Mobile-enhanced Family Integrated Care for preterm infants: A qualitative study of parents' views

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ABSTRACT

Objective: The Family Integrated Care (FICare) model improves outcomes for preterm infants and parents compared with family-centered care (FCC). FICare with mobile technology (mFICare) may improve uptake and impact. Research on FICare in the United States (US) is scarce and little is known about parents' experience.
Methods: We conducted qualitative interviews with nine parents, exploring their NICU experiences, participation in and perceptions of the mFICare program. A directed content analysis approach was used, and common themes were derived from the data.
Results: Overall, parents had positive NICU experiences and found mFICare helpful in meeting three common parenting priorities: actively caring for their infant, learning how to care for their infant, and learning about the clinical status of their infant. They described alignment and misalignment with mFICare components relative to their personal parenting priorities and offered suggestions for improvement. Nurses were noted to play key roles in providing or facilitating parent support and encouragement to participate in mFICare and parenting activities.
Conclusion: The mFICare program showed potential for parental acceptance and participation in US NICUs.
Innovation: The mFICare model is an innovation in neonatal care that can advance the consistent delivery of NICU family-centered care planning and caregiving.
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1. Introduction

The important contributions patients and caregivers make to the design and delivery of safe and high-quality health care is undisputed, benefiting patient and family experience of care, health outcomes and hospital systems [1-3]. Nowhere is family partnered and family-centered care (FCC) more crucial than in the neonatal intensive care unit (NICU), where infants require both parental and health professional caregiving for optimal health and developmental outcomes [4]. Although FCC is promoted as the standard of care in NICUs, challenges in implementing and sustaining this practice remain [5]. Parents continue to describe

acute and prolonged distress, mental health symptoms, a sense of helplessness, inconsistent support from and difficult communication with NICU health professionals, and insufficient contact with their infants. These experiences fundamentally alter or delay parental role attainment [6,7].

1.1. Family Integrated Care (FICare)

Family Integrated Care (FICare) is a NICU care model grounded in FCC principles of mutual respect, information sharing, negotiation, participation, and collaboration [5,8]. With FICare, parents (or other

primary caregivers) are recognized as essential members of an infant's healthcare team. This team works together to promote parent involvement and ensure consistent delivery of the four FICare 'pillars': a supportive physical and social care environment, NICU team education and support, parent education and psychological support, and active parent participation/partnership [5,9]. Research across multiple countries and levels of NICU care demonstrates improved outcomes for infants (e.g., increased weight gain and shorter length of stays) and parents (e.g., decreased maternal stress and anxiety) [5]. The US has notably lagged other countries in implementation and research on FICare.

1.2. The US mobile-enhanced FICare trial (mFICare)

We conducted the first trial of FICare in the US during 2017–2020 [10,11]. In the phase-lagged, multi-site trial, parents in the FCC cohort received general support and were encouraged to spend extended periods in the NICU with their infant. Parents in the FICare with mobile technology (mFICare) cohort received the same general support as the FCC cohort with the addition of parent group education classes 2–5 times per week, access to a peer parent mentor and the mobile app. Parents were supported in training, given encouragement and expanded roles in direct infant caregiving (excluding ventilation management, intravenous fluid or intravenous medication administration, feeding tube placement), participation in weekday rounds, and peer mentorship.

There were several innovative features of this US trial. The trial was nursing-led and parent-partnered from the design to dissemination in presentations and publications. The program development and research design were nurse-led. Nurses with direct patient care roles were involved in the developing the mFICare training curriculum and took on leadership roles in all components of mFICare in partnership with parents, physicians, and other members of the healthcare team. The FICare protocol was also innovative with the inclusion of the We3health™ app, co-designed by NICU parents and healthcare professionals, to supplement content and to make the in-person FICare components accessible for parents at any time or place. The app uniquely enabled electronic research data collection during the trial through automated surveys and data capture of parent journal entries. Parents in the FCC cohort used the app for survey data collection only, and those in the FICare cohort had access to all the app features in addition to survey data collection.

We found that the mFICare protocol reduced nosocomial infection rates for preterm infants [10], depression, and post-traumatic stress symptoms after NICU discharge for mothers experiencing high NICU-related stress [11] compared to the standard FCC offered in each NICU. We also found that NICU health care professionals perceived the model to be feasible and acceptable. Health care professionals provided important feedback for unit-wide implementation beyond the research context, including improvements to the app and clinical rounds workflow [12].

Understanding parental perceptions is an equally important dimension in the evaluation of a new NICU care delivery model. Therefore, the purpose of this study was to investigate the views of NICU parents participating in the mFICare intervention group. Our main research questions were: What were parents' experiences participating in the mFICare program and what were their views about the specific components of the mFICare protocol?

2. Methods

2.1. Study design

This study was part of a larger quasi-experimental, time-lagged, non-randomized trial of the mFICare protocol compared with usual FCC. We investigated parents' mFICare experiences through in-depth interviews and conducted a qualitative thematic analysis to identify important themes and subthemes. The full trial design is reported elsewhere [13]. The study was approved by the Institutional Review Boards at each clinical site and the participating University.

2.2. Setting and sample

We enrolled English-speaking parents of preterm infants ≤33 weeks' gestation from one of the three NICUs involved in the larger trial. The setting was a 58-bed level IV referral NICU with 32 single-family and 13 double rooms in a university health system offering high-risk pregnancy services. All NICUs provided FCC as the model of care and permitted 24/7 parental presence.

