert D. White, MD, in this issue.

### Support Groups and Parent-to-Parent Support

Contact with other families who have or had an infant in the NICU and who effectively adapted to or integrated the experience can be a valuable source of information, hope, advice, and support, especially when parents connect with other parents whose infant has or had a similar condition.<sup>1,11,20,23</sup> Methods of linking current NICU parents with former NICU parents include, but are not limited to, parent education hours, parent support groups, activities, such as scrapbooking nights, and initiatives in which former NICU parents volunteer to provide bedside or telephone support to new NICU parents.<sup>23,24</sup> Nevertheless, it is important to recognize and prevent any potential detriments of providing parent-to-parent support by individuals who have not been properly screened, prepared, trained and supported themselves.<sup>20</sup>

NICU parent support groups give parents a caring place to share their feelings and receive advice and information. Support groups positively influence parent-staff communications, parental coping, and parent-infant interactions.<sup>25,26</sup>

Hospitals in which parent support programs are developed through collaborations between parents and staff tend to have more numerous and enduring parent support services.<sup>27</sup>

### Online and Technology-Based Support

The Internet can provide a valuable round-the-clock source of parent support and may offer services to parents who do not feel comfortable joining a face-to-face parent support group. Many websites that are designed for all parents, including non-profit sites, such as <http://www.marchofdimes.com>, and commercial enterprises, such as <http://www.babycenter.com> have active message boards devoted to parenting infants who are premature or are in the NICU. A March of Dimes online community, <http://www.shareyourstory.org>, for parents who have or had a baby in the NICU has accumulated 35,550 members since its inception in 2004<sup>28</sup>; 12,000 members actively post stories and discussions online each year demonstrating a clear need for such a service.<sup>29</sup> The site has an infrastructure of health education, technical staff and parent volunteers with direct access to March of Dimes resources and information.<sup>29</sup>

Although consumer health information can be easily accessed on the Internet, parents should be cautioned and guided due to the risk of obtaining outdated or inaccurate information from unreliable websites or erroneous postings on unmonitored message boards.<sup>30</sup>

Technology-based support can be especially helpful when families are distant from the NICU. Videoconferencing technology can help families remain connected to the NICU if they are unable to visit their infant.<sup>8</sup> Families evacuated from New Orleans to states far away during and immediately after the 2005 hurricanes were provided photographs of their babies via e-mail, along with online information and resources.

Another example of available technology-based support modality is the March of Dimes NICU Family Support® Centers (computer kiosks or computer-on-wheels), which provide access to hospital and March of Dimes Web sites for information about the NICU and infant health conditions. At the computer kiosk in 42 host NICUs, families can also connect with and gain support from other families via online communities for NICU families. Hospitals that have installed the kiosks report high levels of family satisfaction with the service, with families logging into the Centers for an average of 4 minutes per visit (Bolzak, D. "NFS Center Usage Tracking Survey" March of Dimes, July 2010).

## Aspects of FCC and Family Support in the NICU (Fig. 2)

### Parent Education

Educating parents about the NICU environment, their infant's condition, and relevant procedures helps facilitate their active participation in family-physician discussions.<sup>2,11</sup> Parent education sessions and materials on topics such as infant development, NICU conditions, the emotional strain associated with a NICU experience, transition to home, and supporting siblings are rated highly by parents as helping to

### Aspects of family centered-care and family support in the NICU

- ✓ Information/materials
- ✓ Breastfeeding support
- ✓ Skin-to-skin holding
- ✓ Transport support
- ✓ Sibling support
- ✓ Photography
- ✓ Palliative care support
- ✓ Parent education seminars
- ✓ Family support activities (scrapbooking/craft)
- ✓ Parent to parent support
- ✓ Transition to home support
- ✓ Bereavement support
- ✓ Unlimited parent presence
- ✓ Parent participants in care and decision making
- ✓ Parents on rounds
- ✓ Support of specific populations (e.g., rural families, Native Alaskans, adolescent mothers)
- ✓ NICU staff emotional support
- ✓ NICU staff FCC development
- ✓ Parents as faculty
- ✓ Family advisory councils

**Figure 2** Aspects of FCC and family support in the NICU.

reduce their stress and increase parental confidence.<sup>20</sup> Best practice standards for the design of a NICU now recommend a family library or education area.<sup>22</sup> Educational materials that should be available to parents in the NICU or family library include audiovisual materials, publications, and Internet resources; lay and medical information about NICU conditions and procedures, infant loss and grieving; and information about local resources.<sup>11,22,31</sup>

