Title
Former NICU Families Describe Gaps in Family-Centered Care

Journal
Qualitative Health Research, 30(12)

ISSN
1049-7323

Authors
Sigurdson, Krista
Profit, Jochen
Dhurjati, Ravi
et al.

Publication Date
2020-10-01

DOI
10.1177/1049732320932897

Published in final edited form as:
Qual Health Res. 2020 October ; 30(12): 1861–1875. doi:10.1177/1049732320932897.

Former NICU Families Describe Gaps in Family-Centered Care

Krista Sigurdson[1], **Jochen Profit**[1], **Ravi Dhurjati**[1], **Christine Morton**[1], **Melissa Scala**[1], **Lelis Vernon**[2], **Ashley Randolph**[3], **Jessica T. Phan**[4], **Linda S. Franck**[5]

[1]Stanford University School of Medicine, Palo Alto, California, USA

[2]Vermont Oxford Network, Burlington, Vermont, USA

[3]GLO Preemies, Sacramento, California, USA

[4]University of South Florida, Tampa, Florida, USA

[5]School of Nursing, University of California, San Francisco, California, USA

Abstract

Care and outcomes of infants admitted to neonatal intensive care vary and differences in family-centered care may contribute. The objective of this study was to understand families' experiences of neonatal care within a framework of family-centered care. We conducted focus groups and interviews with 18 family members whose infants were cared for in California neonatal intensive care units (NICUs) using a grounded theory approach and centering the accounts of families of color and/or of low socioeconomic status. Families identified the following challenges that indicated a gap in mutual trust and power sharing: conflict with or lack of knowledge about social work; staff judgment of, or unwillingness to address barriers to family presence at bedside; need for nurse continuity and meaningful relationship with nurses and inconsistent access to translation services. These unmet needs for partnership in care or support were particularly experienced by parents of color or of low socioeconomic status.

Keywords

family-centered care; neonatal care; quality-of-care; grounded theory; patient-and-family engaged research; California; qualitative

A growing body of literature documents parents' critical role in promoting the health outcomes of low birthweight and preterm infants and a variety of models have been promoted toward that end (Franck & O'Brien, 2019). Historically, families were not permitted in the neonatal intensive care unit (NICU) or were only permitted on a limited

---

Corresponding Author: Krista Sigurdson, Department of Pediatrics, Stanford University School of Medicine, MSOB Room x1C19, 1265 Welch Road, Stanford, CA 94305, USA, ksigurd@stanford.edu.

Authors' Note
Jessica T. Phan is now affiliated to Stanford University School of Medicine, Palo Alto, California, USA.

Declaration of Conflicting Interests
The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supplemental Material
Supplemental material for this article is available online.

schedule as "visitors" (White et al., 2013). Family-centered care, as an approach to NICU care, recognizes the strengths and needs of a patient's family and their important role in promoting recovery from illness and long-term health outcomes (Franck & O'Brien, 2019).

The origins of family-centered care can be traced back to British children's hospitals in the 1950s when nurses began to involve parents in the care of their hospitalized children (Jolley & Shields, 2009). The approach came to influence care in the United States over the 1980s, as families gradually came to be seen as active care partners of their children (Brewer et al., 1989). Family-centered care, consisting of interrelated principles and practices that recognize the central importance of family members in an individual's health and well-being, has since been widely applied across the lifespan and in various health care settings (Davidson et al., 2017; Johnson, 2000). It is now understood under the larger umbrella concept of "patient- and family-centered care" in that the principles of working *with* patients and families (rather than doing "to" or "for" them) can be applied to any care setting (Institute for Patient- and Family-Centered Care, 2020). For the purposes of this project involving parents of former NICU patients, we use the term "family-centered care" throughout.

Models of care that explicitly involve families are now considered best practice in the NICU and the implementation of family-centered care promotes mutual respect and shared decision-making between clinicians and families, ensuring timely and quality psychosocial supports and hospital resources that facilitate family well-being and involvement (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; Franck & O'Brien, 2019). Family-centered care also includes direct care delivered by families to their infants, which is associated with better infant and parent outcomes and improved quality of care (Charpak et al., 2017; Franck et al., 2019; Patra et al., 2017). Despite expressed commitment to family-centered care, hospital systems and NICUs inconsistently and incompletely support the integration of family members as partners in infant care-giving and decision-making.

Although principles of family-centered[1] care have been identified (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012) and guidelines for the implementation of family-centered care in the NICU have been developed (Davidson et al., 2017), three significant challenges with family-centered care practice and research in the NICU remain: (a) a lack of unifying metric for family-centered care in the NICU (Dhurjati et al., 2019), (b) variation in family-centered care practice and in related models across American and International NICUs (Franck & O'Brien, 2019; Gooding et al., 2011), and (c) racial/ethnic and socioeconomic inequities in access to family-centered care in the NICU (Sigurdson et al., 2018).

Improving equity in high-quality family-centered care may prove to be an important lever for improving neonatal care overall and may require a careful re-orientation of professional roles and responsibilities (Mikesell & Bromley, 2012). However, we know little about the

---

[1] We draw core principles for family-centered care from those for "patient- and family-centered care." We wanted to use broad principles of care to encourage participants to explore the quality of their care rather than comparing their care against guidelines developed for family-centered care in the NICU setting (Davidson et al., 2017).

gaps in NICU family-centered care as experienced by parents, particularly by families of color and those of low socioeconomic status. The aim of this analysis was to understand the care experience of NICU families in relation to the principles of FCC. We were interested in exploring gaps in the receipt of family-centered care and unmet needs for partnership in care or support, particularly those experienced by parents of color and/or of low socioeconomic status. The specific objectives were to (a) understand family experiences of NICU care vis-à-vis family-centered care and (b) generate family feedback on pilot measures for family-centered care. In this article, we report on the first aim.

Method

Setting and Sample

This qualitative exploratory study was co-led with two research collaborators with personal and professional expertise as parents of preterm infants who were cared for in NICUs who then became advocates for this population. These parent-collaborators participated in every level of the research process, from designing the interview/focus group guide to executing data collection and performing data analysis and manuscript preparation, a level referred to as “shared leadership” when referring to patient and family engagement (Carman & Workman, 2017).

For this study, former NICU parents in California were invited to participate in semi-structured in-depth interviews or focus groups, based on their preferences. Advantages of individual interviews are the convenience and greater privacy of a one-on-one conversation, while advantages of focus groups are meeting other people who had experienced a similar event and sharing experiences and perceptions. Some chose individual interviews for the convenience of being able to participate remotely via teleconference, while others chose focus groups for the opportunity to meet other families and share experiences.

Individuals were invited to participate if they were a family member of a very low birth weight (less than 1500g) and/or preterm infant (22–29 weeks gestational age) cared for in a California NICU in the last 5 years, who lived more than 3 days after NICU admission, and was discharged more than 2 weeks prior to the interview.[2] We made particular efforts to recruit socioeconomically vulnerable families and racially/ethnically diverse families by partnering with Glo Preemies (GLO Preemies, 2019), a support organization for former NICU families that serves families in Sacramento, the majority of whom are low income and/or of color. A former NICU parent who leads this organization used social media sites for parents of preterm infants to recruit participants. Former NICU families from Lucile Packard Children’s Hospital Stanford were also invited to participate by their clinicians. We

---

We used these inclusion and exclusion criteria to be consistent with our umbrella organization, California Perinatal Quality Care Collaborative (CPQCC) in its alignment with the Vermont Oxford Network (VON), which has a world-wide membership, and of which CPQCC is a state-level member. CPQCC contributes data to VON on infants who are low birth weight (less than 1500 g) and/or 22 to 29 weeks gestational age and who live at least 3 days after admission. Twenty-two to 29 weeks gestational age is used as one of two possible criteria for inclusion in this data set because the initial focus of neonatology was on *very low birth weight infants*. These infants are at highest risk for prematurity-related morbidity, mortality, and long-term neurodevelopmental impairment. In addition, they represent a smaller subgroup of patients, limiting data collection burden. More recently efforts are emerging to collect data on all infants requiring NICU care. We also wanted to ensure that participant NICU experiences were fairly recent but that the infant and family was stable at home. As such, we required that the infant was cared for in the last 5 years but that discharge occurred at least 2 weeks ago.

piloted our recruitment strategy and materials with the NICU Family Advisory Council at Lucile Packard Children's Hospital.

