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Patient Perceptions

Does *she* think she's supported? Maternal perceptions of their experiences in the neonatal intensive care unit

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Abstract
Parents' involvement in the care of their infants in the neonatal intensive care unit (NICU) is critically important, leading many NICUs to implement policies and practices of family-centered care (FCC). Analyzing narrative interviews, we examined whether mothers of premature infants who participated in an intervention to help reduce anxiety, stress, and depression felt that their NICU experience reflected four key nursing behaviors previously identified as being necessary to achieving FCC. Fifty-six narratives derived from semi-structured interviews with the mothers were analyzed qualitatively and quantitatively to examine whether the women experienced emotional support, parent empowerment, welcoming environment, and parent education, as well as whether differences in reported experiences were related to sociodemographic factors or maternal coping styles. Overall, the mothers reported more negative than positive experiences with respect to the four behaviors, and those who had negative interactions with the hospital staff felt a sense of disenfranchisement and failure as mothers. Sociodemographic factors and coping styles were significantly associated with the mothers' perceptions of their experiences, although these relationships were not consistent. Achieving actual FCC in the NICU may require parent-informed evidence-based changes in NICU personnel training and infrastructure.

Keywords
Perceptions of care, family-centered care, maternal satisfaction, maternal experience

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Introduction

The premature birth experience can happen to any mother indiscriminate of income, education level, or race, making it an interesting condition to examine when considering the patient experience. Women who give birth prematurely often experience stress, anxiety, depression, and a sense of loss or fear, while their infants are in the neonatal intensive care unit (NICU).[1–3] When staff support for parents of ill children is inconsistent, parents worry about how involved they should be in their children's care, which can produce feelings of inadequacy, and confusion.[1,4] However, hospitals that successfully adopt a family-centered care (FCC) approach, where families are more engaged in infant care, and more involved in decision-making, have improved outcomes for both mothers and their infants.[5,6] A systematic review by Cleveland[7] identified four nursing behaviors important for helping parents cope with the NICU experience: (1) emotional support, where supportive communication and information-sharing with the nursing staff result in parents feeling supported; (2) parent empowerment, including parents being involved in decisions about their infants' care; (3) a welcoming environment with supportive unit policies, conveyed by the attitude and actions of the staff; and (4) parent education with opportunities for parents to practice new skills through guided participation, thereby helping them to feel more enfranchised.

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Recognizing that parents are important contributors to quality care of their children, hospitals are increasingly emphasizing FCC[8] and evaluating whether FCC fosters parent engagement and satisfaction with care.[9,10] Several studies have shown that interventions designed to improve communication and maximize the FCC approach can be delivered successfully,[11,12] but some have indicated that implementation of FCC policies may require additional education, training, and resources to truly be effective.[12]

Two NICU-focused studies found that the discrepancy between parents' expectations of what care should be and its actual reality was associated with a lack of satisfaction with care, and confirmed that perceptions of care play a large role in parent satisfaction.[13,14] Similarly, a relationship between maternal social support (both in and out of the hospital) and satisfaction with infant care has consistently been observed.[13,15] Racial, ethnic, and socioeconomic disparities in satisfaction with healthcare are well documented.[16,17] A 2006 FCC study of children with special healthcare needs found that Black and Hispanic parents were twice as likely as White parents—and Spanish-speaking parents four times as likely—to report dissatisfaction with their children's care, partly because of healthcare workers' lack of respect for culture and customs and parent exclusion from decision-making processes.[18]

Some evidence suggests that coping style affects maternal anxiety in the NICU and subsequent development of symptoms of post-traumatic stress disorder,[19] although the role of mothers' coping style in feeling satisfied with their infants' care remains unclear. Factors such as symptoms of anxiety and depression have also been linked to mothers' satisfaction with a maternal engagement intervention in the NICU.[20] However, data on a possible association between maternal psychosocial factors and satisfaction with NICU care remain limited.

The current study, conducted in two FFC practicing California Bay Area hospitals, investigated whether maternal perceptions of their interactions with NICU personnel reflected the presence or absence of the nursing behaviors. We sought to answer the following questions: 1) Did the mothers of premature infants spontaneously describe experiencing the four nursing behaviors that are important for FCC?; and (2) What were the characteristics, including sociodemographic factors and coping styles, of mothers who were most and least likely to endorse experiencing these behaviors?