### Parental Participation in Decision-Making

Collaboration between medical staff and family members to manage the infant's care is one of the cornerstones of FCC.<sup>11,18</sup> For a high-risk pregnancy, education should begin before birth when possible.<sup>16,20</sup> Informing a family during pregnancy of a known or high probability, potentially life-threatening condition can afford them time to accept the news, gather information, and discuss potential decisions they might make.<sup>11,31</sup> After NICU admission and throughout the duration of the NICU stay, parents should be offered frequent information about their infant's condition, including realistic prognosis based on the infant's condition and the capabilities of neonatal care.<sup>11</sup>

To keep parents informed and involved, some NICUs welcome parents on medical rounds to help them better understand their child's condition and to share their own perspectives about how the infant is faring.<sup>11,32,33</sup> Pediatric intensive

care unit parents preferred rounds, including the teaching portions, to be conducted at their child's bedside in their presence.<sup>33</sup> Including parents on pediatric oncology bedside rounds increased parent satisfaction with how much time the team spent with them, how many questions health care providers answered, how well their child was respected, and how seriously the staff took parents' concerns, echoing findings in several other research studies.<sup>33,34</sup>

In open-bay NICUs, concerns about confidentiality, including other families overhearing conversations, is one of the primary obstacles expressed by staff regarding parent-attended rounds.<sup>32</sup> However, some hospitals report solutions. Parents may be given or encouraged to use personal music players to block the conversations from other infants' rounds. Baptist Health Systems includes parents when rounding on their own infant, but asks that no other families be present in that area of the NICU while the rounds are underway.<sup>35</sup> Moreover, the recent trend in construction to single-room care helps alleviate privacy concerns and has enabled families to have more participation in rounds.

Providing information is important, but staff must accompany information with the context of the situation and implications of the decision; therefore, sharing not only information but the *meaning* of information is important to parents and begets shared decision-making (Table 1).<sup>20</sup> Decision-making, according to Campbell and Fleischman, should be neither "unidimensional nor unidirectional."<sup>36</sup> Shared decision-making is ideal because it avoids overwhelming parents with the sole responsibility for decision-making during a highly stressful time (a drawback of the patient autonomy model), yet welcomes more parent input than the paternalistic model.<sup>37</sup> Further, families should know that they are free to relinquish involvement in the decision-making process if they so desire.<sup>11</sup>

### Parent Presence and Participation in Care-Giving

Parent presence from admission to discharge with few or no limitations in the NICU allows parents to participate as fully as possible in the care of their infant, be present during both milestones and difficult procedures and build parental confidence long before discharge (Table 2).<sup>11,38,39</sup> Upon NICU admission, parental involvement in caretaking can begin with the father, other family member or family support person accompanying the infant to the NICU while the mother recovers from birth.<sup>8</sup> If the infant must be transferred to another hospital, it is important that parents be given a chance to see and touch the infant and take a picture before transfer occurs, to receive contact information for the other hospital, and to accompany the infant whenever possible.<sup>8</sup> A surprisingly high proportion of parents do not have the opportunity to see or hold their infant within the first 24 hours after birth, and this is associated with greater parental stress.<sup>40</sup> Connecting families with local resources and accommodations can also help parents remain involved in care-giving during the hospitalization.<sup>8</sup>

In the NICU, staff should help parents participate in feedings, procedures, and daily care. Special efforts to help fa-

**Table 1** Family-Centered Care Characteristics and Their Importance in the NICU, Pre- and Post-Implementation

Characteristic	Importance Preimplementation		Importance Postimplementation	
	Important or Extremely Important, %	Completely or Somewhat Unimportant, %	Important or Extremely Important, %	Completely or Somewhat Unimportant, %
Open and honest communication between professionals and parents on medical and ethical issues	84.1	3.0	91.6	0.9
Sharing information and the meaning of information with parents	82.2	3.9	93.3	1.8
Involvement of parents in decision-making	73.5	4.3	84.6	1.8
A partnership between professionals and parents in the provision of care	70.6	7.0	83.3	3.5
The development of policies and programs to promote parenting skills and family involvement	67.4	8.9	89.9	0.9

NICU staff survey, from Cooper et al.<sup>20</sup>

$P \leq 0.001$  for each characteristic.

thers create care-giving and bonding moments are important because they may encounter more barriers to establishing a relationship with their infant in the NICU than mothers do, and often are not able to spend time in the NICU as frequently.<sup>12</sup> The experience should be made as personal as possible, with staff referring to the infant (and parents) by name, and encouraging families to personalize the infant's area if they desire with photographs or other keepsakes.<sup>8</sup>