Ethical Considerations

This study was approved by the Stanford University Human Subjects Research and Institutional Review Board. Participants gave consent verbally after listening to a script describing the study and given a written information sheet about the project. In this article, identifying attributes (e.g., workplace) are avoided or fabricated.

Data Collection

Interview guide development.—In partnership with former NICU parent-researchers, we piloted interview/focus group guide at the 2017 meeting of the Preemie Parents Alliance and received preliminary data and feedback on our research strategy. We conducted interviews and focus groups in 2018 using a semi-structured interview/focus group guide (see Supplementary Appendix A). Part 1 was organized around the core principles of family-centered care (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; see Figure 1).

Consistent with grounded theory methodology, we used the principles of family-centered care (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012) as "sensitizing concepts" (Blumer, 1969) to "form interview questions, to examine data, to listen to interviewees and to think analytically about the data" (Charmaz, 2006, p. 17). These sensitizing concepts guided our methodology as directions along which to look, not prescriptions of what to see (Blumer, 1954). That is, the principles of family-centered care offered a point of departure from which to study the data, facilitating the identification of *new* concepts and principles to emerge (Charmaz, 2003). Interviewers asked open-ended questions that invited participants' perspectives on the core principles of family-centered care. For instance, with regard to the principle of receiving support, interviewers asked participants to elaborate on the support services received in the NICU and whether they were available when needed. We adapted our semi-structured interview/focus groups to follow up on concepts identified in previous interviews/groups until our data reached theoretical saturation. At the end of each focus group, participants completed a demographic questionnaire (included in Supplementary Appendix A).

Procedures.—We held in-depth interviews in person, by phone, or by videoconference and held focus groups at Valley Hi Family Resource Center in Sacramento, California. Interviews were conducted in English with the exception of three interviews conducted in Spanish. Participants were given the option to participate in focus group or interview to maximize participation. To facilitate participation, we provided food and beverages as well as child care at focus groups. We thanked interview and focus group participants with a $50 gift card.

Data Analysis

After interviews and focus groups were transcribed and translated, the data were entered into and analyzed using Dedoose,[3] a mixed methods data management and analysis tool, according to inductive principles of grounded theory for themes, concepts, and patterns using two independent coders. We took field notes after interviews and focus groups and analyzed the data by memoing and constant comparison resulting in analytic codes and categories (Charmaz, 2006). We provided our parent research partners with preliminary code books alongside transcript excerpts to conduct member checking, a validation technique where initial analyses are presented to study subjects (or proxies) for confirmation, or elaboration (Charmaz, 2006). Following the process of member checking, we reorganized and renamed codes based on feedback from our parent research partners. These codes were then used to re-organize excerpts and concepts resulting in a final code book.

Results

Eighteen former NICU parents participated in this study, 10 through in-depth interviews and eight through two focus groups (see Supplementary Appendix B: Demographic Characteristics of Participants). Although all family members were invited in our recruitment efforts, we successfully recruited only parents, 16 female-identifying mothers and two male-identifying fathers ranging from 26 to 42 years of age. Six participants identified as White, five as Hispanic or Latino, four as Asian, and three as Black or African American. The vast majority (15) of our participants were married or common law co-habitants and just over half ($n = 10$) had a college degree or higher education. Estimated annual family income varied among participants, with about half ($n = 9$) making less than $50,000 per year.

Participants’ infants were born from 24 weeks through 34 weeks gestational age, with the vast majority (14) born 29 weeks gestation or less. All of the participants’ infants were also of low birth weight (less than 1500 g). The infants were cared for in 11 different NICUs representing a mix of levels, academic affiliations, geographic location, and urbanicity and had a NICU stay from 14 to 135 days, depending on the severity of the infant’s condition. Three participants had multiple preterm infants, with each of the infants cared for in different NICU. Three participants had infants who were transferred from their hospital of birth to a hospital with a higher level of neonatal care.

Many participants spoke very highly of the neonatal care they received. These families were particularly grateful for the feeling of partnership and support from their care team, particularly from nurses with whom they developed a close bond. Despite these positive experiences, accounts also revealed gaps in the receipt of family-centered care and unmet needs for partnership in care or support. Our analysis revealed the following challenges in care that weaved across the six principles of family-centered care: (a) family lack of knowledge/ambivalence regarding social work or conflict between families and social work, (b) staff judgment of, or unwillingness to, address barriers to presence at bedside, (c) unmet family-identified need for nurse continuity of care and a meaningful relationship with nurses, and (d) inconsistent access to quality translation services. We identified two underlying dimensions raised by these challenges: a lack of mutual trust and a lack of power

---

Dedoose Version 8.2, web application for managing, analyzing, and presenting qualitative and mixed method research data (2019). Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com.

sharing. Our findings suggest that these dimensions underlie the successful implementation of the already identified principles of family-centered care (see Figure 2). Participants' accounts told of a lack of mutual trust between clinicians and families, particularly in that clinicians did not always trust families as capable and worthy. Participants' accounts indicated a sense of powerlessness to gain needed resources, influence hospital policy or procedures, or stand up for their own self-worth as parents. In the discussion, we return to these overarching themes, particularly how they relate to already identified principles for family-centered care (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012).

Family Lack of Knowledge/Ambivalence Regarding Social Work or Conflict Between Families and Social Work

Participants wanted to receive strengths-based formal and informal support in the NICU and one of the major gaps that emerged in this area involved social work. "Formal support" generally refers to paid support offered by an organization (e.g., neonatal social work or psychiatry) while "informal support" to the unpaid support of family and friends (Chan et al., 2011; Lyons & Zarit, 1999). "Strengths-based" refers to approaching health care experiences as an opportunity to build upon innate family strengths (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012).

Participants had a variety of experiences with NICU social work: while some found social workers helpful, many parents were uninformed or ambivalent about social work, or had conflictual experiences with social work. Families pointed to their need to share power with social workers such that families are informed about their scope of work (rather than social workers deciding when a family needs social work), to know how/when to call on them and to feel that social workers trust them as capable parents doing the best they can under difficult circumstances. Similarly, families indicated a lack of mutual trust between themselves and their social workers. Some felt that social workers were quick to judge parents as incapable rather than appreciating their strengths and offering support services.

Lack of knowledge or ambivalence.—Many parents were not informed of the scope of the social worker role, and this effectively put the onus on parents to know what to ask for, from who and when, rather than receiving information about the role and availability of social work services early in their NICU stay. For this reason and because of delays in getting needed resources from social workers, some of these families deemed social work services as having little value for them. For some families, this dynamic manifested into finding out about needed resources late or not at all. For example, a White mid-income mother had a planned cesarean due to intrauterine growth restriction. Knowing ahead of time that her baby would be born early, she toured the NICU where her baby would be cared. She told us that this tour helped introduce her to the NICU experience and helped her mentally prepare but that this tour did not include information on social work. This mother reflected that during her baby's hospitalization, she did not know she was eligible for MediCal (California's Medicaid program), nor did she know about available NICU family housing supports. She told us that she would have liked social work to tell her about these resources in a more timely fashion:

> There definitely should be a NICU social worker [but] for us, *we had no idea that we were eligible for MediCal. We needed the social worker to tell us that.* So, I think that's really important for supporting families later so that they don't get … a huge bill … [but] *we didn't get told about MediCal until a few weeks later* … For some reason, [the social worker] didn't tell us about the MediCal program until later … I don't know what the reasons are, but she was checking in regularly. We didn't realize that we needed to ask for the information, you know?