Methods

Participants

Mothers of premature infants were recruited into a previously described randomized controlled trial[21,22] to evaluate whether a six-session psychosocial/educational intervention reduced their symptoms of emotional stress. The current study included 56 English- or Spanish-speaking mothers who completed the interventional arm of the trial, during which they created a narrative of their experience in the NICU. The trial was approved by the institutional review board of Stanford University.

Measures

The following self-reported sociodemographic characteristics were recorded for each participant: age, race, ethnicity, education level, employment status, household income, primary language, number of previous children and previous premature births, and previous reproductive trauma. Maternal coping style was evaluated by administering Brief COPE,[23] a 28-item instrument that assesses coping style with respect to 14 dimensions (Table 1). At study entry, mothers were asked to rate the extent to which they had been using each coping behavior since delivery of their infants on a fully anchored four-point scale, from "I haven't been doing this at all" to "I've been doing this a lot." Only one mother reported using alcohol or drugs to cope, so responses relating to this behavior were dichotomized (none vs. any) for the analyses.

Table 1. Brief COPE[23] dimensions

Coping Dimension	Maternal behavior related to dimension
Active Coping	Actively trying to deal with NICU situation
Planning	Making plans for managing NICU situation or baby's release
Positive Reframing	Looking for positives/benefits of the situation for baby or herself
Acceptance	Accepting NICU situation, coming to terms with challenges
Humor	Using humor to handle challenges of NICU situation
Religion	Seeking comfort in religion
Using Emotional Support	Actively seeking or accepting emotional support
Using Instrumental Support	Actively seeking or accepting advice from medical team
Self-Distraction	Turning to activities to think less about situation
Denial	Unable to believe what is happening or to accept baby's condition
Venting	Expressing negative feelings
Substance Use	Using alcohol or drugs to feel better or manage situation
Behavioral Disengagement	Has given up trying to deal with situation
Self-Blame	Blaming herself for what has happened

Semi-structured interviews

The content of maternal narratives solicited during one of the intervention sessions was used to create the eight perception outcomes relating to the nursing behaviors in this study. The researchers guided each mother through a semi-structured interview focusing on the pregnancy, birth, and NICU experience, including the effect of these experiences on the mother and the family. Interviews lasted from 20 to 70 minutes, depending on the level of detail provided by the interviewees. The interviews were recorded, transcribed, and translated if necessary, for subsequent analysis.

Analysis of narratives

Using qualitative content-analysis techniques,[24] two coders analyzed the transcriptions of the narratives, identifying quotations where mothers spontaneously described experiencing the presence or absence of the four nursing behaviors (eight total outcomes). Narratives were initially coded independently, and any discrepancies in assigned codes were subsequently reconciled during discussions between the coders. For each narrative, the positive and negative comments related to each nursing behavior were counted.

Statistical analysis

Data were summarized using counts and percentages for categorical responses and means and standard deviations for normally distributed measures. Associations of maternal characteristics and coping styles with any positive or negative comments related to parent education with opportunities to practice were examined using logistic regression, as 96% of the sample had either 0 or 1 comment for these outcomes. For the other three nursing behaviors, associations with the number of positive or negative comments were examined using Poisson regression, with the total number of comments as the offset. All regression analyses were adjusted for hospital as a design. Results of the logistic regression analyses are summarized using odds ratios (OR) and 95% confidence intervals (CIs), while Poisson regression analyses are summarized via rate ratios (RR) and 95% CIs. Statistical significance was set at .05 and no adjustments were made for multiple comparisons. SAS version 9.3 (SAS Institute, Inc, Cary, NC) was used for all analyses.

Results

Participants

The sample consisted of mothers with an average age of 34.0 (± 6.5) years. Nearly 60% were born in the U.S., and 41% were White, Non-Hispanic (Table 2). Those categorized as "Other races" represented a variety of different groups in small numbers, including Pacific Islander, South Asian/Indian, East Asian, and African American, and many were foreign born. Seventy percent of mothers reported that this was their first child, and 16% had a history of a previous reproductive health trauma.