Much progress in expanding parent visiting hours, preferably referred to as "parent presence," has been made in recent years and some NICUs now have unrestricted parent visiting practices or an "open NICU." Still, many NICUs continue to close during nursing shift changes and reports, medical rounds, new admissions, emergencies, and neonatal deaths, and parents often are asked to step out during medical procedures, despite the evidence that parental presence can reduce a child's pain as well as reduce parental anxiety.<sup>1,40</sup>

During the hospitalization, some NICU parents report feeling that they are not truly parents until they are able to establish a

more tangible connection with their infant than viewing him or her through an incubator. Encouragement by staff of physical contact between parents and infants is extremely valuable. Breastfeeding and the exclusive provision of breast milk when possible is strongly encouraged,<sup>41</sup> enabling mothers to be highly involved and essential to their newborn. In addition, holding one's infant is one of the most comforting activities for NICU parents,<sup>20</sup> and skin-to-skin holding provides extensive benefits to the infant.<sup>42-44</sup> Further, skin-to-skin holding care has been shown to increase feelings of connectedness with the infant and increased satisfaction with parenting, as well as increased milk volume in breastfeeding mothers.<sup>45</sup> Hand-swaddling or facilitated tucking and similar forms of touch are also beneficial<sup>46,47</sup> and provide options for parents when an infant is not ready for holding.

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is demonstrated to provide individualized, family-centered, developmentally supportive care,<sup>48,49</sup> and involves parents directly in the care of their infant by teaching parents to read their infants' cues,

**Table 2** Activities in Which Parents Desired Greater Involvement in the NICU

Activity	Total (n = 109), %	Gestational Age, Weeks		
		35-36 (n = 40), %	33-34 (n = 46), %	≤32 (n = 23), %
Holding my baby	70.6	72.5	71.7	65.2
Knowing what tests were being done and why	68.8	67.5	69.6	69.6
Bathing	55.0	45.0	69.6*†	43.5
Nursing at the breast	41.3	42.5	41.3	39.1
Changing diapers	41.3	42.5	45.7	30.4
Kangaroo care	33.0	17.5	37.0*	52.2*
Administering medications	28.4	17.5	34.8	34.8
Holding the nasogastric tube during feedings	23.9	15.0	21.7	43.5*
Providing breast milk	20.2	25.0	19.6	13.0

From Berns et al.<sup>14</sup>

\* $P \leq 0.05$  vs 35-36 weeks.

† $P \leq 0.05$  vs 32 weeks.

understand their unique strengths and needs, and respond appropriately.<sup>48</sup>

### Family Presence in the NICU

Creating a family-centered environment encompasses making the NICU a place where the whole family feels welcome and valued as important contributors to the infant's well-being and where the needs of the family unit are supported. A fundamental component of family support is making visiting hours for siblings and other family members as flexible as possible.<sup>8</sup> A family support approach addresses the needs of siblings who are often sidelined while a family's newborn becomes the center of crisis and attention. Visiting the NICU provides older siblings a valuable opportunity to get to know the newest member of their family, understand the infant's condition in a developmentally appropriate way, and receive reassurance that they remain a valued member of the family.<sup>50</sup> Allowing opportunities for family interactions beyond the parents results in improved parent-infant relationships.<sup>38</sup>

In the past, NICUs have typically limited child visitation because of concerns about increased risk of infection and worries that the sensory and emotional experience of the NICU might be traumatic for young children.<sup>50</sup> When children are prescreened for illness before entering the NICU, they may present no greater risk of infection than adults do.<sup>51</sup> Similarly, when children are informed of what to expect, are prescreened for psychological readiness to visit the NICU, and are provided with information and activities appropriate to their developmental level, visiting the infant can be healing, not harmful, for siblings.<sup>50,51</sup>

Methods of educating and supporting children when they visit their sibling include offering reading and coloring books to help them make sense of the experience and express their thoughts and feelings.<sup>52</sup> Conducting activities designed specifically for sibling groups help the siblings have fun, boost self-esteem, and express their emotions.<sup>52</sup> During these group meetings, parents receive advice on how to support siblings during an infant's hospitalization. Such groups are especially effective when they do not focus solely on how siblings are handling the NICU environment but when they serve as a more general emotional outlet for all aspects of the siblings' daily lives.<sup>52</sup>

### Supporting Families When An Infant Dies

For families anticipating or grieving their infant's death, a compassionate and culturally sensitive approach to bereavement support is critical. The death of a newborn often leaves families grieving the hoped-for plans, dreams and wishes for a child and may leave very few actual memories of time spent or life mementoes. Therefore, staff should encourage families to create as many family memories as possible while the infant is alive, including but not limited to holding the infant in their arms or through skin-to-skin holding; cuddling; breastfeeding; and caring for the infant through dressing, diapering, bathing, and feeding.<sup>31</sup> Including older siblings in these rituals is important. When interviewed in adulthood, siblings of infants who died in the NICU reported wishing

that they had had more chances to see and hold the infant in the NICU when he or she was alive, and appreciated the memories they had of doing so.<sup>53</sup>

