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Mothers' Experiences in the NICU Before Family-Centered Care and in NICUs Where It Is the Standard of Care

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Abstract

Background: Family-centered care (FCC) in neonatal intensive care units (NICUs) was initiated in 1992 to promote a respectful response to individual family needs and support parental participation in care and decision-making for their infants. Although benefits of FCC have been reported, changes in the maternal experience in the NICU are unknown.

Purpose: The purpose of this study was to compare mothers' experiences in NICUs where FCC is the standard of care and to compare these with the experiences of mothers 2 decades ago.

Methods: In this qualitative descriptive design, mothers of infants born under 32 weeks postconceptional age were asked to describe their experiences with their infant's birth and hospitalization. Open-ended probing questions clarified maternal responses. Saturation was reached after 14 interviews. Iterative coding and thematic grouping was used for analysis.

Results: Common themes that emerged were: (1) visiting; (2) general caregiving; (3) holding; (4) feeding; and (5) maternal ideas for improvement. Findings indicated important improvements in privacy, mother–nurse relationship, ease of visiting, and maternal knowledge and participation in infant caregiving.

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Implications for Practice: Mothers suggested improvements such as additional comforts in private rooms, areas in the NICU where they can meet other mothers, and early information on back-transport. Better recognition and response for mothers without adequate social support would provide much needed emotional assistance.

Implications for Research: Future research addressing benefits of webcams, wireless monitors, back-transport, maternity leave, and accommodations for extended visiting for siblings would address other needs mentioned by mothers.

Keywords

family-centered care; infant holding; NICU; social support

Neonatal intensive care units (NICUs) were developed in the early 1960s to decrease morbidity and mortality of infants born prematurely, but the emphasis was on physical care and not family involvement.[1] Family-centered care (FCC) was officially proposed in 1992 to ameliorate parental complaints of difficulties obtaining accurate information about their infants' conditions, treatments, and prognoses; parental exclusion from medical and ethical decision-making; unnecessary impediments to the nursing and nurturing of infants in the NICU; and frustration over inadequate discharge planning and follow-up.[2] Thus, FCC promotes a respectful response to individual family needs and values through attending to family visitation, general infant caregiving, infant-holding practices, and feeding. Essential components of the model include private rooms instead of open units with limited privacy that were the normative environment of the early NICU, 24-hour visitation that includes siblings, partnership between parents and healthcare providers, skin-to-skin (STS) holding of the infant on the parent's chest, and support for human milk feeding.[3]

Increased efforts were made to implement FCC after guidelines published by the Institute of Medicine in 2001, and these efforts are ongoing.[3-6] Benefits of FCC are shortened length of infant hospitalization, reduced hospital readmissions, better neurodevelopmental outcomes and infant weight gain, less maternal anxiety, and higher-quality maternal caregiving.[7-9]

Although qualitative and quantitative descriptive studies have been published about mothers' NICU experiences, we do not know how the maternal experience in the NICU has changed since inception of FCC. This inquiry is part of a larger mixed-methods study to examine current maternal visiting and participation in infant care that includes holding and feeding in the NICU. This qualitative component of the study was conducted to examine mothers' experiences in NICUs where FCC is the standard of care, and to compare these experiences with those of mothers 15 to 25 years ago as reported in the literature. Findings of this study were expected to highlight positive changes in maternal experiences, persisting problems, and ideas for future NICU enhancements.

LITERATURE REVIEW

To compare prior understandings of mothers' experiences of visiting, holding, and feeding their infants in the NICU with the current qualitative study, we first conducted a thorough review of the literature in the years 1993 through 2003. During this time

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guidelines were being developed on how to implement FCC, but it was not standard practice in most NICUs.[10] We searched the PubMed database using the following search terms combined with NICU (eg, Family Centered Care AND NICU): Family Centered Care; Maternal Visiting; Visiting; Back-Transport; Social Support; Maternal Caregiving; Discharge; Mother-Nurse Relationship; Kangaroo Care; Kangaroo (KC) Holding; Skin-to-Skin (STS) Care; Skin-to-Skin Holding; Holding; Feeding; and Breast Feeding. Inclusion criteria for articles were qualitative or quantitative research; NICUs in the United States; and mothers' experiences. Also included were quantitative studies that showed percentages of back-transport, maternal caregiving, kangaroo (STS) holding, and feedings in the NICU. Excluded were opinions of nurses and/or physicians about FCC, literature reviews, guidelines, quality improvement projects, and case studies.

We found 146 articles from the years 1993 through 2003 about the topics of interest and eliminated articles on guidelines (n = 45); literature reviews (n = 6); case studies (n = 16); nurse/physician opinions (n = 6); and articles outside the United States (n = 36). We used 29 articles addressing maternal perceptions or experiences, and 8 studies that measured percentage of human milk use, kangaroo holding, and back-transport policies in the NICU, for a total of 37 studies. Of these studies, 12 were qualitative, and 25 were quantitative. Designs used in the 25 quantitative studies were: descriptive (n = 2); survey (n = 11); chart review (n = 4); experimental cross-over (n = 3); phase-lag (n = 2); quasi-experimental (n = 1); and randomized controlled trial (n = 2).

Samples ranged from 10 to 44 (qualitative), 36 to 537 (survey), 15 to 42,891 (chart review), and 8 to 169 (quantitative). The literature review is organized into 4 components of family-centered care: (1) visiting, (2) general caregiving, (3) holding, and (4) feeding.

Visiting

The original design for NICUs was an open ward with multiple beds and a curtain providing limited between-bed privacy.[1,11] The lack of privacy made extended visiting uncomfortable. Mothers complained that the lack of privacy, constant unit activity, and noise from alarms interfered with holding, breastfeeding, and feeling close to their infants.[11-13]

They also mentioned annoyance when overhearing personal conversations of other families, nurses, and physicians.[11-13] Responses to a mailed survey (n = 207) indicated that, in addition to the NICU environment and personal stress, transportation difficulties/lengthy distance from the hospital, lack of affordable overnight housing, childcare for siblings, extended NICU hospitalization, and restricted visiting policies made visiting their infants very difficult.[11] Mothers reported visiting daily to every 2 weeks with length of time between visits related to distance from the hospital and extended length of hospitalization for the infant.[11,14]

Mothers highly valued social support from their parents, other relatives, and friends, reporting that this support helped to reduce their stress and increase coping with their infants' illness.[15,16] However, having the infant hospitalized far from home, visiting restrictions, and lack of understanding of the mother's experience resulted in withdrawal of these individuals in some cases. Mothers described how painful and disappointing it