She described not understanding why the social worker was asking particular questions because they were never linked to potentially available resources:

> Like when the social worker came to talk to us, initially, she was kind of checking in. She was asking a couple of questions and then she asked, "How far away do you live?" and stuff and then just kind of left. *She didn't actually say, "Oh, we can provide a bed for you or a sleep room here if you wanted to stay here*," *She didn't … she didn't really explain why she was asking the questions she was asking.* (laughs) So later on, I kind of realized it. I was, like, "*Oh*, they have sleep rooms." And I heard them talking to other parents and I heard that … someone who lived two hours away or something was able to stay at the Ronald McDonald House. *So, I got it, later on, but I think that some of that wasn't communicated.* (laughs).

This mother reflected that ideally, a social worker would provide information on their scope of work in a handout or packet that would include the most common information or resources they could provide a NICU family. Regardless of their overall impression of whether the scope of social work was communicated adequately, nearly all participants felt like information about available resources that originate in social work, particularly Medicaid coverage, arrived too late or not at all.

Another example of the difficulties in interaction with social workers occurred for an Asian mom of pre-term twins born spontaneously at 29 weeks. This mother discovered over time that her social worker did not provide her with needed information, and, when she did, it felt like a "hassle":

> During my whole stay there, I never really talked to [the social worker] … *And during the discharge, [the social worker] told me she was going to sign them up for early intervention and that was another whole ordeal. It took a lot of going back and forth for them to actually sign me up for early intervention* … to get the actual paperwork. But what I was really upset about was that [the social worker] never told me … of all the available services that I could have gotten while the babies were in the NICU and one of them was the SSI … So now I'm thinking, "What *else* did I not know about that I could have gotten for my kids to help out my kids?" *Because everything that she was supposed to help me out with was a hassle … like, she didn't really do her job.* Because I don't know what other services [I missed out on] … Actually, one other thing … that I wish I knew about was the Medicaid coverage—that I could have applied for government medical coverage for the babies. So, yeah, and because I paid like a big deductible while they were in the hospital, so I wish I would have known about that, too. So, yeah, the social worker didn't tell me anything about that.

This mother’s experience suggests that families rely on social workers to educate them about available entitlements and services. When that information is not shared in a transparent and timely manner, families may lose confidence in social workers and wonder about what “other” resources they are missing out on.

Conflict.—Six low-income participants, including the three Black/African American participants, spoke of an adversarial relationship with social work. These parents felt social workers lacked empathy for their situation and were quick to involve child protective services (CPS) without reaching out to parents first, to understand the context and/or what resources were needed. For example, one mother felt judged by NICU staff for being poor and for having mental health challenges. She felt that her social worker knew she was poor but did not take the time to find out from her what she needed, but rather raised alarm bells after reviewing her medical record that indicated a mental illness.

> I didn’t like [the social worker]. She accessed my medical record. I don’t know how she did that without my permission and it said [I have] attention deficit disorder, so between that and me not able to be there all the time, she assumed I couldn’t take care of the baby. So, she called CPS. So, she was the only social worker and she wasn’t very helpful.

It may be that many NICU parents do not realize that social workers have access to their medical record, and experience similar conflict as a result. For this mother, this dynamic established a relationship of distrust and reaffirmed already existing negative attitudes she held about social workers as a low-income mother.

A number of low-income mothers, particularly Black mothers, spoke of strained relationships with social workers and CPS that spanned their lifetime experiences in health care, including neonatal care. They spoke of a looming threat of social work calling CPS to “take their children” for situations that were misunderstood or misconstrued. One participant, a Black homeless mom who was escaping domestic violence at the time of preterm birth, described the tense dynamic as follows:

> [Social workers] make an assumption, like, based off of … where you’re at in your life at that moment, *they kind of assume, “Okay, well, she’s going through all this. She can’t take care of her kid.” You know, well that’s not the case.* You know, you don’t know what someone’s going through or, you know, the steps that they’re taking to make sure that they can take care of their kid and not just assume that, “Oh, she doesn’t have this. She doesn’t have that. She’s going to have this baby. What is she going to do?” [Social workers] were quick to call CPS on me for every little reason in my situation with the dad and it was just like they use that against you. They use your downfall against you. That’s what I don’t like … *It’s not a good feeling to be judged when you know what you’re capable of.*

Some of the participants who had negative interactions with social work spoke of this stemming from missed follow-up appointments after NICU discharge. One mom had missed her son’s specialist appointment because, at the scheduled time, she was unexpectedly with her son in the emergency room (ER). She did not have a chance to notify anyone about missing the appointment, and rather than checking in with her first, the social worker called CPS:

> One thing that bothered me is that [social workers are] very quick to call CPS. They don't call the parent if they miss an appointment or what have you. So, we had a follow-up appointment the same day I took him to the ER and the social worker called CPS. Like, they didn't notify me, say, "Hey, you missed your appointment," you know, or anything. Strictly called CPS. *"But you have my phone number … come on, guys. Why didn't you call me? You have my number."*

A general sense of distrust of social workers was palpable at our focus groups when the topic came up. At one focus group, two of the parents had their infants cared for in the same NICU and agreed that there was a particular social worker there who was known to be the "number one caller of CPS." These families stated that they felt judged by social workers when CPS was called without offering family supports to ensure infant safety and well-being. These families identified a need for mutual trust with their social workers such that perceived weaknesses in parents (e.g., missing an appointment) would be met with services and supports (e.g., a phone call, a taxi voucher, etc.) rather than with punitive interventions (e.g., calling CPS).

Staff Judgment or Unwillingness to Address Barriers to Parental Presence at Bedside

Participants wanted to collaborate with nursing staff as partners but found that one of the major gaps in this area concerned interpersonal staff–family dynamics. Some participants experienced negative judgment from NICU staff who felt there was inadequate parental involvement or lack of presence in the NICU. At times, participants experienced this as the clinician's unwillingness to address salient barriers to parents' physical presence at the bedside. In some cases, families described interactional dynamics with NICU clinicians underpinned by judgments, which they experienced as a form of racial or socioeconomic discrimination. These dynamics strained clinician–family relationships and further prevented participants from engaging as trusting and *trusted* partners in the NICU. Accounts pointed to a power differential such that staff had the power to judge, demean, and distrust families. Through their accounts, families identified a need to share power with clinical staff in the sense that the staff trusts and treats them as capable caregivers of their infants and believes they are doing the best they can under difficult circumstances, such as structural barriers to parental presence at bedside.

Staff judgment or dislike of families.—Families sometimes felt as though NICU staff *disliked* them and this impression created significant barriers to parental engagement, particularly when that dislike was perceived to be socioeconomically or racially motivated. In general, we found that families spoke a great deal about whether staff "liked" or "disliked" them and that this dynamic influenced whether parents felt welcomed to be involved in the care of their hospitalized infant and whether NICU staff were willing to help address barriers to parental presence at the bedside. Some families did not believe that NICU staff were giving equal support and attention to all families, regardless of whether a family was well "liked." This indicated a lack of underlying mutual trust between NICU staff and families.

A low-income White mom, who experienced preterm birth in three of her pregnancies, spoke of being made to feel like a “bad mom” by NICU staff because she was judged for not being in the NICU “enough.” Her experience illustrates how working mothers, particularly those of low income, have acute challenges when work prevents them from presence in the NICU:

> Yeah, I was working. My husband, he would go [to the NICU] during the day and just give her the bottles. But then [the NICU staff] got mad because they wanted me to come up and breastfeed, because that’s better for the baby. So, they got mad about that and I wanted to sleep, so I can’t be there every three hours because I had to work and I had an older daughter, too. So … I sent [my husband] and they didn’t like the idea. Because he worked at KFC. I worked at McDonalds …So it was, like, we have both different shifts. He worked nights, I worked days, so … sometimes, we just went together every three hours when I could. But [name of NICU], I don’t like them. […]
>
> Interviewer: You kept using the phrase, “They didn’t like that.” How did you know that they didn’t like that? What was being said to you?
>
> They were just, like, snobby and their body language, they had attitudes all the time. This mother and her husband returned to shift work in fast food while their infant was hospitalized. Instead of feeling empathy or receiving support from the NICU care team, they felt judged and blamed as bad parents due to their socioeconomic status.