When there are ethnic or cultural differences, health care providers may not be aware of heritage and cultural practices surrounding the birth experience and end-of-life traditions and families may experience difficulty communicating those to health care providers.<sup>54</sup> Having bicultural and bilingual team members and training all staff to be sensitive to other cultural beliefs and customs surrounding death and dying is important to supporting families appropriately.<sup>31</sup>

Many NICUs hold an annual memorial service such as at Brigham and Women's Hospital, to honor the infants who have died, allowing families and staff to remember the infant together.<sup>53,55</sup>

### Transition-to-Home Support

A standard mantra for NICU professionals is that *discharge begins at admission*, and FCC is consistent with this approach.<sup>56</sup> However, many families report being ill-prepared for discharge and lacking confidence about their ability to provide for their infant's care after leaving the NICU.<sup>14,20</sup> If parents are encouraged to be involved in their child's care from the beginning, they become increasingly prepared for hospital discharge as the NICU stay continues.<sup>56</sup> Because NICU infants are more likely to have continuing medical problems needing further treatment at home, this hands-on care-giving practice before leaving the hospital is important.<sup>57</sup>

Parent education classes and workshops can be held as discharge nears, giving parents the opportunity to learn skills such as infant cardiopulmonary resuscitation. These sessions also provide opportunities to discuss such topics as the prevention of sudden infant death syndrome; safe-sleeping practices; smoke-free homes; respiratory syncytial virus; car seat use; preventive measures related to reducing risk in subsequent pregnancies, such as that for preterm birth; and more.<sup>20,58</sup>

Spending the night with their infant in a transition room before discharge can help prepare parents for going home.<sup>59</sup> Families can also help document the infant's progress, participate in discharge planning rounds, and help individualize the content of discharge planning to their family's situation.<sup>56</sup>

## Outcomes of FCC and Family Support Practices in the NICU

### Supporting Families' Psychological Wellbeing

Various FCC initiatives have shown promising results in relation to improved parental mental health. Mothers who participated in the Creating Opportunities for Family Empowerment (ie, COPE) program, an audiotaped educational-behavioral program about how to engage with and care for their hospitalized infant, were less stressed than mothers who did not participate in the program.<sup>60</sup> Mothers who had contact with a March of Dimes NICU Family Support Specialist reported less stress and higher parenting confidence<sup>20</sup> and parents in NICUs with fully established FCC programs feel more at ease

helping to care for their infant in the NICU.<sup>20</sup> New mothers of very preterm infants who received peer support through a “buddy” program experienced less state anxiety, less depression, and greater social support than mothers who did not participate in the program.<sup>61</sup>

Positive outcomes of sibling visits include fewer behavior problems and decreased aggressive and regressive behavior among siblings<sup>51</sup> and a sense of increased family unity for parents.<sup>50</sup>

There is strong evidence for skin-to-skin holding contributing to parental well-being, stress reduction and feelings of confidence and competence in parenting.<sup>43,62</sup> An additional benefit for mother’s well-being may be reduced maternal postpartum depression and anxiety symptoms.<sup>63,64</sup> For fathers, skin-to-skin holding may reduce fears of harming the fragile infant.<sup>65</sup>

## Bonding and Attachment

Developmentally supportive care methods, particularly skin-to-skin holding, have been shown to positively impact maternal sensitivity, affectionate behaviors, and bonding.<sup>43,62,66-68</sup>

Premature and low birth weight infants may be at heightened risk for later abuse and neglect.<sup>69</sup> One study reported that infants who were later abused or neglected had been visited less by their parents during hospitalization.<sup>70</sup> FCC can contribute to prevention of these negative outcomes through increased parent–infant bonding and attachment during the hospitalization.

## Length of Stay

Several programs that support families and promote an FCC approach have successfully decreased NICU length of stay. One such program is COPE, which has been found to decrease NICU stay by an average of 4 days.<sup>60,71</sup>

NIDCAP also decreased average age at hospital discharge, with observed decreases varying from 2.19 to 19.6 weeks.<sup>72-75</sup> Although parent involvement and participation in care is an important component of developmentally supportive care—and essential to some developmental care practices, such as skin-to-skin holding—it is not clear the degree to which parent involvement in the practices studied was a factor in length of stay reduction.