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was if their normal social support networks pulled away after the birth.[17] Lower levels of social support were associated with higher levels of anxiety, hostility, and depression in one study.[17] In a study conducted in 1995, 54% of mothers desired a support group in the hospital. Of these mothers 73% desired talking to other parents whose infant had a similar condition.[11] The benefits of support provided by experienced and trained volunteer parents were being investigated. Volunteer parents offered emotional, informational, and role-modeling support through hospital visits, phone contact, and home visits during the infant's hospitalization and throughout the infant's first year of life.[18] When compared with a control group, mothers who received the parent-to-parent intervention reported significantly less stress, anxiety, and better self-esteem 4 months postdischarge and optimal mother–infant interaction at 12 months postdischarge.[19]

Back-transport of convalescing infants to community hospitals close to their homes was done to avoid overcrowding in the high-acuity NICUs.[20] Although 80% of community hospitals could accept an infant requiring an incubator, tube feedings, and oxygen, back-transport was limited by a shortage of appropriately trained nurses.[20] Mothers reported worrying about complications during the transfer, differences in environment and caretaking practices, and feelings of powerless in decision-making regarding the transfer. Maternal perceptions of a positive transfer were associated with better pretransfer preparation, fewer infant medical problems after transfer, longer hospitalization in the high-acuity NICU, and availability of support systems close to home.[21,22]

General Caregiving

Mothers recalled extreme anxiety and fear of hurting their preterm infant even when the infant was considered medically stable. Medical rounds held away from the bedside impeded mothers from participating in decisions and learning about their infant's condition.[2,23] Monitor wires, feeding tubes, and mechanical ventilation were mentioned as obstacles to caregiving.[13,24] Loss of the parenting role and lack of knowledge were a common complaint and source of stress.[14,24-26] Findings from a mail survey about maternal caregiving (n = 207) showed that 90% of mothers held their infant, 79% brought toys and clothing, 19% fed, bathed, and/or diapered their infants, and 18% gave medications.[11]

The role of the nurse was an important factor in the mothers' feelings about caregiving. In some studies, mothers described nurses as important, competent, and helpful.[15,24,27] They reported less stress and more satisfaction with caregiving when they had a good relationship with nurses.[25,28] In other studies, the relationship between parents and nurses in NICUs was described from a power perspective, with the nurse possessing the power. Sometimes the relationship became hostile.[29,30] Mothers related feeling powerless, like outsiders, and needed to leverage their communication/behavior to assume the ability to care for their infant.[29,30] They did not want to take over the nurses' role or ask for help because the nurses seemed too busy.[29]

Anxiety about taking the infant home was reported. This was primarily related to dependence on the cardiac and pulse oximetry monitors and concern about the infant's fragility and potential health problems.[25,26,31,32] Conversely, mothers reported happiness

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about the ability to make their own decisions about their infant and that at home the infant was truly theirs.[14]

Holding

Articles on holding primarily addressed safety of the STS (eg, temperature, heart and respiratory rate stability, and sleep).[33-36] Anxiety was reported in regard to mothers holding their infant, especially STS holding. Mothers who were fearful of harming their infant hesitated to ask for nursing assistance because they believed that the nurses would think they were incompetent.[13] Nevertheless, when asked to discuss their feelings during STS holding, mothers related an increased sense of meaning, mastery, self-esteem, and healing after holding STS for 3 consecutive weeks.[37] Mothers also described feeling a special quality of the parent–infant interaction, intense connectedness, and active parenting. STS holding, however, was not routinely used or promoted, and some mothers waited several weeks before they were able to hold their infant by any method.[13] Barriers to STS holding were infant safety concerns and nurse, physician, or mothers' reluctance.[38]

Feeding

Efforts were being made to promote breastfeeding using parent teaching, lactation support, or education for nurses.[39] Provision of human milk during and after hospital discharge continued longer when mothers were given support such as expression and collection of human milk, sessions on breastfeeding, and consultation as needed before and after discharge.[39] STS holding also was used to promote feeding of human milk. In a phase-lag study, 24-hour milk volumes 2, 3, and 4 weeks after delivery showed that mothers who held STS had a strong linear increase in milk volume while no change in volume was found for mothers who did not hold STS.[40] Mothers were more likely to continue providing human milk after discharge if they had held STS in the hospital,[33] but most mothers fed their infants using bottles.[39] Mothers related that they felt a tangible claim to their infant knowing that they were providing the healthiest nutrition, and perceived that the infant was tranquil while breastfeeding.[40]

Several retrospective chart review studies were conducted to determine the percentage of mothers who provided human milk in the NICU. One review of 151 charts shows that 50% of infants received any human milk during their hospitalization.[41] A review of charts for all admissions in 124 NICUs in the United States (n = 42,891 infants) also showed that 50% of infants were discharged on some human milk.[42] In a review of 350 charts, maternal initiation of providing human milk increased from 31% to 47% after instituting a lactation service.[43] Human milk feeding increased from 35% to 74% according to a chart review of all infants in a 15-bed NICU examined 1 year before and after establishment of Baby Friendly Policies (delivery of human milk feeding support). At 2 weeks, continuance of human milk feedings increased from 28% to 66%, and exclusive human milk feedings at 2 weeks increased from 9% to 39%.[44]

In summary, findings of studies conducted on components of FCC from 1993 to 2003 showed that visiting was uncomfortable and restricted, with mothers often traveling long distances to see their infants. The social support they desired was limited by time traveling

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to the hospital and lack of understanding by others. Parent-to-parent support groups were being formed that eased stress and anxiety of mothers. Mothers expressed anxiety about caregiving and holding their infants, and expressed hesitation to ask for help from nurses. Provision of human milk feedings was aided by lactation support programs.

METHODS

With a goal of comparing the aforementioned experiences of mothers 15 to 25 years ago to current maternal experiences in the NICU, we conducted a qualitative descriptive study to provide an in-depth depiction of current maternal experiences when FCC is the standard of care in the NICU. We recruited participants from 2 teaching hospitals in the Western United States. One NICU is located in a children's hospital that serves infants born prematurely and at term with complex medical or surgical issues. Infants often are transferred from other hospitals in a wide catchment area that includes the metro area, as well as several neighboring states. The unit consists of 74 private rooms and 8 twin rooms for a total of 82 bedspaces with a pull-out bed and a recliner in each room. Both parents can stay overnight with their infant. Nine lactation consultants cover 3 breastfeeding clinics, outpatient ambulatory clinics, and all inpatients in the hospital. The second recruitment site is a NICU within a university-based birthing hospital where most infants are in-born. The unit is divided into 4 pods, each holding 8 to 12 infants. Each bedspace has a private area that is closed with a curtain. There are 6 twin spaces, private family rooms where parents can stay and be close to their infant, and 2 "rooming-in" rooms where the infant stays with parents and is monitored while parents provide care with NICU team support. Parents either request the "rooming-in" rooms or are encouraged by the NICU team to stay a night or two before taking their infant home. A lactation support specialist is available.