Racially based judgment.—Other participants experienced racist staff judgment related to barriers to their presence in the NICU. One mother, an unemployed Black mother of two children, one of whom was born preterm, took the bus for 3 hours from her home to the NICU where her infant was receiving care. Her experience contrasts with other families we spoke with who *were* able to find temporary housing closer to the hospital or had financial resources to cushion the impact of having an infant in the NICU.

> I feel like [NICU staff] were judgy and racist because I only had certain clothes, so they didn’t like that I kept wearing the same clothes and they put that in her medical file, that I kept wearing the same clothes. But I don’t understand how that had anything to do with [my baby] because she had a lot of clothes. And I had to take the bus. So, it took me three hours to get to [the NICU]. And by the time I got there, it was time to leave because the bus stopped running early and [the NICU staff] didn’t like that, either. So eventually, the social worker called CPS to make sure I was capable of taking care of her and I got cleared within 30 days.
>
> Interviewer: How were you made to know that all of these things about you were being watched? How did they express “We don’t like the fact that you’re wearing the same clothes?”
>
> I didn’t know until I looked at her medical chart because I needed to apply for social security and that’s when I seen all the comments about me made … And they

> made me feel bad because I couldn't breastfeed a lot and I couldn't transport breast milk because it would get bad by the time I got there and they didn't like that.

This mother felt that the NICU team did not support her feeding decisions or her efforts to provide breast milk, an enormous challenge for many NICU families, but especially for Black and Hispanic/Latino families who have been found to have lower breastfeeding rates in NICUs (Lee et al., 2011; Parker et al., 2019; Profit et al., 2017). She described a strained relationship with NICU staff, illustrated by staff making excuses for not facilitating skin-to-skin care or parent-led diaper changing when she was available. The relationship devolved to the extent that staff called CPS on her without talking to her about her socioeconomic challenges or offering her support.

In some cases, overarching poor relationships between Black/African American NICU families and staff were described by participants as relating to a long history of distrust between Black/African American families and health care institutions. One low-income Black mother who gave birth to each of her three children prematurely, reflected that African American families adapt to racism by keeping their problems and challenges to themselves and distrusting institutional authority. This came up in regard to a historical fear of state intrusion:

> What I know for African Americans is that we are taught to keep whatever happens in our family in our household … and if you tell anyone on the outside, now you're bringing people into your home, which you don't need—such as child protective services and things like that. So, a lot of mothers feel scared and skeptical to come forward and talk to their doctors because they don't want to be judged … and they're scared if they are judged, what will be the consequence of being honest …

Some interviewed families expressed a lack of mutual trust between Black families and clinicians that was not limited to the walls of the NICU but rather spanned health care and was strengthened by the power of CPS to remove children when families are deemed unfit.

Fathers feeling excluded, judged, and unwelcome.—Many interviewed families stated that fathers *in general* did not feel included in the care of their hospitalized infants and that Black fathers felt *further* excluded or unwelcome. While this phenomenon does not fit neatly under staff judgment or unwillingness to address barriers to presence, it tells of something related—that fathers, and particularly Black fathers, may not feel welcome in the NICU, and that staff attitudes or judgments may be a barrier to a father's presence. One mother told us about the significance of Black fathers not feeling welcome in the NICU:

> It's important to just make the parent, especially of color, feel more welcome and more wanted. I do hear from a lot of African American fathers [that] they do not feel welcome at all. And they feel that when they walk in there, all eyes are on them … the nurse comes and starts inquiring with questions, you know, "Why is she asking questions? Was she asking questions before I came?" and now [the dad is] feeling like they're being judged again … With my husband, he came to the NICU —I would say maybe once every two weeks—and he would stay. But you could tell he was very uncomfortable … I have spoken with [other] Black fathers who have been there every day. But if I had to put a number on it, I would say about 65%

> either never go or very seldomly go … And I ask them [why] and it’s usually, “I don’t feel comfortable,” or, “It’s not my place to be there.” And it’s, like, why is it not your place to be there? It’s your child, too, you know? I don’t know. Maybe, in honesty, it might be that they view that it’s a mother’s time to go and bond and breastfeed because that’s what you always hear when you’re there … And there’s not anything specifically for the father to do. So he doesn’t feel included.

Similarly, participants mentioned Black fathers being questioned unnecessarily about their relationship to the mother or employment status to the extent that fathers avoided spending much time in the NICU. For instance, a White mother who went into spontaneous labor at 25 weeks described how her NICU experience, in general, felt like a “battle” to be heard and involved. She described how her Black husband felt particularly judged and unwelcome in the NICU. The staff repeatedly confused the fact that her husband *worked* at a prison with him *being* a prisoner, which caused her to feel that she needed to defend him as a good father:

> Interviewer: What were the moments where [your husband] felt judged?
>
> Um, numerous times when my husband wasn’t around, they asked *if he worked*. It was just very weird. So, finally, my husband wrote on the board, “I work at Folsom Prison. Not an inmate there.” … I would just say there were stereotypes about him. My husband is the complete opposite of any of those, so I think that’s probably what makes him so frustrated … Like, I’ve literally felt like I have to defend him … Like, if you talk to any one of their kids, they’d be, like, “My dad’s the best dad in the entire world.” Hard working and … you know what I mean? But I’m, like, you know what? It’s none of your business. You judge all you want. I know the facts. You know, it’s just … very sad in society today that that is still happening and it’s 2018. But I also know that [stereotypes are] a reality …

Families who feel judged for their barriers to presence at the bedside, or who feel they were met with unwelcoming or racist clinician attitudes are not receiving family-centered care. These challenges in care point to underlying gaps in the dimensions of mutual trust and power sharing that underlie the successful implementation of family-centered care.

Unmet Family-Identified Need for Nurse Continuity of Care and a Meaningful Relationship With Nurses

Participants spoke of the importance of continuity in nursing care, and of developing meaningful relationships with their bedside nurses, as essential components to information sharing and collaborative participation. Families frequently referenced the key role of primary nurses and having the ability to influence nurse assignment as important components toward these principles. Some families described that their experiences of building mutual trust and sharing power with nurses, led them to feel safe leaving their infant with a particular nurse who trusted the family to participate in care such that partnership would be prioritized and accommodated. However, many participants experienced significant gaps around shared power and mutual trust, impeding their ability to positively and effectively collaborate and partner with NICU staff. In particular, it was clear that not all families had equal access to continuity of nursing care or primary nursing. Those who did have access described how it developed by happenstance rather than an intentional, equal allocation of this particular resource.

Many participants were able to differentiate between “status quo nursing” versus situations where nurses went the extra mile or got to “know their baby.” Parents were dissatisfied when nurses provided impersonal care and were unfamiliar with their infants’ behaviors, history, or unique quirks. These feelings and perceptions led families to identify a need for a meaningful and trusting continuous relationship with nurses. Such a relationship is most often associated with primary nursing (where a nurse is assigned to care for one infant for the duration of the NICU stay), or at the very least, parents’ ability to influence nursing assignments. One participant, an Asian mom who went into spontaneous labor at 24 weeks, described primary nursing in the NICU as “cutting her anxiety in half.” She described her dissatisfaction with other nursing care, as many other participants did, with reference to some nurses not bothering to do more than basic care required:

> There was this time where I have this nurse that I don’t like. I don’t like because, you know … because she only sits at the computer near my baby … *Yeah, and this nurse just goes and sits there and then sits forever* and then I tell her, “Okay, I think it’s feeding time.” And she goes, “Oh, yeah! Yeah, yeah! Let me prepare the milk.” And gets the milk, does not even warm it, fed my baby this really cold milk straight from the fridge and I go, “What?”