A recent study in Stockholm suggests that an aspect of family-centered care—unlimited parent presence—did enhance the parent’s role and, potentially, the impact of developmentally supportive care.<sup>39</sup> Facilities for parents to stay in the NICU 24 hours per day from admission to discharge were shown to reduce length of stay in intensive care, and to reduce total hospital length of stay. Total length of stay for premature infants (<37 weeks of gestation at admission) was 5.3 days shorter in the group of infants whose parents had unlimited stay in the NICU.<sup>39</sup>

## Infant Health

Skin-to-skin contact is the FCC-related practice with the strongest evidence of impact on infant health. Numerous studies demonstrate various infant health improvements, in-

cluding decreases in apnea episodes,<sup>76</sup> more time in sleep which is critical for brain development,<sup>77</sup> increased maturation rate of the circadian system,<sup>78</sup> more regular heart rate,<sup>42</sup> and reduced infection frequency.<sup>79</sup> The aforementioned Stockholm study also reported lower prevalence of moderate-to-severe bronchopulmonary dysplasia in the infants whose parents had unlimited access, which may indicate that parental involvement could impact infant morbidity.<sup>39</sup>

## Parent Satisfaction With Care

Families who perceive their relationship with their infant’s physician as being positive and family-centered are more likely to be satisfied with overall care received.<sup>80</sup> Moreover, positive communication between physician and parents, which FCC fosters, increases how satisfied parents are with care and improves their perception of the physician’s competence, regardless of the severity of a neonatal adverse outcome.<sup>81</sup> FCC programs can also increase parent satisfaction by making parents feel that their opinions are being respected and providing them with more opportunities to become involved in their child’s care.<sup>20</sup> Parents whose infants were cared for using the NIDCAP developmental care program have been shown to be significantly more satisfied than parents of infants who received traditional care.<sup>49</sup>

## Staff Satisfaction

Improved staff satisfaction because of hospitals’ commitment to FCC in pediatric and adult hospital settings has been associated with more positive feelings about work,<sup>1</sup> decreases in nursing vacancies,<sup>82</sup> and improved job performance<sup>1</sup>. In the NICU, some positive staff attitudes are shown to accrue from one aspect of FCC – parent participation in care – but there are negative attitudes as well.<sup>9</sup> Hospital administrators where NICUs have a designated March of Dimes NICU Family Support staff person report greater ability to recruit and retain NICU staff.<sup>20</sup>

## Conclusion and Recommendations for Further Study

Despite the significant need to support families with infants in intensive care and the clear benefits of such support, significant progress is needed in both uptake of FCC and family support and in building the base of evidence for discrete practices and for comprehensive FCC programs.

Numerous individual components of FCC have been demonstrated to be successful and several comprehensive program models have seen strong success in establishing FCC practices. Models and approaches noted for success in this article and cited elsewhere include the efforts of the Institute for Patient- and Family-Centered Care, policies and guidelines of the American Academy of Pediatrics, Vermont-Oxford Network collaborative, the Family-Centered Care Map,<sup>83</sup> March of Dimes NICU Family Support, Creating Opportunities for Family Empowerment (COPE) program, and incorporating developmentally supportive care initiatives,

including NIDCAP. In addition, many hospitals have instituted components of FCC and have distributed their lessons learned and best practices.

Despite the progress of these organizations and programs to disseminate FCC practices and models, the uptake by NICUs has not been widespread or rapid. Even skin-to-skin holding, which has been clearly demonstrated to have numerous health and other benefits, has not been fully adopted in U.S. NICUs. Organizations committed to FCC dissemination should continue to develop approaches to removing the barriers to FCC in the NICU, promote best practices and models in FCC and family support, and work together to share methods to facilitate adoption.

Although there are a large number of excellent studies on some components of FCC, there are few large-scale randomized control studies to support most FCC practices or models of care. There are multiple research gaps in demonstration of the impact of FCC: (1) some components of FCC need initial or additional evidence to support their implementation in the NICU; (2) population-based research regarding family support in the NICU is minimal; (3) information and outcomes about inequities among populations is particularly lacking; (4) the impact of family support in the NICU on maternal health, especially related to risk in subsequent pregnancies, has yet to be studied; (5) the impact of family support in the NICU on family stability and security is needed; (6) the impact of NICU FCC on infant/child health, including rehospitalization, potential abuse and neglect, and longer-term child health needs much further evidence; and (7) financial and other resource implications of FCC and family support is not fully documented. Finally, dissemination and uptake of FCC in the NICU will be advanced best by the examination of the complex interplay of a comprehensive set of FCC components for its potentially wide-ranging and far-reaching impact on the family, the infant and the NICU staff.