Table 2. Maternal Characteristics

	N (%) or Mean ± SD
Age (mean ± SD)	34.0 ± 6.5
Race/Ethnicity	
White, Non-Hispanic	23 (41.1%)
Hispanic	16 (28.6%)
Other	17 (30.4%)
Primary Language is English	33 (58.9%)
Born in U.S.	33 (58.9%)
Education	
Less than college	17 (30.4%)
College degree	19 (33.9%)
Post-graduate degree	20 (35.7%)
Employed	39 (69.6%)
Married/cohabitating	53 (94.6%)
Household income	
<$50k	15 (26.8%)
$50-$99k	9 (16.1%)
≥$100k	30 (53.5%)
Missing	2 (3.6%)
First child	39 (69.6%)
Other preterm children	5 (8.9%)
Prior reproductive health trauma	9 (16.1%)

The total number of comments per narrative ranged from 17 to 73 (median= 30). Overall, 57% of the comments were unrelated to the four nursing behaviors, 29% were negative comments pertaining to the behaviors, and 14% were positive. Most mothers made both positive and negative comments regarding parent empowerment (79%), emotional support (68%), and welcoming environment (52%); whereas, 14%, 28%, and 46%, respectively, had only negative comments about these behaviors. Mothers made significantly more negative than positive comments about emotional support and welcoming environment ($p<0.001$). Only 16% of mothers had positive comments

and 25% had negative comments about parent education with opportunities to practice.

The participants expressed global feelings of anger and frustration, along with perceptions of maltreatment, thereby endorsing negative iterations of all four behaviors, as this quote by a Spanish-speaking participant illustrates.

Yes, it increases my desire to be there [the hospital], because when I went there and he was cold, I told my husband, and if we don't go, he [the baby] has an hour and a half before eating, and if we don't go during that 1.5 hours, [the nurses] won't check him, they won't check to see if he's cold. . . . Because this baby doesn't cry. He doesn't cry. He doesn't complain, he doesn't do anything, he's just lying there, or he moves, but if they don't turn around and look, if the machine doesn't sound, then they won't look at him. I mean, I don't expect them to hold him, or console him, but just to watch him to make sure he's okay.

Emotional support

A higher level of education, being employed, and higher household income were significantly related to positive comments about emotional support (Table 3). Mothers with a college degree made positive comments at a rate 2.5 times higher than that of mothers with less education. Among employed mothers, the positive-comment rate was 88% higher than among those not working. A household income above $50,000 was associated with twice the rate of positive comments as an income under $50,000. With respect to negative emotional support comments, the rate increased by 3% for each year increase in maternal age and was 74% higher among mothers who had a previous preterm delivery compared with those who did not. Each one-point increase in the Brief COPE score for active coping style was associated with a 15% decrease in the rate of negative comments.

The comments about the presence and absence of emotional support indicated that a mother's belief that she

Table 3: Maternal characteristics and coping styles significantly associated with comments about emotional support*

	Emotional Support			
	Positive		Negative	
Characteristic	**RR (95% CI)**	**p-value**	**RR (95% CI)**	**p-value**
Age	----	----	1.03 (1.00, 1.05)	.04
Education†				
Less than college	reference	.02	----	----
College degree	2.51 (1.29, 4.88)			
Post-graduate degree	1.78 (0.92, 3.47)			
Employment				
Not employed	reference	.03	----	----
Employed	1.88 (1.06, 3.33)			
Household income‡				
<$50k	reference	.03	----	----
$50-$99k	2.83 (1.30, 6.13)			
≥$100k or no answer	2.23 (1.13, 4.40)			
Other preterm children				
No	----	----	reference	.01
Yes			1.74 (1.14, 2.65)	
Active coping style	----	----	0.85 (0.76, 0.94)	.003

* Poisson regression analyses adjusted for hospital with total number of comments as the offset.
† Post-graduate degree vs. college degree: RR = 0.71 (95% CI: 0.44, 1.13)
‡ ≥$100k or no answer vs. $50-$99k: RR = 0.79 (95% CI: 0.46, 1.35)
---- indicate that the variable was not statistically significant.
RR: rate ratio. CI: confidence interval.

had support had a substantial impact on her level of stress, acceptance of the situation, and ability to cope. Thus, mothers reported feeling a need to bond with the nurses, who provided emotional support and built trust for mothers, to feel comfortable leaving their babies at the hospital.

All of the nurses. . . .They were wonderful. Just, you never realize someone else's job until you see them do it. Not just for our babies but everyone's. It's kind of an emotional thing for both my husband and I, because they're so loving with all the babies. So specialized in what they're doing. And, they enjoy what they're doing. So, that really helped us to be able to go home each day.

Many mothers also reported how important pumping breast milk was for them because it offered involvement in the NICU and help with their infants' care, despite the challenge of generating milk after an early delivery. Comments about breastfeeding indicated the importance of emotional support provided by lactation consultation.