Eligibility criteria for participant mothers included: infants (1) less than 32 weeks postconceptional age at birth, (2) at least 33 weeks postconceptional age, and (3) hospitalized in the NICU for at least 2 weeks at the time of the interview. Mothers were excluded if they were diagnosed with a psychiatric disorder such as bipolar disorder or schizophrenia and/or recorded or stated illicit substance use. Purposive sampling identified a diverse sample of mothers, and enrollment stopped when no new perspectives on the research questions were obtained.[45] We obtained human subject approval from the hospital and university institutional review boards. Mothers signed informed consents.

The nurse researcher on the team, who was skilled in interviewing mothers in the NICU, used semistructured, open-ended questions to explore mothers' experiences. Mothers chose to be interviewed at their infant's bedside or in a private room within the NICU. The interviewer opened the conversation by asking mothers to describe their pregnancy and birth experiences. Open-ended questions about visiting, availability of social support (eg, family and work), and care experiences in the NICU followed. The researcher asked open-ended questions about holding and feeding in the NICU and discharge concerns if not mentioned by the mothers.

Interviews were transcribed verbatim by a paid research assistant. The interviewing researcher and another investigator began the coding process by individually reading the

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transcripts several times to immerse themselves in the data. A theoretical approach[46] was used to focus on mothers' narratives relating to maternal visiting and infant caregiving, holding, and feeding. To connect closely with the data, the researchers chose not to use analysis software.

The 2 researchers independently bracketed sections of each interview that addressed the topics of interest and labeled these with code words.[47,48] They each compiled a table of participant statements that supported researcher-identified themes. They then discussed their coding and interpretations until agreement was reached. Rigor was addressed[48] in several ways. We strengthened credibility with (1) ongoing discussion between the 2 investigators about the emerging themes; (2) summarization of participant comments; and (3) use of the mother's own words during data analysis to help preserve participant perspectives. Purposive sampling addressed transferability. Confirmability and dependability were addressed with an electronic audit trail that included field notes, and coding rationale.

For the larger study, mothers completed diaries about their visiting, caregiving, holding, and feeding while in the hospital. For this qualitative portion of the larger study, a research assistant calculated averages of these activities. We used those averages to describe our sample's visiting, caregiving, holding, and feeding activities and for comparison with past research.

RESULTS

The sample consisted of 14 mothers. One infant was hospitalized in an open unit out of state and then transferred to the children's hospital. Seven infants (50%) were hospitalized in the children's hospital, 6 infants (43%) in the university hospital, and 1 infant in both units. The average length of travel time to the hospital was 54 minutes, with a range from 5 minutes to 3 hours. All infants were is the NICU. Table 1 lists demographic information in the sample.

Mothers' comments corresponded well to the 4 themes of interest: visiting, general caregiving, holding, and feeding. They are detailed next.

Theme 1: Visiting

Mothers interviewed for this study visited often. Only 4 mothers visited fewer than 6 days a week. Daily visiting time ranged from 2.5 to 24 hours, with a median of 6.5 hours. Postpartum complications of the mothers were Bell's palsy, poor recovery from a cesarean section (C-section) (resulting in hospitalization), infection, and preeclampsia. Unless mothers were hospitalized out of town or had an infection, they visited or stayed with the infant in spite of their pain/discomfort.

Necessity for childcare for siblings, however, made visiting difficult for some mothers:

> Because I had my child in the summer, it helped a lot. I was able to leave the 8 year-old and the 2-year-old with the 16-year-old. But it got difficult when school started back up because they're at school and I can't bring the 2-year-old up here because he's very active, so I have to wait until they are out of school.

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Extended infant hospitalization resulted in financial issues. The hospitals did fund a portion of food and fuel costs, but sometimes this was not enough. Several mothers discussed that back-transport of the infant to hospitals closer to their homes would have eased visiting the infant:

> We're a 45-60 minute drive away so I've been coming on the bus in the morning during the week so that I can be here for his 9 a.m. care, and drive home in the afternoon, because we have dogs at home. So drop them off at doggie daycare, then come back in the afternoon (with husband) and drive home in the evening together around 8 pm or so. We just found out that it would cost $2500.00 for the back-transfer. Obviously, we were spending money coming here every day, but at that point we were already 4 weeks into it. If we had known about that (back-transfer) earlier it would have made more sense. It would have been essentially the same cost as what we have been spending on daycare for the dogs, and coming in and food and stuff.

> Definitely being able to be closer to where you live if there's not a medical necessity, it would just reduce a lot of stress and result in better bonding, Like if we were in Longmont, we'd get to see him every day. Cause like right now it's not like you can come in and go home for a couple of hours. It's like you're committed to staying here.

Mothers who lived at the greatest distances from the hospital roomed in with the infant or stayed in hotels or with family near the hospital. Comfort was important to these mothers.

> This is like my second home chair right here. Some nights I'll just spend the night in here, cuz they have family rooms for the moms to be able to stay in, and I'll rent those out sometimes. If I can't I'll just stay here. I ask "do you mind if I hang our here?" And they'll be like "that's no problem." So I'll just sit here and stay up with her, and go home the next day.

> Well, it's really nice here. I feel comfortable, I feel safe. I enjoy being here. It is just like it would be at home. I have a TV in front of me, a laptop on my lap and 3 meals a day or whenever I want to eat. Honestly, when I come here I get sleepy because it's so peaceful.

> They have only the one kind of comfortable chair where you have to hold the baby on, and my husband wanted to do skin-to-skin. I'm just post-op after having a C-section, and there was nowhere comfortable for me to sit.

Mothers expressed varied opinions about private rooms and open-pods.

> I'm very grateful for the private room and I'm a social person so I've met moms other ways. It's really a comfortable environment."

> I like the open pod because I can see other mothers. It is easy to meet them and talk. The nurses can see the babies all the time."

Social support from their spouse, other family members, friends, and community seemed important to mothers in this study. The infants' fathers visited whenever they were not working. Mothers also expressed appreciation for other support.

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> Our church (members) were very supportive. They made meals for us every night so that we didn't have to cook or anything. My husband's parents are about an hour away. They come every other day to the hospital. And my mom is planning on coming down here for a week.
>
> The community and my family, they are so sweet. Everyone just reaches out and tries to help." My mom comes every Thursday and then my husband and I come here together on Saturdays and Sundays. I have an incredible family. My great aunts and niece have visited. My husband's two sisters and my parents live close. One of my best friends has my other son almost every Saturday and Sunday of the last two months."

These comments contrasted with 2 mothers whose husbands visited but the mothers either had no supportive friends or family, or who perceived inadequate support:

> My mom is elderly and has health issues. My sister came and visited for a couple of days. Both of my brothers have their own family stuff going on, same with my husband's brother. We don't have family close by and we only moved here less than 2 years ago. Most of the time here I've been dealing with pregnancy complications so we haven't really developed a large network of people here. I am looking for a postpartum doula. We do not have experience with infants to help with that transition to becoming parents. So being first-time parents, and not having family close by, I thought it would be good to have someone.