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## References

- American Academy of Pediatrics: Policy statement: family-centered care and the pediatrician's role. *Pediatrics* 112:691-696, 2003
- Johnson B: Family-centered care: four decades of progress. *Fam Syst Health* 18:137-157, 2000
- Griffin T: Family-centered care in the NICU. *J Perinat Neonat Nurs* 20:98-102, 2006
- Brosco J: The early history of the infant mortality rate in America: A reflection upon the past and prophecy of the future. 1. *Pediatrics* 103:478-485, 1999
- Davis L, Mohay H, Mothers EH: Involvement in caring for their premature infants: an historical overview. *J Adv Nurs* 42:578-586, 2003
- Silverman W: Incubator-baby side shows. *Pediatrics* 64:127-141, 1979
- MacDorman M, Menacker F: Trends and characteristics of home and other out-of-hospital births in the United States, 1990-2006. *CDC. Natl Vital Stat Rep* 58:1-16, 2010
- Phillips C: Family-Centered Maternity Care. Boston, Jones and Bartlett Publishers, 2003
- Power N, Frank L: Parent participation in the care of hospitalized children: A systematic review. *J Adv Nurs* 62:622-641, 2008
- Committee on Quality of Health Care in America, IoM: *Crossing the Quality Chasm: A New Health System for the 21st Century*: Washington, DC, National Academics Publishing Group, 2001
- Harrison H: The principles for family-centered neonatal care. *Pediatrics* 92:643-650, 1993
- Johnson BH, Abraham M, Conway J, et al: *Partnering With Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*. Bethesda, MD, Institute for Family Centered Care, 2008
- Brown W, Pearl L, Carrasco N: Evolving models of family-centered services in neonatal intensive care. *Child Health Care* 20:50-55, 1991
- Berns SD, Boyle MD, Popper B, et al: Results of the premature birth national need-gap study. *J Perinatol* 27:S38-S44, 2007
- Franck L, Cox S, Allen A, et al: Measuring neonatal intensive care unit-related parental stress. *J Adv Nurs* 49:608-615, 2004
- Shaw R, DeBlois T, Ikuta L, et al: Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics* 47:206-212, 2006
- Browne J: New perspectives on premature infants and their parents. *Zero to Three* 24:4-12, 2003
- Feldman H, Ploof D, Cohen W: Physician-family partnerships: the adaptive practice model. *J Dev Behav Pediatr* 20:111-116, 1999
- Bowen N: The role of the NNP in facilitating family-centered care. *Neonat Netw* 26:271-272, 2007
- Cooper L, Gooding J, Gallagher J, et al: Impact of a family-centered care initiative on NICU care, staff and families. *J Perinatol* 27:S32-S37, 2007
- Kowalksi W, Leef K, Mackley A, et al: Communicating with parents of premature infants: who is the informant? *J Perinatol* 26:44-48, 2006
- White R: Recommended standards for newborn ICU design. *J Perinatol* 26:S2-S18, 2006
- Lindsay J, Roman L, DeWys M, et al: Creative caring in the NICU: parent-to-parent support. *Neonat Netw* 12:37-44, 1993
- March of Dimes. For Families: the NICU Family Support Program. Available at: [http://www.marchofdimes.com/prematurity/index\\_families\\_5769.asp](http://www.marchofdimes.com/prematurity/index_families_5769.asp). Accessed November 2, 2010
- Bracht M, Ardal F, Bot A, et al: Initiation and maintenance of a hospital-based parent group for parents of premature infants: key factors for success. *Neonat Netw* 17:33-37, 1998
- Nottage S: Parents' use of nonmedical support services in the neonatal intensive care unit. *Issues Compr Pediatr Nurs* 28:257-273, 2005
- Vale IN, de Souza SR, Carmona EV: Nursing diagnoses identified during parent group meetings in a neonatal intensive care unit. *Int J Nurs Terminol Classifications* 16:65-74, 2005
- Share Your Story. Available at: <http://www.shareyourstory.org>. Accessed: September 16, 2010
- Soohoo J, Gooding J: Bringing comfort through an online community (poster presentation). 22nd Annual Gravens Conference for the Physical and Developmental Environment of the High-Risk Newborn, 2009
- Dhillon A, Albersheim S, Alsaad S, et al: Internet use and perceptions of information reliability by parents in a neonatal intensive care unit. *J Perinatol* 23:420-424, 2003
- Catlin A, Carter B: State of the Art: creation of a neonatal end-of-life palliative care protocol. *J Perinatol* 22:184-195, 2002
- Bramwell R, Families WM: Views on ward rounds in neonatal units. *Arch Dis Child Fetal Neonat* 90:F429-F431, 2005
- Landry M, Lafrenaye S, Roy M, et al: A randomized, controlled trial of bedside versus conference-room case presentation in a pediatric intensive care unit. *Pediatrics* 120:275-280, 2007
- Lewis C, Knopf D, Chastain-Lorber K, et al: Patient, parent and physician perspectives on pediatric oncology rounds. *J Pediatr* 112:378-384, 1988
- Baptist Health Systems: NICU orientation packet. Available at: <http://www.mbbc.org>. Accessed November 2, 2010
- Campbell D, Fleischman A: Limits of viability: dilemmas, decisions, and decision makers. *Am J Perinatol* 18:117-128, 2001
- Davidson J, Powers K, Hedayat K, et al: Clinical practice guidelines for support of the family in the patient-centered intensive care unit—