She [the NICU lactation consultant] wasn't judgmental at all, and her first question was, "do you have any sort of hormonal imbalances that might be leading to this?" And, it was the first time anyone had said it. And I was like, "oh well actually I have this," and she's like, "well that's what it is; you can't do more than what you're doing, you don't have whatever"—and I don't know what it is, but I mean she knew right away. She knew enough to ask that question. So now, I felt like, she was like, "actually you're doing phenomenally well given that."

Other comments indicated that the NICU staff failed to recognize that the NICU experience could be a bewildering and traumatic experience for parents, even when routine for the staff.

I think after she was born there were a couple times early on when they [medical team] referred to her as a "very sick little girl" or, you know, "the honeymoon is over and now the roller coaster begins," and this was after the first week, where I felt like I had already been on a roller coaster. "If this treatment doesn't work, what's the next option?" and some of them saying "Oh, there are no other options"—those unclear or end-of-life kind of statements were stressful, for sure.

Mothers also described feeling judged by the medical staff for not doing enough, doing too much, or being too demanding, resulting in feelings of guilt, anger, and frustration.

When I walked in, the first thing she [the nurse] said to me was "it's really important for you to be here a lot." They have this rotation so she hadn't really noticed us before or hadn't realized that we are here all the time. And, my first thought was like, are we not here enough? We're here all the time. What are you saying? What are you saying? And she said, "at the 8:30 feeding he was really awake and alert. And I gave him a bottle. You weren't here to breastfeed." OK, so let's think about all the buttons: you're not here enough, you weren't here to breastfeed, I gave him a bottle.

Parent empowerment

No maternal sociodemographic characteristic was significantly associated with positive or negative comments about parent empowerment. However, greater use of denial coping style was significantly associated with a lower rate of positive comments (Table 4). Any substance use versus none as a coping strategy was linked to a higher rate of negative comments.

Mothers expressed that being kept informed and knowing what to expect helped alleviate their sense of a lack of control over the situation.

I think it really did help me talk to the doctors and nurses to know . . . what's going on and what's next for him. . . . If anything, I felt good talking to them and the nurses and knowing about his progress, how he is doing, what is to be expected later of him, and how soon he can recover.

Table 4: Maternal characteristics significantly associated with comments about parent empowerment*

	Parent Empowerment			
	Positive		Negative	
Characteristic	**RR (95% CI)**	**p-value**	**RR (95% CI)**	**p-value**
Substance use coping style				
None	----	----	Reference	.009
Any			1.90 (1.17, 3.09)	
Denial coping style	0.84 (0.74, 0.95)	.007	----	----

* Poisson regression analyses adjusted for hospital with total number of comments as the offset.
---- indicate that the variable was not statistically significant.
RR: rate ratio. CI: confidence interval.

Table 5: Maternal characteristics significantly associated with comments about the NICU environment*

	Welcoming Environment			
	Positive		Negative	
Characteristic	**RR (95% CI)**	**p-value**	**RR (95% CI)**	**p-value**
Education†				
Less than college	Reference	.01	----	----
College degree	3.46 (1.48, 8.08)			
Post-graduate degree	1.98 (0.84, 4.71)			
Planning coping style	0.81 (0.68, 0.97)	.02	----	----
Self-blame coping style	0.84 (0.74, 0.97)	.02	----	----

* Poisson regression analyses adjusted for hospital with total number of comments as the offset.
† Post-graduate degree vs. college degree: RR = 0.57 (95% CI: 0.32, 1.03)
---- indicate that the variable was not statistically significant.
RR: rate ratio. CI: confidence interval.

In contrast, mothers who felt as if they did not know what was going on or thought that the staff was not paying sufficient attention to them or their infant started questioning themselves and their infant's care.

> *I was an emotional wreck, 'cause I'd go and they [the twins] were actually both doing quite well, but almost all the time the nurses that were watching them were on break or working on other babies, and my babies were—you know I never had anybody to talk to. Several times, I went in there, you know either by myself, or with [my husband], or with a friend, like "who can I talk to about my babies?" "Oh she's on break"—you know, that kind of thing. So it was emotional. I was a little angry.*

Welcoming environment with supportive unit policies

The rate of positive comments on the NICU environment was significantly higher among college-educated mothers than those with less education, whereas higher scores on the planning and self-blame coping style scales were associated with a lower rate of positive comments (Table 5). No maternal characteristics were related to negative comments about the environment.

Mothers noted that feeling welcome in the NICU enabled them to connect more with the nurses and bond more with their infants and that it increased the likelihood that they would engage in caregiving tasks.