For many families, wanting to exert “nurse preference” or wanting a primary nurse originated in having a bad relationship with and ultimately “firing” a nurse. Like other parents we interviewed, one mother described this occurring after witnessing rough handling of an infant or feeling as though the parent’s intuition and observations about their infant was not listened to or respected:

> I don’t know what I would have done without a primary … Because there were times before that I was, like, “That [nurse] will not touch my baby again.” I talked to the charge nurse, “You better take her off the rotation in this area.” So, I had two really traumatic experiences. One time, I was still in the hospital. My husband [and cousin saw] a male nurse that … just grabbed our daughter and flipped her (snaps fingers) without any care. So much that my cousin was, like, “Excuse me, sir. I don’t know if you’re supposed to do that.” They asked for the charge nurse. [Another time], my daughter had a couple of PICC lines (peripherally inserted central catheter lines) and one infiltrated and [she] got a staph infection in her clavicle bone and *I told [the nurse] something was wrong, and she told me I was crazy. And I was, like, something is wrong with my daughter. My mother’s intuition, so far, has not been off one time. I’m telling you something is wrong.* [After I complained] … I never even saw [that nurse] on our side of the NICU again. And it wasn’t like I complained about a lot of people, but I was, like, “I don’t feel comfortable with her and I don’t care. They’re not allowed to touch my baby again.”

Participants told of an absence of norms in the process of being assigned a primary nurse, most often referencing “hearing” about it, or awkwardly asking a nurse to be their primary. Primary nursing was not equally available to all families or in all units. For all families where it was available, getting a primary nurse involved an awkward social interaction that many described as akin to "dating":

> [The charge nurse] told me, "Yeah, if you want a nurse, if you're impressed with a nurse or something and you want this nurse to be the primary nurse, she could be dedicated to your baby every time she's on duty." I was, like, "Wow! Really? Is that possible?" It's, like, "Yeah! As long as the nurse also wants to be a primary." So I started taking down names of the nurses that I want and then I talked to them and asked them, "Can you be the primary nurse?"

Families recounted many benefits of having a nurse they preferred (or of having a primary nurse they selected). Participants felt like the primary nurse knew their baby, provided exceptional care, or provided exceptional support or communication, allowing the family to feel confident their baby was well cared for. Nicole described how she felt she could "relax" when the primary nurse was on duty:

> Just having primary nurses felt really good. I felt so much more … I mean, I know *all* the nurses were competent … but anytime my primary nurse was on duty, I felt like I could relax a little bit more, you know? And I felt like they cared about my babies more and would look out for them more even though, you know, all the nurses have to care for all the babies. It just emotionally felt safer.

One participant, an Asian mom of preterm twins born at 27 weeks for intrauterine growth restriction, asserted that having a primary nurse brought out the best forms of partnership between her family and the NICU care team. She described how having a primary nurse calmed her even in the scariest of moments and fostered an atmosphere where milestones, like birth, were celebrated and photographed, creating a NICU experience that was not just about fear and worry:

> I feel like [primary nurses] were great advocates with us. Like, I felt like we were a team. Early on, we kind of realized that, oh, we should have primary nurses. *Like, somebody kind of gave us that tip!* So they became the best partners because … every time we had them, they were, like, "Okay, here's our plan." So, even when my sons were born, we already had the plan that [husband] was going to go out with them. And even our neonatologist was explaining everything to him. But then at the same time, he's like, "Take pictures, dad," as he's like, "Whoa." You're bagging him, you know? They're like, "Oh, celebrate this moment," (laughs) you know? But it's things like that where they were really encouraging, which we probably would have just freaked out, you know? So, I felt like it was a good team. We did have some experiences where it's, like, I didn't care for a certain nurse … so, I'd be like … so, I'd be, like, "She's never caring [for my baby again]."

Like many other participants, this mother was pleased when primary nurses advocated for her baby's progression through NICU care. For instance, participants spoke of primary nurses as especially helpful in convincing the care team that an infant was ready for, for example, skin-to-skin care, breastfeeding, or discharge. In this sense, many parents associated primary nurses with feelings of mutual trust, power sharing, hope, and optimism around their child's progression, improvement, and discharge.

Inconsistent Access to Quality Translation Services

One of the important barriers to parents communicating effectively with their NICU care team concerned access to quality translation. Participants with limited English proficiency spoke very highly of the care they received; however, their accounts revealed limited access to translation services. Families with limited English proficiency, particularly undocumented immigrants, may not know what language services they should expect in an American NICU and without that knowledge, may be left in the dark. Participants revealed a need for health professionals or hospitals to prioritize family needs for support and integration (e.g., for translation services) over the needs of a hospital system or health professionals (e.g., for efficiency and expediency). It appears especially important to attend to the needs of those who cannot advocate for themselves, for instance when family members do not ask for translation services because they are not aware of what is available. This indicates a need to share power, such that patient and family needs, even when not loudly advocated for, can take precedence over an institution's tendency to "move things along" or move patients through pathways of care the sake of routine and efficiency (Kaufman, 2006).

For example, we interviewed an immigrant family from Central America who reported that they had *no complaints* about their NICU stay. At the same time, they reported that a great deal of translation was conducted by family members with limited English proficiency or by providers who did not speak Spanish well. This mother told us:

> Well, I thought it was perfect, the NICU, I do not see anything bad, everything felt good. I liked the environment of the NICU, the nurses always supported me and all … I don't see anything bad about the NICU … we always felt welcomed, the NICU nurses came to us and asked us if we had any questions and they kept us updated about how my son was doing.

When we asked this family about how they communicated with their providers, given their limited English proficiency, it became clear that they had inconsistent access to translation services. Instead, they often relied on the father's limited English and a provider's limited Spanish:

Interviewer Ok, how did you communicate? Did you communicate in Spanish, in English?

Mother In Spanish, I don't speak much English, so, sometimes somebody [a translator] would come from the hospital or they would give me a tablet and somebody translated via video chat or sometimes it would be my husband that speaks very little English, he tried to explain to me a little bit … They always respected me and were very polite with me, and they often tried to speak a little bit in my language but not so well but they tried to explain what was going on.

Although these parents did not note any problems getting needed information by relying on informal or limited translations, other families experienced challenges.

Some families felt NICU staff made insufficient and deficient efforts to obtain translation services. Even native English-speaking families observed the variation around getting interpreters for their NICU neighbors when needed:

> Interviewer: Did you experience a lot of families around you that didn't speak English well?
>
> Yes, and I saw varying levels of effort put in to getting interpreters versus not. There were a lot of times there were no efforts for interpretation.
>
> Interviewer: So what would be an example of that, of no effort?
>
> Um, yeah, just the nurse saying something to the mother that she clearly didn't understand. But, like, they were usually small things like—I don't know—one or two sentences of, "Your baby weighs this much or something." And it was such a small thing, they didn't get an interpreter to say it. But you can just tell the mom doesn't understand. I feel like those moments are important and they add up.

Others spoke of the deficiencies of phone or iPad translation (more readily available) compared with in-person translation services (less available). A Hispanic/Latina NICU mother who spoke English, observed other parents struggling:

> I have something to say about the translations. Uh, the thing I didn't like … it's like they offer you phone translation, … which I think is really hard for the people that don't understand English perfectly, I think [phone translation] doesn't make a difference, *seriously*, because it's really hard to hear and understand the phone translators, so I wish they could have had more [in-person translators] … I know they have some, but sometimes they're not available, like one-on-one … so they can explain, you know, and make sure they're understanding.

We asked her how she viewed iPad translation systems compared with phone translation services. She responded,

> Yes, like, it's hard for families to understand [iPad or phone translation] because … Even like, one-on-one it's hard to understand because you have to take time to rethink and kind of analyze what the translator is saying. Imagine on the phone or iPad, it's like what are they saying or what is … so, I think it's like having to go through another step.