- American College of Critical Care Medicine task force. *Crit Care Med* 35:605-622, 2004-2005
38. Franck L, Spencer C: Parent visiting and participation in infant caregiving activities in a neonatal unit. *Birth* 30:31-35, 2003
  39. Örténstrand A, Westrup B, Broström E, et al: The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity. *Pediatrics* 125:e278-e285, 2010
  40. Franck L, Cox S, Allen A, et al: e, in Parental Concern and Distress About Infant Pain: Disease in Childhood-Fetal and Neonatal, Edition 2004, UCL Eprints. Available at: <http://eprints.ucl.ac.uk/10218/>. Accessed November 2, 2010
  41. Merewood A, Philip B, Chawla N, et al: The baby-friendly hospital initiative increases breastfeeding rates in a US neonatal intensive care unit. *J Hum Lact* 19:166-171, 2003
  42. Aucott S, Donohue PK, Atkins E, et al: Neurodevelopmental care in the NICU. *Mental Retardation and Developmental Disabilities* 8:298-308, 2002
  43. Ferber S, Makhous I: The effect of skin-to-skin contact (kangaroo care) shortly after birth on the neurobehavioral responses of the term newborn: a randomized, controlled trial. *Pediatrics* 113, 2004
  44. Tessier R, Cristo M, Velez S, et al: Kangaroo mother care: a method for protecting high-risk low-birth-weight and premature infants against developmental delay. *Infant Behav Dev* 26:384-397, 2003
  45. Nagorsky-Johnson A: The maternal experience of kangaroo holding. *J Obstet Gynecol Neonatal Nursing* Nov Dec: 568-573, 2007
  46. Cignacco E, Hamers J, Stoffel L, et al: The efficacy of non-pharmacological interventions in the management of procedural pain in preterm and term neonates: a systematic literature review. *Eur J Pain* 11:139-152, 2006
  47. Harrison L: The use of comforting touch and massage to reduce stress for preterm infants in the neonatal intensive care unit. *Newborn Infant Nurs Review* 1:235-241, 2001
  48. Westrup B: Newborn individualized developmental care and assessment program (NIDCAP)—family-centered developmentally supportive care. *Early Hum Dev* 83:443-449, 2007
  49. Wielenga J, Smit B, Unk K: How satisfied are parents supported by nurses with the NIDCAP model of care for their preterm infant? *J Nurs Care Qual* 21:41-48, 2006
  50. Montgomery L, Kleiber C, Nicholson A, et al: A research-based sibling visitation program for the neonatal ICU. *Crit Care Nurse* 17:29-40, 1997
  51. Ballard J, Maloney M, Shank M, et al: Sibling visits to a newborn intensive care unit: implications for siblings, parents and infants. *Child Psychiatry Hum Dev* 14:203-214, 1984
  52. Munch S, Leveck J: I'm special too: promoting sibling adjustment in the Neonatal Intensive Care Unit. *Health Soc Work* 26:58-64, 2001
  53. Fanos J, Little G, Edwards W: Candles in the snow: ritual and memory for siblings of infants who died in the intensive care nursery. *J Pediatr* 154:849-853, 2009
  54. Shaefer J: Cross-cultural expressions of grief and loss. II. When an Infant Dies (volume 2). *NFIMR Bull* Nov:2-29, 2003
  55. NICU memorial service held. Brigham and Women's Hospital Bulletin, 2005 Available at: <http://www.brighamandwomens.org/publicaffairs/publications/DisplayBulletin.aspx?articleid=3161>. Accessed December 2, 2010
  56. Griffin T, Abraham M: Transition to home from the Newborn Intensive Care Unit: applying the principles of family-centered care to the discharge process. *J Perinat Neonat Nurs* 20:243-249, 2006
  57. Sheikh L, O'Brien M: Parent preparation for the NICU-to-home transition: staff and parent perceptions. *Child Health Care* 22:227-239, 1993
  58. DeFranco E, Stamilio D, Boslaugh S, et al: A short interpregnancy interval is a risk factor for preterm birth and its recurrence. *Am J Obstet Gynecol* 197:264-266, 2007
  59. Broedsgaard A, Wagner L: How to facilitate parents and their premature infant for the transition home. *Int Nurs Review* 52:196-203, 2005