The second mother had family who were taking care of the other children.

> It's just us and our family. It's hard being away from the family. It's definitely not very accommodating here to bring my kids. I think there could be a little more leeway for the restrictions. We were rushing to get all four of our other kids up here and we had to do it separately, two at a time, just to get them up here so they were able to at least meet the babies.

Although many mothers shared some concerns or negative experiences about their time in the NICU, the 2 mothers who lacked support seemed to have more negative experiences than the others. Their interviews were long and seemed to reflect a need to process their frustrations.

Support groups led by a health professional were available in both hospitals. Mothers also mentioned talking to other mothers in the NICU or online support groups. However, not every mother appreciated support groups.

> I ran into this lady who had a little girl. It was really helpful just talking. We went to see the motorcycles together, so that was a lot of fun. I ended up talking with her kind of a lot and that was really helpful because she was kind of in the same boat. And then I talked to another lady down the hall. It made a big difference talking to another mom as opposed to talking to anyone else.
>
> One of the things that helped me was I joined a couple of NICU support groups (online) which kind of helped me know what to expect from other moms and help me understand some of the terms from a layman's perspective. And then there are

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> some moms in there whose other kids are 2 or 3 years old. So to kind of know that as far as milestones.
>
> I don't really participate in them cuz they just ask stupid stuff, like they're probably not going to listen to you anyways. They post something and there's 30, 45 moms commenting on 30 different things. I'd rather just call an aunty or someone I know who actually knows what they're talking about, not just a bunch of random moms on the internet that think they're doctors.

Theme 2: General Caregiving

Mothers in the FCC units in this current study related anxiety about caregiving when their infants were first admitted to the NICU. Mothers related comments such as:

> It's just the noisy equipment and the wires.
>
> You're obviously intimidated because they're tiny and there are a lot of things hooked up to them and they're in a box (incubator) which is scary.

In spite of the initial anxiety, however, these mothers related that they were changing diapers and doing other simple caregiving tasks within the first week. Most mothers were able to touch their infant within the first 24 hours. All performed routine cares (eg, diaper change and bathing), spending an average of 28% of their visiting time on these activities.

> I could hold her. I could change her diaper. They could never not let you do that. It was just a matter of you had to make sure you were here at her exact care times or right before and get help with cares. But now that she's breathing better and can tolerate her feeds, I can get her out, say I come at like 11:30 and her feeds are at 11, they will let me take her out cuz they are more familiar with me and they're familiar with her.
>
> At first we could do hand hugs which is just resting pressure on him, because he was really sensitive to touch. I think it was like when he was a week old, we started to be able to interact a bit more and change his diaper.

Mothers appeared knowledgeable and comfortable with medical terminology and jargon.

> Do you know what a PDA is? At the beginning, I think it was within the first week or so of his life, they did an ECHO to discover that the PDA was open and large so they tried Indocin for a period. It didn't close it, but it shrunk enough to where it wasn't causing symptoms.
>
> She has been taking the bottle for the past few days and that's new for her. She's learning to drink and breathe at the same time. Whenever she wakes up, that's when we start to bottle feed her, and you don't force it on her. She gets excited and she starts to suck and forgets to breathe. It's pretty scary, but you have to stay calm and just know what to do.

Daily medical rounds were conducted at the bedside of each infant, and mothers could attend these regularly. Mothers used several ways to become comfortable with medical terms.

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> Talking to the therapists, nurses, just asking a lot of questions. Because I don't really know. This is my first premature baby. I was so terrified when I first had him, I didn't know what to do, so I had to learn. So I read a lot, reading helps a whole lot.
>
> They ask you if you want to be in for the rounds every time and I'm like, "of course I want to be in for the rounds." They'll just open up the door and let you sit in.

Mothers readily discussed their relationship with the nurses.

> Obviously there's a lot of different nurses here, but they've been really good about helping teach you what to do and help you learn new things. They're going beyond just providing him care; they're helping us learn to be parents.
>
> In the beginning I was less confident. I didn't want to take over, you know the nurses are here for a reason. As time has gone by I think building a primary team has been huge for us. They have confidence in me. They know that I am capable. They are totally fine with me picking them up and holding them, or kangarooing, or changing a diaper, or turning off the alarm for the food.
>
> We don't have many primary nurses. We have the one evening nurse and she's really great, so that's helped having her consistently watch him and having one person see him as he grows and see the changes in him. It takes away the anxiety of being here. They all know what they're doing which is helpful and they're willing to share the latest information.

Mothers were less happy with inconsistent care:

> There has been a high turnover rate for nurses with me. Instead of keeping the same nurse for a week, I would have different nurses. They didn't know that I loved to do cares.

If a mother felt the nurses had not advocated for her, she expressed some resentment. A mother whose twins were separated for routine room cleaning and was told that her infants would be back in their rooms by morning explained:

> The next day I got here like 1 p.m. after work, and they were still in those rooms, still separate, and there was no movement of getting them back into their old rooms. And I just remember that … looking back it was a weird to get so upset about it but it was very … you know when everything is so out of whack, when you're one comfort is knowing that they're in a room together, safe, and then all of a sudden they're not … I remember having a hard day that day.

All mothers interviewed in our study related confidence in their ability to care for their infants. Several mentioned that they felt ready to take their infant home the day of the interview. Regardless of the amount of confidence the mothers reported, most mentioned that their greatest fear was taking their infants home without a monitor or pulse oximeter:

> I think the biggest thing is just that worry of is everything going to be okay? Here he's on the monitor all of the time so you've got that safety blanket that if something goes wrong, a) you'll know about it and b) there's people here that jump

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> right in and help with it. Because even now he still has times where his heart rate drops or his oxygen drops, and I know you (infant) have to go a certain amount of time without that happening before you can be discharged, but I'm a worrier by nature so it's the kind of what if? Because sometimes too, he'll be sleeping on me like this and I don't notice something is wrong until the alarms go off. So it's like when I'm home and don't have that am I going to miss something?
>
> I am hyperaware of everything and I think the separation of no longer seeing it (monitor) but being able to tell just be looking at him will be hard. Because right now he looks fine, and then I look at the monitor and I know he's okay. But without it. I'm kind of dependent on it. Here he has 24/7 care by multiple people, so that will be different when it's just me.

Theme 3: Holding

On average, mothers held their infants on day 3 following admission/birth (ranging from day of admission to 10 days). Skin-to-skin holding was the standard of care and often was done soon after admission even when the infant required assisted ventilation. All mothers held skin-to-skin style for 1 to 7 hours per day, which was an average of 28% of their visiting time. Only 7 mothers held the infant wrapped in a blanket in their arms in addition to skin-to-skin. Most mothers were positive in their comments.