Similarly, other participants spoke of observing problems with providers assuming a level of English proficiency in families that was not enough to understand medical information, or of providers getting by using their own poor Spanish skills. One mother told us,

> Translators should be available, definitely, because … there's so much different information that you get every day. There was actually a baby across the way from us who … had a Spanish-speaking only family … and just from me sitting there for hours every day, I was listening to everything everyone was saying and … because I didn't have anything else to do … and the baby had a heart problem. The baby needed heart surgery and they had translators for that, but there were many other times that I know the nurse didn't get a translator and I was thinking wow, you could miss so much information if they didn't know … what they were saying … And there were nurses who did speak Spanish, and a few of the doctors that did, but there were a few times I heard them try to tell the parents something in broken Spanish and they were, like, [after a while] "Okay, hold on. Let me get a

> translator." And in my head, I was, like, *"Well, you should have just done that in the beginning and you would have saved yourself a lot of time."* (laughs)

We conducted three of the interviews with Hispanic/Latino participants in Spanish since they spoke limited English. We found that these participants were very cautious about discussing their immigration status given the punitive climate around documentation in the United States. This cautious approach parallels how undocumented parents may be reluctant to draw attention to themselves by advocating for NICU translation services.

Discussion

In this article, we described gaps in family-centered care in the NICU and unmet needs for partnership in care or support in 11 different California NICUs, particularly as perceived by parents of color or of low socioeconomic status. The challenges described are (a) family lack of knowledge/ambivalence regarding social work or conflict between families and social work, (b) staff judgment of, or unwillingness to, address barriers to presence at bedside, (c) unmet family-identified need for nurse continuity of care and a meaningful relationship with nurses, and (d) inconsistent access to translation services.

We identified two dimensions underlying the principles of family-centered care: mutual trust and power sharing (see Figure 2). These were revealed through gaps and unmet needs described in this article. It appears necessary to draw out these key concepts from the principles already identified and make them more explicit to enable effective implementation of the principles of family-centered care. That is, for the six principles identified by the American Academy of Pediatrics and the Institute for Patient and Family Safety (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012) to be adequately implemented, hospitals and clinicians need to share power with and trust families. Doing so would result in families feeling trusted and worthy of quality care, feeling a greater sense of empowerment and equality in caring for their infants within the hospital environment.

NICU nurses are known for their unflagging devotion to their infant charges (Cricco-Lizza, 2011). Our suggestion that nurses (and other NICU staff) share power with and trust families reflects best practice in provider–parent interaction (Davies et al., 2017), However, our suggestion challenges routine NICU nursing care. That is, prior research has found that NICU nurses manage the inherent uncertainty in infant care trajectories in the NICU through tight control of care, reliance of technology, and maximal efficiency in use of time (Cricco-Lizza, 2011). Family-centered care challenges NICU staff and hospital systems to adjust these patterns of care by prioritizing mutual trust and power sharing with families.

The analysis presented here on family lack of knowledge/ambivalence regarding social work or conflict between families and social work does not offer a complete picture of the social work role in the NICU. We do not know the scope of social work in the NICUs the participants' infants were cared for in. However, our finding of family lack of knowledge/ambivalence regarding social work, or conflict between families and social work, suggests variation in the implementation of social work standards as set out by National Association of Perinatal Social Workers (NAPS) and California Children's Services (CCS) (Department of Health Care Services, 1999; NAPS, 2007). The NAPS (2007) provides standards for social work services in the NICU that outline the social work role emphasizing support, availability, accountability, and advocacy. California Children's Services (CCS) mandates social work services be provided in NICUs by medical social workers at a rate of one full-time medical social worker for every 15 patients, and that family interviews, care plans, and progress notes be completed according to a required timeline (Department of Health Care Services, 1999). Furthermore, CCS requires a written job description with social workers' responsibilities, including the provision of psychosocial support within an interdisciplinary team. Some parents in this study were not informed about the scope of the social worker's role and many did not know to use them as a resource. One way to achieve better transparency may be to explicitly communicate the NAPS standards for social work services in the NICU to families and clinicians through standardized information materials regarding the social work role and the resources they may be able to offer. To meet the CCS mandates and the NAPS guidelines, NICU social workers need to be adequately resourced and fully integrated into the NICU care team.

Social work as a profession has a deep-rooted problematic relationship with race and socioeconomic status, particularly when it comes to child welfare (Corley & Young, 2018; Roberts, 2002). Roberts explores the racialized dynamics of child welfare arguing that the child welfare system is a state-run program that disrupts, restructures and polices black families" despite little evidence that the foster care system improves the lives of Black families and children. We heard from Black families and poor White families who felt unfairly judged by social workers when CPS was called without first checking in about needed supports first. This dynamic strained the relationship between social workers and families. At the same time, the profession's core values include social justice (National Association of Social Workers, 2017) and, as such, the profession, in its philosophical orientation, aims to reduce the burden of oppression and injustice, rather than exacerbate it.

Our findings of staff judgment of, or unwillingness to address, barriers to presence at bedside are troubling. Families who are poor and/or of color with barriers to presence in the NICU may be particularly vulnerable to staff insensitivity, even though they are likely the ones who need the most support. This article adds to the body of literature documenting how families of color experience discrimination, racism, and disrespect in health care encounters (Altman et al., 2019; Edwards et al., 2020; McLemore et al., 2018). It adds to our understanding of the mechanisms that underpin racial/ethnic disparities in the receipt of family-centered care and in family satisfaction of neonatal nursing care (Martin et al., 2016; Sigurdson et al., 2018). Furthermore, examples of Black fathers feeling unwelcome in the NICU in this article provide illustration of stressors from interpersonal and institutional racism experienced by Black men (Ornelas et al., 2009).

A recent policy by American Academy of Pediatrics on "The Impact of Racism on Child and Adolescent Health" (Trent et al., 2019) describes racism as a "socially transmitted disease passed down through generations, leading to the inequities observed in our population today" (p. 3). They suggest that to ameliorate the effects of racism on children and adolescents,

> Pediatricians can implement systems in their practices that ensure that all patients and families know that they are welcome, that they will be treated with mutual respect, and that high-quality care will be delivered regardless of background using the tenets of family and patient-centered care. (p. 5)

We would add to this that the principles of family-centered care be viewed through a racial and socioeconomic equity lens and that the overarching domains of mutual trust and power sharing underlie implementation.

Our finding of an unmet family-identified need for nurse continuity of care and a meaningful relationship with nurses suggests that families may not have equal access to primary nursing and/or continuity of nursing care in NICUs. This lack of equal access starts with lack of equal education and information about primary nursing and how to access it. When families do not have access to continuity in nursing care or primary nursing, the parental role as partner-in-care may be reduced. As such, the effects of separation (including adverse parental mental health issues such as depression and post-traumatic stress; Craig et al., 2015) and potential negative long-term childhood outcomes may be exacerbated (Mefford & Alligood, 2011). If families lack information about primary nursing and why it is important, families and infants are especially vulnerable to the effects of separation.

There is a body of research linking limited English proficiency with poorer health outcomes among racial and ethnic minority children (Eneriz-Wiemer et al., 2014). Our finding of inconsistent access to translation services suggests that disparities in opportunities for partnership in care in the NICU may sometimes be invisible to health professionals when families do not advocate for supports. It is incumbent on health professionals and health care systems to identify and prioritize family needs such as translation services to achieve equitable family-centered care and outcomes.

This study should be viewed in light of its design. Our study is limited by a convenience sample and not intended to be representative of all family experiences in all NICUs, nor are we able to compare experiences in different units given the small size of our sample. Results may be different had infants been cared for in different units or in different states. Results may be specific to sites of care and the institutional practices of these NICUs (e.g., whether a NICU offers primary nursing care, or the quality and staffing of social work). Remarking on these institutional practices is beyond the scope of this study. Our analyses were limited to exploring four challenges in family-centered care that pointed a need for mutual trust and power sharing that underlie the principles of family-centered care. This is an exploratory, hypothesis generating study and may contain inherent biases such as a sampling bias toward those with strong views about their experiences of care or those whose responses were influenced by patient outcome. It may also omit alternate explanations for the care families received. For instance, a family-identified clinician’s unwillingness to address barriers to presence at the bedside may indicate a clinician’s lack of resources for assisting that family or clinician burn-out.