  60. Melnyk B, Feinstein N, Alpert-Gillis L, et al: Reducing preterm infants' length of stay and improving parents' mental health outcomes with the creating opportunities for parent empowerment (COPE) neonatal intensive care program: a randomized, controlled trial. *Pediatrics* 118:e1414-e1427, 2006
  61. Preyde M, Ardal F: Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. *CMAJ* 168:969-973, 2003
  62. Gayle G, Vandenberg KA: Kangaroo care. *Neonat Netw* 17:69-71, 1998
  63. Anderson GC, Moore E, Hepworth J, et al: Early skin to skin contact for mothers and their healthy newborn infants. *Birth* 30:206-207, 2003
  64. De Alencar AE, Arraes LC, de-Albuquerque EC, et al: Effect of kangaroo Mother Care on postpartum depression. *J Trop Pediatr* 55:36-38, 2009
  65. Bauer J, Sontheimer D, Fischer C, et al: Metabolic rate and energy balance in very low birthweight infants during kangaroo care holding by their mothers and fathers. *J Pediatr* 129:608-611, 1996
  66. Morrison B: Kangaroo care for fullterm infants: state of the science. Available at: <http://kangaroo.javeriana.edu.co/encuentros/6encuentro/abstract2.pdf>. Accessed November 3, 2010
  67. Feldman R, Eidelman A, Sirota L, et al: Comparison of skin-to-skin (kangaroo) and traditional Care: parenting outcomes and preterm infant development. *Pediatrics* 110:16-26, 2002
  68. Furman L, Kennell J: Breastmilk and skin-to-skin kangaroo care for premature infants: avoiding bonding failure. *Acta Paediatr* 89:1280-1283, 2000
  69. Spencer N, Wallace A, Sundrum R, et al: Child abuse registration, fetal growth and preterm birth: A population based study. *J Epidemiol Community Health* 60:337-340, 2006
  70. Hunter R, Kilstrom N, Kraybill E, et al: Antecedents of child abuse and neglect in premature infants: a prospective study in a newborn intensive care unit. *Pediatrics* 61:629-635, 1978
  71. Melnyk B, Feinstein N: Reducing hospital expenditures with the COPE (creating opportunities for parent empowerment) program for parents and premature infants. *Nurs Adm Q* 33:32-37, 2009
  72. Als H, Lawhon G, Duffy F, et al: Individualized developmental care for the very low-birth-weight preterm infant: medical and neurofunctional effects. *JAMA* 272:853-858, 1994
  73. Fleisher BE, Vandenberg K, Constantinou J, et al: Individualized developmental care for very-low-birth-weight premature infants. *Clin Pediatr* 34:523-529, 1995
  74. McAnulty G, Duffy F, Butler S, et al: Individualized developmental care for a large sample of very preterm infants: health, neurobehavior and neurophysiology. *Acta Paediatr* 98:1920-1926, 2009
  75. Peters KL, Rosychuk RJ, Hendson L, et al: Improvement on short-and-long term outcomes for very low birthweight infants: Edmonton NIDCAP trial. *Pediatrics* 124:1009-1020, 2009
  76. Cleary GM, Spinner SS, Gibson E, et al: Skin-to-skin parental contact with fragile preterm infants. *J Am Osteopath Assoc* 97:457-460, 1997
  77. Graven S, Graven M: The full-term and premature newborn: Sound and the developing infant in the NICU: conclusions and recommendations for Care. *J Perinatol* 20:S88-S93, 2008
  78. Feldman R, Eidelman AI: Skin-to skin contact accelerates autonomic and neurobehavioral maturation in preterm infants. *Dev Med Child Neurol* 45:274-281, 2002
  79. Ludington-Hoe SM: Physiological responses to skin-to-skin contact. *Heart Lung* 19:445-451, 2003
  80. Van Riper M: Family-provider relationships and well-being in families with preterm infants in the NICU. *Issues Neonat Care* 30:74-84, 2001
  81. Moore P, Adler N, Robertson P: Medical malpractice: the effect of doctor patient relations on medical patient perceptions and malpractice intentions. *West J Med* 173:244-250, 2000
  82. Conway J, Johnson B, Edgman-Levitan S, et al: Partnering with patients and families to design a patient-and-family-centered health care system: a road map for the future. *Inst Famcentered Care* 14-15, 2006
  83. Dunn M, Reilly M, Johnston A, et al: Development and dissemination of potentially better practices for the provision of family-centered care in neonatology: the family-centered care map. *Pediatrics* 118:s95-s108, 2006