> He did love it (skin-to-skin holding), and that's the only choice they give you, so that's what we did up until he got extubated.
>
> We did skin to skin the night they were born. They were on CPAP. I do skin-to-skin with both of them together now every day.
>
> I'll start her feeding doing skin-to-skin. I learned that she digests better when she's doing skin-to-skin on her stomach. Sometimes I'll cradle her but usually I'll do skin-to-skin because she likes it the most. I know it's great for the baby when you're breast feeding. They say it helps you produce milk. It helps the baby gain and maintain weight, so it's beneficial. It helps the baby get closer to you, and I feel great when she's just laying there. I'm like, my little baby is right here.

All mothers held skin-to-skin in the initial days of hospitalization, but 7 began making their own holding decisions, holding both blanket and STS or discontinuing STS.

> It's been harder now that I am actually breast feeding every three hours, because I try to breastfeed whoever is awake, and then I pump for 30 minutes, to truly empty. And then by that time when there is really only an hour and 15 minutes before the next time that we are going to be waking somebody up and trying to feed them. So I am getting the hang of this new schedule, which has been for a week. Before that I did kangaroo care every day. When they were all tubes, I did kangaroo care at least 2 to 4 hours a day."
>
> I find myself liking to hold then just like a normal kiddo wrapped up just cuz they can see you and it's just fun to be able to do that.

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> It depends on what outfit I'm wearing really, like today I would just hold her with a blanket, but yeah if I'm wearing an outfit that's suitable for me to do a kangaroo hold, I'll do that. Either way, I enjoy holding her. I don't really care how I'm holding her.

Theme 4: Feeding

Lactation support was readily available in both nurseries, and mothers stated how easily they could obtain assistance with breastfeeding. Half of the mothers provided human milk. The other mothers had inadequate milk supply, had an infant still receiving nasogastric feedings, or chose not to provide human milk.

> Everyone's here to help you, but then you go to the other side of it where he has to meet certain minimums to go home and it's hard to calculate how much you're getting by breast, so it's one of those … it's a bummer because I would love to just breastfeed him but I also want him to get his numbers so that he can come home, So I'm like, let's get him home, and then we'll work on it once we get home.

> Well, I was breastfeeding solidly, you know, but I recently stopped. I'm just trying to wean her on to formula because I'm going to start working and it's going to be hard to work and pump. And I know they say that it's the law for employers to allow you to pump but that's just going to be so much work, and I don't know if I'm ready for that. It's a life style choice, Breast feeding is not just something you can do like "oh yeah, I'm going to breastfeed now." No, it's something that you do that your life revolves around. Completely. It's hard. It's definitely a struggle.

Theme 5: Maternal Ideas for Improvement

Mothers were asked if they had ideas for change. In spite of the general positivity expressed by mothers, they suggested improvements.

> My god … if the monitors could be wireless, it would change everything. The technology is there. It's just somebody taking the time to do it!

> It would be nice to have a dedicated space for NICU families. Since you're spending so much time here, it's not like you're just here for a couple of days. People are living here, spending weeks, if not months. Having something just for NICU families where you could get food sent to you if you wanted to buy it or whatnot, I think would be a lot. Again, just all those things that are extra to stress about, and worry about, and deal with.

> There were two things that I was so jealous of (in online support groups). One of them was that when they had their babies, their hospital beds were in the NICU so that they didn't have to go – because I had to go down a floor and I actually had to walk across, and I had a C-section so it was a slow, long walk to get here. And then the other thing I saw that quite a few of the hospitals had was cameras that were on the baby 24 hours a day so that they could log on to the internet to see their babies.

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If there are two parents, having two chairs that are comfortable to sit in, especially if you're going to be spending all day here, which we have been spending a lot of time here, would be nice.

It would be nice to have a fridge because I didn't realize I wasn't eating and spent a week munching on a box of crackers. And then after a week it wasn't even all finished and that was the only thing I had eaten and I didn't realize it.

Maybe follow-up with parents that can't be down here all the time, follow up with them doing the rounds type thing, or calling them more often with happy things, cuz every time the phone rings, it's like "Oh no." And then the primary nurse thing. Even as your baby gets stable, it's still nice to have primaries. I have been here for 14 weeks and I never knew this (parent lounge) was here! Maybe, like, after parents get settled in if they're going to be here for the long road to be able to show them their resources and actually show them where they are. Because I didn't know where case management was until I started to get the boys moved to our local hospital and I was calling everyone I could possibly think about. The social worker came by and said "Hi", but because I wasn't here all the time…it just would have been nice for someone to say, "Here are their offices if you ever need to talk to them. Here's lactation offices, here's the family lounge, help yourselves to whatever is in here," just stuff like that.

DISCUSSION

This study compared experiences of mothers of infants in the NICU 15 to 25 years ago with those of mothers of infants in NICUs currently practicing FCC. Comments of mothers in this study indicate that FCC has eased some of the difficulty and distress of extended NICU hospitalization, but also that more can be done. Implementation of FCC is continually evolving to maximize infant development and parent involvement. Because survival rates are increasing for extremely low birth-weight infants without a corresponding decrease in neurological disability, emphasis is being placed on medical and psychosocial interventions within the first 72 hours.[4] The Neonatal Integrative Developmental Care (NIDC) model includes 7 measures with a NICU healing environment (eg, appropriate touch, smell, taste, sound, and light input),[49] partnering with families, positioning and handling, safeguarding sleep, optimizing nutrition, protecting skin, and minimizing stress and pain.[4] Another model is the Neonatal Intensive Parenting Unit (NIPU),[5] which is focused on psychosocial support for the family's involvement with their infant. Components are family-centered developmental care, mental health professional support, peer-to-peer family support, staff education and support, postdischarge follow-up, and palliative and bereavement care.[5]

Mothers now may stay with their infants 24 hours a day if they have parental leave, childcare, no other responsibilities at home, and no infectious disease. In some NICUs, parents receive economic assistance in the form of vouchers for food and gas, which alleviates some of the financial burden. Private rooms allowing extended stays for families often are an integral part of FCC,[3] NIDC,[4] and NIPU,[5] and have been found to enhance infant neurodevelopment by increasing maternal visiting time, initiating and maintaining skin-to-skin holding, increasing parent–infant bonding, and optimizing nurse support.[4-9]

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Although mothers mentioned pros and cons of private rooms and open pods, positive comments did not differ between mothers in staying in the open bay and the unit with private rooms, most likely because other facets of FCC were practiced in both units.

Other aspects of the NIDC and NIPU were practiced in these units and mentioned by mothers. Because relatives can spend time with the mother at the bedside and both parents can spend the night in FCC units, more social support is available to the mother than in the past. Online and on-site support groups for mothers of preterm infants are available even after discharge for mothers who are interested. Mothers who lacked close family support can now search for pre- and postnatal doulas, who offer support and education to parents about prenatal care and assist them with care.[50] Mothers did not mention postdischarge visitation by a health professional that is a component of NIPU, but incorporating home visitation into FCC care might lessen the need for parents to search for a doula.