> *When I first come in, I always want to see how he is doing and I ask the nurses…and I expect to get a whole run-down on what he has done since the last time I have seen him…there are a lot of moments when there is a lot going on, but even when they are being rushed for something it is still kind of calm…especially when I am holding [baby] it is really peaceful and calm just to hold him. So maybe I attribute that to the whole NICU.*

However, when mothers did not find the NICU staff welcoming, they felt restrictions about being engaged in their infants' care, leading to feelings of frustration and disengagement from their infants.

> *At the beginning in the NICU there was – I think in general they tried to kind of limit how we interacted with her, or when. Which makes sense because she was new; they had to protect her and make sure she was okay. But it felt…awkward, and it kind of frustrated me a little bit with the nurses that kind of had ideas of what we should be doing and how everything should go. And we just had to kind of do that.*

Many mothers also found the NICU itself very harsh and unwelcoming, which caused a great deal of stress.

> *Definitely the loudness. Especially after they say they want to keep it as quiet as possible…Also, just the brightness. I'm actually amazed at how bright these rooms get. And, they don't care. I thought it would be low lights, low noise, a very quiet environment. Maybe the bells would still be going off because they need to know. I just feel like everyone is loud…They're loud, they're moving things, and they slam doors and [the baby] will jolt when they slam.*

Parent education with opportunities to practice

Non-Hispanic, non-White mothers had significantly higher odds of making a positive comment about parent education then did White, non-Hispanic mothers (Table 6). Compared with college-educated mothers, those having a postgraduate degree had a 6.6-fold increased odds of making a negative comment.

Table 6: Maternal characteristics significantly associated with the odds of comments about parent education with opportunities to practice*

	Parent Education with Opportunities to Practice			
	Positive		Negative	
Characteristic	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Race/Ethnicity†				
White, non-Hispanic	reference	.05		
Hispanic	0.68 (0.06, 8.27)			
Other	6.46 (1.06, 39.25)			
Education‡				
Less than college			reference	.05
College degree			0.62 (0.09, 4.51)	
Post-graduate degree			4.10 (0.87, 19.46)	

* Logistic regression analyses adjusted for hospital.
† Other vs. Hispanic: OR=9.56 (95% CI: 0.96, 95.28) ‡ Post-graduate degree vs. college degree: OR=6.58 (95% CI: 1.18, 36.77)
OR: odds ratio. CI: confidence interval.

The participants relied on the NICU nursing staff both to take care of their infants and to teach them how to do so. Mothers felt that they needed practice performing care activities to feel confident that they would have the necessary caregiving skills for their newborns after discharge.

> *The nurses tried to help me . . . learn how to feed him and change the diaper and stuff like that, 'cause I had never changed a diaper before. They were just really helpful, 'cause I hadn't made it to my, you know those educational classes about how to take care of a baby—that was scheduled for [after baby was actually born]. So, they were just altogether wonderful, they really helped a lot.*

When mothers did not feel as if they were given opportunities to learn, they felt a sense of failure as a parent.

> *So when I changed the diaper and there was just pee everywhere and the nurse was getting off shift, and this was going to take her time to have to redo all the bedding. So she got frustrated. Or, not really frustrated, just anxious that she had to do that. She just kind of jumped in. I was changing it and he started to pee and I said "Oh my god he's peeing" and she said "Aah ooh! Ok!" And just took over. And, I just felt horrible. I felt like I had completely failed in all aspects of parenting at this point. . . . If she would have laughed about it or said "Oh, it happens to everybody" instead of getting all "I've gotta take care of this right now, because clearly you can't." That was hard. That was really hard.*

Discussion

Sociodemographic factors

Our study found evidence that, overall, FCC as practiced in the participating NICUs did not meet maternal expectations. Moreover, no clear general pattern emerged regarding associations between perceptions of care and maternal characteristics, although, as in previous studies,[15,17] some relationships were observed.

A higher level of maternal education was associated with a greater number of positive statements about emotional support and the NICU environment, but more negative statements about parent education with opportunities for practice. This indicates that highly educated mothers notice and appreciate feeling welcomed and supported and have a greater need to feel that they are being given opportunities to actively participate in their infant's care. These mothers may feel that they are due a certain level of support, communication, and inclusion, whereas less educated mothers may feel more intimidated and less comfortable with active care-giving responsibilities. Mothers not given an opportunity to participate in their infants' care reported feeling disenfranchised, a finding consistent with maternal disengagement.[1,25]

Non-Hispanic, non-White mothers may have made more positive comments about parent education with opportunities to practice than White mothers because of a relatively low expectation of being involved in their infants' care and were thus pleasantly surprised by the

opportunity and guidance offered. It is also possible that these mothers had different expectations because many were from countries where medical practices, including parental involvement in care, may vary from those in the United States.