Conclusion

The traumatic separation of hospitalized critically ill infants from their families can be exacerbated by limiting parental involvement. Although families interviewed frequently spoke highly of the care they received, they identified several gaps and challenges to the provision of family-centered care, particularly for families of color and of low socioeconomic status. The expanded conceptual model presented in this article, wherein the dimensions of mutual trust and power sharing underlie the six principles for family-centered care, will guide further research and has implications for neonatal practice. We propose here that any approach to improving family-centered care, especially one targeting the improvement of racial/ethnic and/or socioeconomic disparities in family-centered care, needs to emphasize underlying dimensions of mutual trust and power sharing through whatever intervention is utilized. These underlying principles are, in fact, values implicit in family-centered care and made more explicit through our analysis of family accounts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

We are grateful to the Preemie Parent Alliance for allowing us to pilot our focus group questions at their 2017 meeting and for participants in giving us feedback on this work-in progress. Thank you to the Lucile Packard NICU Family Advisory Council for reviewing and helping to improve study flyers and interview guides. Thank you to Valley Hi Resource Center for donating child care and space for us to hold our focus groups. We are especially grateful to the parents who participated in focus groups or interviews and shared their NICU stories with us.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Stanford University Maternal and Child Health Research Institute Postdoctoral Fellowship; and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (R01 HD083368-01, PI Jochen Profit).

Author Biographies

Krista Sigurdson was a postdoctoral fellow in the Division of Neonatal and Developmental Medicine in the Stanford School of Medicine, where she is now a collaborator. Her research concerns racial/ethnic disparities in NICU quality of care and human milk exchange. She currently teaches in the Department of Gender, Sexuality and Women's Studies at Simon Fraser University in Vancouver, BC, Canada.

Jochen Profit is Associate Professor of Pediatrics, Division of Neonatal and Developmental Medicine at Stanford University and Chief Quality Officer of the California Perinatal Quality Care Collaborative. His research focuses on the optimization of quality of neonatal-perinatal health care delivery.

Ravi Dhurjati is Research Scientist in the Department of Pediatrics at Stanford University and at the California Perinatal Quality Care Collaborative. Dhurjati's research focuses on the relationship between the structure of perinatal health care system and outcomes, with the goal of improving care for vulnerable infants and mothers.

Christine H. Morton, is a medical sociologist at Stanford University School of Medicine, U.S. Her research focuses on maternal and neonatal mortality and morbidity, and associated health inequities in perinatal health in California.

Melissa Scala is Clinical Associate Professor of Pediatrics, Division of Neonatal and Developmental Medicine at Stanford University. Her research interest is in improving developmental care in hospitalized infants.

Lelis Vernon is a former NICU mother and a family leader in Patient and Family-Centered Care advocacy in the US. She currently serves as faculty in the Vermont Oxford Network, is a Clinical Advisor for the QI Measures Task Force at the American Academy of Pediatrics, SoNPM, is a member in the advisory board of experts on racial/ethnic disparities in NICU quality of care with the Profit lab at Stanford University and in the NEC Society, and is a international speaker and collaborator in the Argentine Pediatric Society in her hometown of Argentina.

Ashley Randolph runs a support and advocacy group for preemie parents called GLO Preemies in Sacramento, California that serves African American parents but welcomes all families. She is a former NICU mother who is a member in the advisory board of experts on racial/ethnic disparities in NICU quality of care with the Profit lab.

Jessica T. Phan graduated from the University of California, San Diego with a degree in Human Biology and a minor in Political Science and is currently a fourth year medical student at the University of South Florida Morsani College of Medicine. She is interested in research that focuses on health care disparities, cultural competency, and quality improvement.

Linda S. Franck holds the Jack and Elaine Koehn Endowed Chair in Pediatric Nursing at the University of California, San Francisco (UCSF) School of Nursing and is the Director of Postnatal Research for the UCSF California Preterm Birth Initiative. Her research focuses on improving patient and family partnered health research and care delivery.

References

Altman MR, Oseguera T, McLemore MR, Kantrowitz-Gordon I, Franck LS, & Lyndon A (2019). Information and power: Women of color’s experiences interacting with health care providers in pregnancy and birth. Social Science & Medicine, 238, Article 112491. 10.1016/j.socscimed.2019.112491 [PubMed: 31434029]

Blumer H (1954). What is wrong with social theory? American Sociological Review, 19(1), 3–10. 10.2307/2088165

Blumer H (1969). Symbolic interactionism. Prentice Hall.

Brewer EJ, McPherson M, Magrab PR, & Hutchins VL (1989). Family-centered, community-based, coordinated care for children with special health care needs. Pediatrics, 83(6), 1055–1060. [PubMed: 2726332]

Carman KL, & Workman TA (2017). Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. Patient Education and Counseling, 100(1), 25–29. 10.1016/j.pec.2016.07.009 [PubMed: 27473639]

Chan N, Anstey KJ, Windsor TD, & Luszcz MA (2011). Disability and depressive symptoms in later life: The stress-buffering role of informal and formal support. Gerontology, 57(2), 180–189. 10.1159/000314158 [PubMed: 20424429]

Charmaz K (2003). Grounded theory: Objectivist and constructivist methods. In Denzin NK & Lincoln YS (Eds.), Strategies of qualitative inquiry (2nd ed., pp. 249–291). SAGE.

Charmaz K (2006). Constructing grounded theory: A practical guide through qualitative analysis. SAGE.

Charpak N, Tessier R, Ruiz JG, Hernandez JT, Uriza F, Villegas J, … Maldonado D (2017). Twenty-year follow-up of Kangaroo Mother Care versus traditional care. Pediatrics, 139(1), Article e20162063. 10.1542/peds.2016-2063 [PubMed: 27965377]

Committee on Hospital Care and Institute for Patient- and Family-Centered Care. (2012). Patient- and family-centered care and the pediatrician's role. Pediatrics, 129(2), 394–404. 10.1542/peds.2011-3084 [PubMed: 22291118]

Corley NA, & Young SM (2018). Is social work still racist? A content analysis of recent literature. Social Work, 63(4), 317–326. 10.1093/sw/swy042 [PubMed: 30137608]

Craig JW, Glick C, Phillips R, Hall SL, Smith J, & Browne J (2015). Recommendations for involving the family in developmental care of the NICU baby. Journal of Perinatology, 35(Suppl. 1), S5–S8. 10.1038/jp.2015.142 [PubMed: 26597804]

Cricco-Lizza R (2011). Everyday nursing practice values in the NICU and their reflection on breastfeeding promotion. Qualitative Health Research, 21(3), 399–409. 10.1177/1049732310379239 [PubMed: 20682967]

Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, … Curtis JR (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Critical Care Medicine, 45(1), 103–128. 10.1097/ccm.0000000000002169 [PubMed: 27984278]

Davies B, Steele R, Krueger G, Albersheim S, Baird J, Bifirie M, … Zhao Y (2017). Best practice in provider/parent interaction. Qualitative Health Research, 27(3), 406–420. 10.1177/1049732316664712 [PubMed: 27557925]

Department of Health Care Services. (1999). California children's services manual of procedures: Standards for neonatal intensive care units. https://www.dhcs.ca.gov/services/ccs/Documents/CommunityNICU.pdf

Dhurjati R, Sigurdson K, & Profit J (2019). Patient- and family-centered care as a dimension of quality. American Journal of Medical Quality, 34, 307–308. 10.1177/1062860618814312 [PubMed: 30501498]

Edwards BN, McLemore MR, Baltzell K, Hodgkin A, Nunez O, & Franck LS (2020). What about the men? Perinatal experiences of men of color whose partners were at risk for preterm birth, a qualitative study. BMC Pregnancy Childbirth, 20(1), 91. 10.1186/s12884-020-2785-6 [PubMed: 32041561]

Eneriz-Wiemer M, Sanders LM, Barr DA, & Mendoza FS (2014). Parental limited English proficiency and health outcomes for children with special health care needs: A systematic review. Academic Pediatrics, 14(2), 128–136. 10.1016/j.acap.2013.10.003 [PubMed: 24602575]

Franck LS, Gay C, Kriz R, Bisgaard R, Cormier D, Joe P, … Sun Y (2019). Well-being over time and relationship to family-centered care for parents of preterm infants [Poster presentation]. PAS Meeting, Baltimore, MD, United States.