Mothers without adequate social support in the FCC units viewed the hospital experience negatively and appeared to need an opportunity to voice their distress. Because husbands visited these mothers whenever possible, nurses may not have noted the distress of these mothers without in-depth conversation. Other researchers also reported that negative emotional responses were associated with lower levels of social support and lower perceived control.[17] This is a reminder for nurses that some mothers need more consideration and time than others. Daily visits from a mental health professional, a component of NIPU, could allow mothers a time to express their feelings.[5]

The attitude of mothers toward back-transport has changed. While in the past back-transport was done to alleviate crowding in the NICU and mothers worried about the care their infants would receive in community hospitals,[20-22] mothers now explain that having the infant closer to home would decrease financial and other burdens. This suggests more trust in the abilities of the community hospitals to provide adequate care. A recent study showed that when infants were not transferred to a hospital closer to home, the median length of stay in a level IV NICU after the infant was clinically stable was 28.5 days.[51] Communication about back-transport still seems to be problematic. Comments of mothers in this study suggested that early communication about back-transport would have helped them decide whether or not to pursue it.

Comments of mothers in this study indicated early confidence (even in the first week) in caring for their infants in the FCC NICUs, which is in contrast to 2 decades ago when mothers could wait several weeks before performing any care for their infant.[13] Whereas mothers could not attend rounds in the past, they are now active participants in daily rounds and decision-making about their infant.[52]

The mother–nurse relationship seems to have progressed from a tenuous, and sometimes hostile one[29,30] to one where the mothers believe that the nurses are caregivers, teachers, and advocates. Still, nurses must be aware that mothers may become distressed if the nurse is inconsistent, especially if the mother needs an advocate. Mothers indicated that they regarded nurses as the people in charge of the unit and of caregiving for their infant. Thus, some mothers may be hesitant to make their own choices, particularly in regard to feeding

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and holding, suggesting that nurses consider carefully how they model care and discuss caregiving options.

As in the past, mothers in the FCC units described fears of taking their infants home without monitors because they might miss signs of oxygen desaturation or bradycardic spells.[31,32] More encouragement for mothers to recognize infant physical changes during a bradycardic episode, or use of technology after discharge such as telemedicine or Face Time, may increase maternal confidence, as would the knowledge that home visitation by a health professional would be part of the home transition.[5,53,54]

Much change has been made in promotion of STS holding. After safety of the practice was established, more recent research indicated its benefits such as improved mother–infant interaction, increase in maternal oxytocin that is associated with maternal sensitivity, infant weight gain, human feeding success, and behavioral organization.[55-59] Bergman[60] advocates for continual STS holding, especially in the first 72 hours after birth to provide optimal neuroprotective development. Past research indicated that STS was typically not promoted in the NICU, while now it is standard practice in FCC nurseries. All mothers in this study initially held their infant STS, even if the infants were ventilated. Having readily available nursing assistance to hold eliminated mothers' hesitance to ask for help. Not all mothers continued STS holding, which demonstrates that they felt empowered to make decisions about their infants' care. Mothers in this study visited and held their infants more often than reported recently by Pineda et al,[9] but the sample in this study consisted primarily of mothers who were available for interviews and data collection for the larger study.

Lactation support was an important aspect of early FCC and continues to be promoted, but not all NICUs provide this service.[61] Not all mothers in our study provided human milk to their infants but had ample lactation support. Other researchers found lactation specialists increase provision of human milk but found impediments (eg, inadequate milk supply and home life interferences) similar to those mentioned by mothers in our study.[62] In a recent study, 48% of infants were receiving human milk at discharge from the NICU with lactation support.[63] Mothers in our study described how difficult it was to breastfeed their infants, some of whom were quite ill. Bringing the infant home was more important to them than exclusive breastfeeding, but they did continue to express. Human milk feedings are essential for preterm neurodevelopment,[4] so optimal lactation support seems an area for continued research.

When asked, mothers suggested improvements to the FCC they received. Thorough and repeated orientation of mothers to areas in the unit where they may meet other mothers and/or eat or socialize with other families may lessen isolation of the private rooms. Mothers also suggested having refrigerators and more comfortable beds in the rooms. More research and development are needed for use of wireless monitors and webcams that may increase bonding.[53,54] Distress for several mothers may have decreased if their other children could have been with them, or if their hospital beds were in the NICU. Although much thought and planning would be needed, family rooms that could accommodate extended stay for the entire family might be useful.

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The active involvement of mental health professionals, increased FCC education and administrative and peer support for nurses, and development of small infant units for infants weighing 500 to 1200 g was beyond the scope of this study, but outcomes from these NIDC and NIPU initiatives [4,5] are areas for further research. Ideas for continued improvement in FCC are vital for preterm infant development, parent involvement, and satisfaction. However, mothers and families need to be at the bedside so that implementation of these ideas can be accomplished. Future research to increase maternal visiting and engagement for mothers who have less opportunity to visit, or choose to visit infrequently is necessary. Nevertheless, mothers' statements in this study indicate that much has improved with the implementation of FCC over the past 2 decades. Mothers' suggestions align with NIDC and NIPU and offer potential strategies to alleviate even more of the hardships that mothers endure during their NICU experiences.

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References

1. Gartner LM, Gartner CB. The care of premature infants: Historical perspective. In: Yaffe SJ, ed. Neonatal Intensive Care: A History of Excellence.NIH Publication No. 92-2786.Bethesda, MD: National Institutes of Health; 1992:9–14.
2. Harrison H. The principles for family-centered neonatal care. Pediatrics. 1993;92(5):643–650. [PubMed: 8414850]
3. Celenza JF, Zayack D, Buus-Frank ME, Horbar JD. Family involvement in quality improvement. Clin Perinatol. 2017;44:553–566. [PubMed: 28802339]
4. Altimier L, Phillips R. Neuroprotective care of extremely preterm infants in the first 72 hours after birth. Crit Care Nurs Clin N Am. 2018;30:563–583.
5. Hall SL, Hynan MT, Phillips R, et al. The neonatal intensive parenting unit: an introduction. J Perinatal.2017;37(12):1259–1264.
6. Morrison A, Gullon-Rivera AL. Supporting siblings of neonatal intensive care unit patients: a NICU social story as an innovative approach. J Pediatr Nurs. 2017;33:91–93. [PubMed: 27979495]
7. Gonya J, Martin E, McClead R, Nelin L, Shepherd E. Empowerment programme for parents of extremely premature infants significantly reduced length of stay and readmission rates. Acta Paediatr. 2014; 103(7):727–731. [PubMed: 24766486]
8. Hane AA, Myers MM, Hofer MA, et al. Family nurture intervention improves the quality of maternal caregiving in the neonatal intensive care unit: evidence from a randomized controlled trial. J Dev Behav Pediatr. 2015;36(3):188–196. [PubMed: 25757070]
9. Pineda R, Bender J, Hall B, Shabosky L, Anneca A, Smith J. Parent participation in the neonatal intensive care unit: predictors and relationships to neurobehavior and developmental outcomes. Early Hum Dev. 2018;117:32–38. [PubMed: 29275070]
10. Galvin E, Boyers L, Schwartz PK, et al. Challenging the precepts of family-centered-care: testing a philosophy. Pediatr Nurs. 2000;26(6):625–632. [PubMed: 12026366]
11. Dobbins N, Bohlig C, Sutphen J. Partners in growth: implementing family-centered care changes in the neonatal intensive care unit. Child Health Care. 1994;23(2):115–126. [PubMed: 10134802]
12. Neu M. Kangaroo care: is it for everyone? Neonatal Netw. 2004;23(5):47–54.
13. Neu M. Parents' perception of skin-to-skin care with their preterm infants requiring assisted ventilation. J Obstet Gynecol Neonatal Nurs. 1999;28(2):157–164.