There was a trend for Hispanic ethnicity to be associated with fewer positive comments about emotional support. In particular, Spanish-speaking mothers reported feelings of distress about nurses' absences at bedside, lacking time to attend to their infants, being brusque and unhelpful, and leaving babies crying. This finding mirrored those of Bergman and Connaughton[26], who reported a theme of ineffective medical care that caused mothers' distress because they felt that it negatively affected the care of their children. Our assessment of mothers' narratives could not determine whether Spanish-speaking mothers received different treatment, or if the language barrier precluded casual "chatty" interactions with the nurses[27] leaving mothers feeling unable to build friendly trusting relationships with the staff.[26] However, the language barrier may have affected the mothers' satisfaction with their infants' care because they could not develop the same rapport or easily learn NICU routines and expectations.

Coping factors

Both positive and negative maternal coping styles were previously shown to impact their ability to manage the NICU situation.[19] Our study found some associations between coping style and perceptions of the NICU experience as it pertained to nursing behaviors. Mothers with lower active coping scores made more comments about the lack of emotional support, suggesting that these mothers feel less supported in general or are more sensitive about their interactions with staff. Mothers with low denial coping scores had a greater number of positive comments about parent empowerment, possibly indicating that those who actively accept the circumstances are more able to seek help to feel empowered.

Mothers with low planning and self-blame coping scores made more positive statements about the welcoming NICU environment. Thus, women who feel less of a need to control the situation, or have fewer unfulfilled expectations regarding pregnancy and giving birth, might be more open to being welcomed in the NICU. Taken together, our results suggest that screening NICU mothers for coping styles may help to identify those who would benefit from additional emotional support, resources to feel empowered, or additional engagement with the staff.

Study Limitations

Given the exploratory nature of these analyses, we examined the association of multiple maternal characteristics for each outcome, increasing the chances of a type I error. Due to the small sample size, this study lacked statistical power to detect small effects and precluded us from simultaneously adjusting for multiple covariates in the regression models. Participants were recruited within a limited geographic area, so the results may not be fully generalizable to NICUs elsewhere, although parent experiences similar to ours have previously been reported.[1,7,13,20,28,29] Our participants' narratives were not collected to gather information on the nursing behaviors studied, and the mothers may have shared different information had they been asked direct questions about the behaviors. Finally, the study did not include field observations or surveys of nurses, either of which might have provided a broader view of the mothers' NICU experience.

Implications for Practice

A mother's perception of staff support and communication, her feelings of empowerment, her sense of feeling welcome, and her ability to feel useful as a part of the caregiving team greatly influence satisfaction with the NICU experience, and is most likely similar to what would be found for other critical care settings as well. When the four nursing behaviors that promote this perception are present, mothers are grateful, feel able to connect with their infants, and better manage NICU-related stress. When these nursing behaviors are absent or negative iterations of them are present, mothers feel angry, stressed, guilty, and frustrated, and they may become disengaged from the NICU and their infants.

The findings of our study indicate that principles of FCC were not routinely applied in the NICU despite the hospital's philosophy and commitment to integrate FCC, and we suspect that this may be true in other areas of care as well. As a result, many mothers had negative interactions with the NICU staff and this interfered with the quality of their experiences and their ability to bond with their infants. The findings of our study also suggest that to address these issues, hospitals will have to solicit greater input from parents as well as cultural training of staff and attention to non-English speaking families.

Potential ways to enhance principles of FCC suggested by our findings include reorganizing NICU staffing so that infants always have a nurse specifically assigned to him or her, even when the primary nurse is on break; ensuring that staff are available to provide medical information; and having a dedicated lactation consultant assigned to each mother to increase the maternal sense of being supported. Having detailed paper or smartphone updates on their infant's status over the past 24 hours available on arrival in the NICU would enhance parents' understanding of what happened in their absence, making them feel more empowered. Creation and distribution of handbooks to provide information about how to navigate the hospital environment, understanding NICU rounds, and hospital

services (e.g., food choices, lounge spaces) would help parents feel settled and welcome, as would dedicated, clean, and comfortable spaces for milk pumping.[5,7,11]

Our study offers a window into the perceptions of mothers of infants admitted to the NICU, thereby providing information useful for helping and supporting them during a difficult time. The data can inform changes that make the goals and practices of FCC match maternal perceptions of what it should be.

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