Franck LS, & O'Brien K (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. Birth Defects Research, 111, 1044–1059. 10.1002/bdr2.1521 [PubMed: 31115181]

GLO Preemies. (2019). GLO preemies: A NICU community. https://www.glopreemies.com/

Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, & Berns SD (2011). Family support and family-centered care in the neonatal intensive care unit: Origins, advances, impact. Seminars in Perinatology, 35(1), 20–28. 10.1053/j.semperi.2010.10.004 [PubMed: 21255703]

Institute for Patient- and Family-Centered Care. (2020). Patient and family centered care. https://www.ipfcc.org/about/pfcc.html

Johnson BH (2000). Family-centered care: Facing the new millennium. Interview by Elizabeth Ahmann. Pediatric Nursing, 26(1), 87–90. [PubMed: 12026323]

Jolley J, & Shields L (2009). The evolution of family-centered care. Journal of Pediatric Nursing, 24(2), 164–170. 10.1016/j.pedn.2008.03.010 [PubMed: 19268238]

Kaufman SR (2006). And a time to die: How American hospitals shape the end of life. University of Chicago Press.

Lee HC, Gould JB, Martin-Anderson S, & Dudley RA (2011). Breast-milk feeding of very low birth weight infants as a function of hospital demographics. Journal of Perinatology, 31, S82. 10.1038/jp.2010.179

Lyons KS, & Zarit SH (1999). Formal and informal support: The great divide. International Journal of Geriatric Psychiatry, 14(3), 183–192; discussion 192–196. [PubMed: 10202661]

Martin AE, D'Agostino JA, Passarella M, & Lorch SA (2016). Racial differences in parental satisfaction with neonatal intensive care unit nursing care. Journal of Perinatology, 36(11), 1001–1007. 10.1038/jp.2016.142 [PubMed: 27583386]

McLemore MR, Altman MR, Cooper N, Williams S, Rand L, & Franck L (2018). Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. Social Science & Medicine, 201, 127–135. 10.1016/j.socscimed.2018.02.013 [PubMed: 29494846]

Mefford LC, & Alligood MR (2011). Evaluating nurse staffing patterns and neonatal intensive care unit outcomes using Levine's Conservation Model of Nursing. Journal of Nursing Management, 19(8), 998–1011. 10.1111/j.1365-2834.2011.01319.x [PubMed: 22074302]

Mikesell L, & Bromley E (2012). Patient centered, nurse averse? Nurses' care experiences in a 21st-Century Hospital. Qualitative Health Research, 22(12), 1659–1671. 10.1177/1049732312458180 [PubMed: 22923388]

National Association of Perinatal Social Workers. (2007). Standards for social work services in the Newborn Intensive Care Unit. https://www.napsw.org/assets/docs/NICU-standards.pdf

National Association of Social Workers. (2017). The National Association of Social Workers (NASW) Code of Ethics. https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English

Ornelas IJ, Amell J, Tran AN, Royster M, Armstrong-Brown J, & Eng E (2009). Understanding African American men's perceptions of racism, male gender socialization, and social capital through photovoice. Qualitative Health Research, 19(4), 552–565. 10.1177/1049732309332104 [PubMed: 19201993]

Parker MG, Gupta M, Melvin P, Burnham LA, Lopera AM, Moses JM, … Belfort MB (2019). Racial and ethnic disparities in the use of mother's milk feeding for very low birth weight infants in Massachusetts. Journal of Pediatrics, 204, 134–141.e1. 10.1016/j.jpeds.2018.08.036

Patra K, Hamilton M, Johnson TJ, Greene M, Dabrowski E, Meier PP, & Patel AL (2017). NICU human milk dose and 20-month neurodevelopmental outcome in very low birth weight infants. Neonatology, 112(4), 330–336. 10.1159/000475834 [PubMed: 28768286]

Profit J, Gould JB, Bennett M, Goldstein BA, Draper D, Phibbs CS, & Lee HC (2017). Racial/ethnic disparity in NICU quality of care delivery. Pediatrics, 140(3), e20170918. 10.1542/peds.2017-0918 [PubMed: 28847984]

Roberts DE (2002). Shattered bonds: The color of child welfare. Basic Books.

Sigurdson K, Morton C, Mitchell B, & Profit J (2018). Disparities in NICU quality of care: A qualitative study of family and clinician accounts. Journal of Perinatology, 38(5), 600–607. 10.1038/s41372-018-0057-3 [PubMed: 29622778]

Trent M, Dooley DG, & Douge J, Section on Adolescent Health, Council on Community Pediatrics, & Committee on Adolescence. (2019). The impact of racism on child and adolescent health. Pediatrics, 144(2), Article e20191765. 10.1542/peds.2019-1765 [PubMed: 31358665]

White RD, Smith JA, & Shepley MM (2013). Recommended standards for newborn ICU design, eighth edition. Journal of Perinatology, 33(Suppl. 1), S2–S16. 10.1038/jp.2013.10

Dignity and Respect

- Listening to and respecting children and families. Honoring racial, ethnic, cultural, and socioeconomic background.

Organizational Flexibility

- Ensuring flexibility in organizational policies, procedures, and provider practices.

Information Sharing

- Sharing complete, honest, and unbiased information with patients and their families in ways they find useful and affirming, so that they may effectively participate in care and decision-making.

Formal and Informal Support

- Providing and/or ensuring formal and informal support (eg, peer to-peer support) for the child and family.

Collaboration and Participation

- Collaborating with patients and families at all levels of health care: in the delivery of care to the individual child; in professional education, policy making, program development, implementation, and evaluation; and in health care facility design.

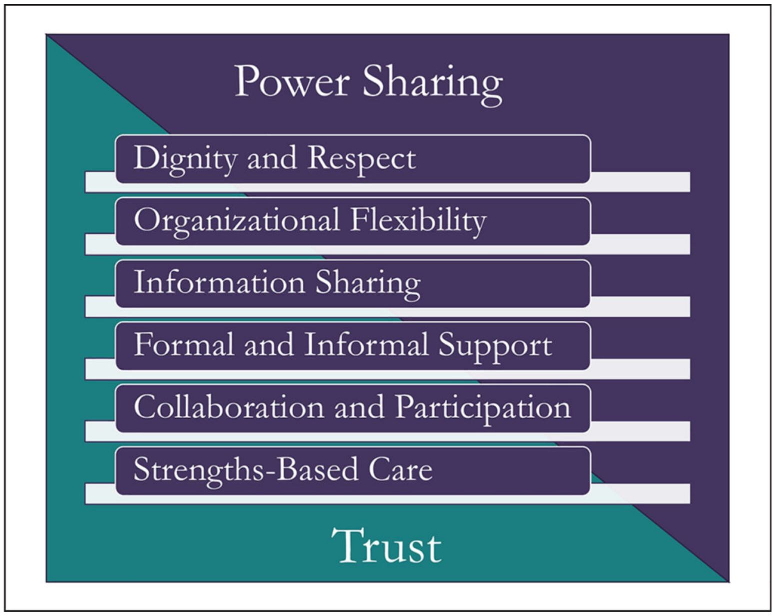
Strengths Based Care

- Recognizing and building on the strengths of individual children and families and empowering them.

Figure 1.

Six core principles developed and described by the Committee on Hospital Care, and Institute for Patient- and Family-Centered Care.

Source. Adapted from “Patient- and Family-Centered Care and the Pediatrician’s Role,” by Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012, Pediatrics, 129(2), pp. 394–404.



Power Sharing

Dignity and Respect

Organizational Flexibility

Information Sharing

Formal and Informal Support

Collaboration and Participation

Strengths-Based Care

Trust

Figure 2.

Two underlying dimensions, power sharing and mutual trust, underlie the implementation of the principles of family-centered care.

Source. Six core principles are drawn from “Patient- and Family-Centered Care and the Pediatrician’s Role,” by Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012, Pediatrics, 129(2), pp. 394–404.