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14. Pinch WJ, Speilman ML. Parental perceptions of ethical issues post-NICU discharge. West J Nurs Res. 1993;15(4):422–440. [PubMed: 8356835]
15. Miles MS, Carlson J, Funk SG. Sources of support reported by mothers and fathers of infants hospitalized in a neonatal intensive care unit. Neonatal Netw. 1996;15(3):45–52.
16. Prudhoe CM, Peters DL. Social support of parents and grandparents in the neonatal intensive care unit. Pediatr Nurs. 1995;21(2):140–146. [PubMed: 7746678]
17. Doering LV, Moser DK, Dracup K. Correlates of anxiety, hostility, depression, and psychosocial adjustment of NICU infants. Neonatal Netw. 2000;19(5):15–23. [PubMed: 11949109]
18. Lindsay JK, Roman L, DeWys M, Eager M, Levick J, Quinn M. Creative caring in the NICU: parent-to-parent support. Neonatal Netw. 1993;12(4):37–44.
19. Roman L, Lindsay JK, Boger RP, et al. Parent-to-parent support in the neonatal intensive care unit. Res Nurs Health. 1995;18(5):385–394. [PubMed: 7676072]
20. Farel A, Kotelchuck M, Metzquer K, Fullar S. Back transfer: capability of community hospitals to serve chronically ill and convalescing infants. J Perinatol. 1993;13(2):132–136. [PubMed: 8515306]
21. Kuhnly JE, Freston MS. Back transport: exploration of parents" feelings regarding the transition. Neonatal Netw. 1993;12(1):49–56.
22. Slattery MJ, Flanagan V, Cronenwett LR, Meade SK, Chase NS. Mothers' perceptions of the quality of their infants' back transfer. J Obstet Gynecol Neonatal Nurs. 1998;27(4):394–401.
23. Raines DA. Values of mothers of low birth weight infants in the NICU. Neonatal Netw. 1998;17(4):41–46.
24. Bruns DA, McCollum JA. Partnerships between mothers and professionals in the NICU: caregiving, information exchange, and relationships. Neonatal Netw.2002;21(7):15–23.
25. Holditch-Davis D, Miles MS. Mothers' stories about their experiences in the neonatal intensive care unit. Neonatal Netw. 2000;19(3):13–21.
26. Wereszak J, Miles MS, Holditch-Davis D. Maternal recall of the neonatal intensive care unit. Neonatal Netw. 1997;16(4):33–40.
27. Scharer K, Brooks G. Mothers of chronically ill neonates and primary nurses in the NICU: transfer of care. Neonatal Netw. 1994;13(5):37–47.
28. Van Riper M. Family-provider relationships and well-being in families with preterm infants in the NICU. Heart Lung. 2001;30(1):74–84. [PubMed: 11174370]
29. Hurst I. Vigilant watching over: mothers' actions to safeguard their premature babies in the newborn intensive care nursery. J Perinat Neonat Nurs. 2001;15(3):39–57.
30. Hurst I. Mothers' Strategies to meet their needs in the newborn intensive care nursery. J Perinat Neonat Nurs. 2001;15(2):65–82.
31. Docherty SL, Miles MS, Holditch-Davis D. Worry about child health in mother of hospitalized medically fragile infants. Adv Neonatal Care. 2002;2(2):84–92. [PubMed: 12881928]
32. Catlett AT, Miles MS, Holditch-Davis D. Maternal perception of illness severity in premature infants. Neonatal Netw. 1994;13(2):45–49. [PubMed: 8139521]
33. Bier JA, Ferguson AE, Morales Y, et al. Comparison of skin-to-skin contact with standard contact in low-birth weight infants who are breast fed. Arch Pediatr Adolesc Med. 1996;150(12):1265–1269. [PubMed: 8953998]
34. Neu M, Browne JV, Vojir C. The impact of two transfer techniques used during skin-to-skin care on the physiologic and behavioral responses of preterm infants. Nurs Res. 2000;49(4):215–223. [PubMed: 10929693]
35. Messmer R, Rodriquez S, Adams J, Wells-Gentry J, Washburn K, Zabaleta AS. Effect of kangaroo care on sleep time for neonates. Pediatr Nurs. 1997;23(4):408–414. [PubMed: 9282055]
36. Bosque EM, Brady JP Affonso DD, Wahlberg V. Physiologic measures of kangaroo versus incubator care in a tertiary-level nursery. J Obstet Gynecol Neonatal Nurs. 1995;24(3):219–226.
37. Affonso D, Bosque E, Wahlberg V, Brady J. Reconciliation and healing for mothers through skin-to-skin contact provided in an America tertiary level III intensive care nursery. Neonatal Netw. 1993;12(3):25–32.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

38. Engler AJ, Ludington-Hoe SM, Cusson RM, et al. Kangaroo care: national survey of practice, knowledge, barriers, and perceptions. MCN Am J Child Nurs. 2002;27(3):146–153.
39. Meier PP, Engstrom JL, Mangurten HH, Estrada E, Zimmerman B, Kopparthi R. Breastfeeding support services in the neonatal intensive-care unit. J Obstet Gynecol Neonatal Nurs. 1993;22(4):338–347.
40. Kavanaugh K, Meier P, Zimmermann B, Mead L. The rewards out-weigh the efforts: breastfeeding outcomes for mothers of preterm infants. J Hum Lact. 1997;13(1):1263–1278.
41. Espy KA, Senn TE. Incidence and correlates of breast milk feeding in hospitalized preterm infants. Soc Sci Med. 2003;57(8):1421–1428. [PubMed: 12927472]
42. Powers NG, Bloom B, Peabody J, Clark R. Site of care influences breastmilk feedings at NICU discharge. J Perinatol. 2003;23(1):10–13. [PubMed: 12556920]
43. Gonzalez KA, Meinzen-Derr J, Burke BL, et al. Evaluation of a lactation support service in a children's hospital neonatal intensive care unit. J Hum Lact. 2003;19(3):286–292. [PubMed: 12931780]
44. Merewood A, Philipp BL, Chawla N, Cimo S. The baby-friendly hospital initiative increases breastfeeding rates in a US neonatal intensive care unit. J Hum Lact. 2003;19(2):166–171. [PubMed: 12744533]
45. Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing best practices based on science and experience. Qual Life Res. 2009;18(9):1263–1278. [PubMed: 19784865]
46. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101.
47. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15(3):398–405. [PubMed: 23480423]
48. Lincoln Y, Guba E. Naturalistic Inquiry. Newberry Park, CA: Sage Publications; 1985:289–331.
49. Als H. Developmental care in the newborn intensive care unit. Curr Opin Pediatr. 1998;10:138–142. [PubMed: 9608890]
50. Hans SL, Edwards RC, Zhang Y. Randomized controlled trial of doula-home-visiting services: impact on maternal and infant health. Matern Child Health. 2018;22(suppl 1):105–113.
51. Bourque SL, Levek C, Melara DL, Grover TR, Hwang SS. Prevalence and predictors of back-transport closer to maternal residence after acute neonatal care in a regional NICU. Matern Child Health J. 2019;23(2):212–219. doi:10.1007/s10995-018-2635-6. [PubMed: 30255218]
52. Weiss EM, Xie D, Cook N, Coughlin K, Joffe S. Characteristics associated with preferences for parent-centered decision making in neonatal intensive care unit. JAMA Pediatr. 2018;172(5):461–468. [PubMed: 29554176]
53. Bonner O, Beardsall K, Crilly N, Lasenby J. "There were more wires than him." The potential for wireless patient monitoring in neonatal intensive care. BMJ Inno. 2017;3:12–18.
54. Epstein EG, Arechiga J, Dancy M, Simon J, Wilon D, Alhusen JL. An integrative review of technology to support communication with parents of infants in the NICU. J Obstet Gynecol Neonatal Nurs. 2017;46(3):357–366.
55. Hurst NM, Valentine CJ, Renfro L, Burns P, Ferlic L. Skin-to-skin holding in the neonatal intensive care unit influences maternal milk volume. J Perinatol. 1997;17(3):213–217. [PubMed: 9210077]
56. Neu M, Robinson J. Maternal holding of preterm infants during the early weeks after birth and dyad interaction at six months. J Obstet Gynecol Neonatal Nurs. 2010;39(4):401–414.
57. Vittner D, McGrath J, Robinson J, et al. Increase in oxytocin from skin-to-skin contact enhances development of parent-infant relationship. Biol Res Nurs. 2018;20(1):54–63. [PubMed: 29017336]
58. Evereklian M, Posmontier B. The impact of kangaroo care on premature infant weight gain. J Pediatri Nurs. 2017;34:e10–e16.
59. Feldman R, Rosenthal A, Eidelman AI. Maternal-preterm skin-to-skin contact enhances child physiologic organization and cognitive control across the first 10 years of life. Biol Psychiatry. 2014;75(1):56–64. [PubMed: 24094511]
60. Bergman NJ. Neuroprotective core measures 1-7: neuroprotection of skin-to-skin contact (SSC). Newborn Infant Nurs Rev. 2015;15(3):142–146.

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61. Froh E, Dahlmeier K, Spatz DL. NICU nurses and lactation-based support and care. Adv Neonatal Care. 2017;17(3):203–208. [PubMed: 28030366]

62. Loverde B, Falck A, Donahue P, Hussey-Gardener B. Supports and barriers to the provision of human milk by mothers of African American preterm infants. Adv Neonatal Care. 2018;18(3):179–188. [PubMed: 29799821]

63. Casavant SG, McGrath JM, Burke G, Briere CE. Caregiving factors affecting breastfeeding duration within a neonatal intensive care unit. Adv Neonatal Care. 2015;15(6):421–428. [PubMed: 26551792]

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What This Study Adds

- A comparison of maternal experiences 2 decades ago before FCC became a more standard form of care with current experiences of mothers in FCC nurseries.
- Positive changes in maternal experiences over the last 2 decades due to FCC.
- Areas that remain problematic for mothers and families.
- Ideas from mothers on how to improve their NICU experience.

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Summary of Recommendations for Practice and Research

What we know:	• FCC in NICUs was initiated to promote a respectful response to individual family needs and values. • FCC supports parental participation in care and decision-making for their infants. • FCC is reported to shorten length of infant hospitalization, reduce hospital readmissions, increase provision of human milk feeding, promote infant physical health, and improve infant neurodevelopmental outcomes.
What needs to be studied:	• Comparison of maternal experiences in the NICU 2 decades ago with current experiences in NICUs where FCC is practiced. • Areas that remain problematic for mothers and families (eg, back-transport and maternity leave options). • Ideas for change that can further improve the NICU experience for mothers, infants, and families.
What we can do today:	• Improve recognition and response when mothers have inadequate social support. • Recognize that some mothers may be hesitant to make choices about their infant's care, even though they have preferences, and consider carefully how to model care and discuss caregiving options. • Assure comfort of mother and family in a private room or around the infant's bedspace. • Orientate mothers to areas of the NICU where they can meet other mothers and/or relax privately outside of the infant's bedspace or room. • Approach the topic of back-transport early in the infant's hospitalization if the option is feasible.

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TABLE 1.

Maternal and Infant Demographics (n = 14)

Variable	n (%)
Ethnicity/race	
White (non-Hispanic)	9 (64)
Hispanic/Latina	1 (7)
Black or African American	3 (22)
American Indian or Alaska Native	1 (7)
Education (n = 13)	
Some high school, high school or GED	4 (29)
Some college or technical	3 (23)
College graduate	5 (38)
Master's degree, or above	1 (8)
Urban/rural residence	
Rural CO	9 (64)
Denver metro	4 (28)
Out of state	1 (8)
Marital status	
Married or living with infan's father	11 (79)
Divorced or separated	1 (7)
Never married	2 (14)
Employment status before birth	
Working full or part time	10 (71)
Unemployed	4 (29)
Income	
<$10,000	3 (21)
$10,000-$49,999	3 (21)
$50,000-$74,999	3 (21)
≥$75,000	5 (36)
C-section birth (n = 12)	6 (50)
Twin birth	4 (29)
First infant	9 (64)
Infant male sex	9 (64)
Infant Female sex	5 (36)
Infant required assisted ventilation (n = 12)	6 (50)
	Mean (SD)
Maternal age, y	28 (5)
Infant postconceptional weeks at birth	29 (2)
Infant postconceptional weeks at discharge	39 (2)
Infant postconceptional weeks at interview	37 (2)
Infant length of stay, wk	11 (4)

Abbreviations: CO, Colorado; C-section, cesarean section; GED, General Educational Development.