During the last nine months of the intervention phase, parents (or other primary caregivers) were eligible to participate in the interviews if they met inclusion criteria and had consented to participate in the mFICare intervention arm of the study, had been in the NICU for a minimum of three weeks, and had been offered all of the mFICare main components. Participation in the interviews was not a requirement of participating in mFICare and separate consent for the interview was obtained.

2.3. Data collection

Interviews were conducted by an experienced NICU nurse with research interview training. Participants were offered the option of in-person, video, or telephone recorded interviews. Participants received compensation in acknowledgement of their time and effort in completing surveys for the mFICare trial but did not receive additional compensation for participating in the interviews.

2.4. Interview guides

A semi-structured interview guide was created by our study team with input from project parent advisors. The interview guide began with questions about parents' experiences of having an infant in the NICU and their role as parents. The focus then shifted to the mFICare study, asking about their participation (why or why not) and experience with each of the mFICare components. Follow-up questions explored the impact of parent involvement in mFICare and probed barriers and facilitators to participation. Finally, parents were invited to provide feedback on what aspects of the program could be improved and ideas for expanding access to all NICU families.

2.5. Data analysis

The interview audio recordings were professionally transcribed and uploaded to a qualitative analysis software package (Dedoose Version 9.0.102, Los Angeles, CA). Analysis involved both inductive and deductive coding, starting with a basic set of codes and developing new codes as we familiarized ourselves with the data. Initial coding was performed by one member of the research team and then reviewed by other members of the research team. Codes were then organized into major themes and subthemes through iterative analysis and discussion. Codes, themes and subthemes were reviewed by the study team and disagreements were resolved by consensus. Finally, we selected representative quotations from participants to illustrate the themes and subthemes. Coding and analysis were led by a research assistant with support and guidance from an expert maternal health sociologist and a junior and senior researcher.

3. Results

3.1. Participants

All nine parents who were invited agreed to be interviewed. Eight of the interviewees identified as mothers and one interview included both a mother and father. The interviews took place between September 2019 and June 2020. Two parents were interviewed before their infant's

discharge. Seven parents participated in video interviews several weeks after the infant was discharged. Parent and infant characteristics are shown in Table 1 and are similar to the larger mFICare cohort [10,11].

3.2. Main themes

All parents in the sample expressed feelings of gratitude and appreciation for the support they received during their infant's NICU stay. They described having overall positive experiences despite the stress and uncertainty of their infant's health. Our thematic analysis revealed three main parenting priorities: Active caregiving for their infant, learning how to care for their infant, and learning about the clinical status of their infant. Parents assessed their experience with the mFICare program based on whether the program components helped them meet their main parenting priorities or provided them with emotional and social support. Impediments to parenting goals and failures or missed opportunities in emotional/social support were identified in relation to both the mFICare program delivery and to the interactions of NICU staff with parents. Parents also spoke about needing social and emotional support to maintain their involvement in their infant's care and achieve their parenting goals as well as their experience using the We3Health app. Fig. 1 provides a graphic depiction of the NICU milieu and parental experiences. Below, we explore these themes as they intersect with the components of the FICare program.

3.2.1. Active caregiving with their infant

A key parental goal was to develop a nurturing bond with their infant through direct caregiving contact with their infant. Parents desired to be present at the bedside and directly involved in their infants' care, including basic caregiving tasks like feeding, diaper changes, skin care and comforting their infant, or holding the infant while they slept.

Parents described how NICU staff, particularly nurses, supported them in actively caring for their infant throughout their stay in the NICU. One mother emphasized that participation in the mFICare program supported her desire to nurture her infant:

"I would urge for more involvement of the parents, having me diaper, having me rub the swab milk and do the oral care, all those things are really important, especially for moms. I think we want to nurture, we want to care, and that's taken away from us for unfortunate reasons, and so it was very important for me to participate [in the FICare program]."

Parents recognized that basic care for a preterm infant required knowledge, skill and coordination and were appreciative of nurses for the effort involved to support parenting in the NICU context. For example, one parent reported how a nurse made extra efforts to facilitate skin-to-skin time with her twins:

Table 1
Participant characteristics.

	Median (range) or n
Parent	
Characteristics	
Maternal age (years)	33 (21–42)
Racial identity	Mixed/Other = 3; Asian = 1; White = 1
Ethnic identity	Latine = 4
Highest education	University or graduate degree = 6; High school graduate = 2; Some college or vocational school = 1
Parent of multiples	Twins = 3
Infant	
Characteristics	
Gestational age (weeks)	28 (25–31)
Birthweight (grams)	1100 (645–1455)
Age at enrollment (days)	24 (11–62)
Length of NICU stay	84 (35–186)

"She (nurse) just really went above and above to help accommodate skin-to-skin because like when they're really little, you've got to be careful not to take them out of the incubator too many times… it's hard to coordinate with all the wires pulling two babies… she was the first one that said, 'Let's just do it, let's put [twins] on your chest at once,' and it was beautiful." - Participant 191.

This parent further noted how the NICU team encouraged her to feel empowered and be an effective advocate for their infant:

"All the docs and the nurses [made] me feel more in charge and be more of an advocate for them and to be more involved in their daily care, you know, the skin-to-skin and all about like what they're doing with the milk, like the fortification and how important it was to try and breastfeed and teach them how to suck, and changing their diapers and just feeling like this was a team that was there to support us, you know."

In summary, actively caring for their infant was a priority that parents valued and sometimes struggled to achieve. Parents described how mFICare enabled them to meet this goal, and identified the important role of NICU staff, particularly nurses.

3.2.2. Learning how to care for their preterm infant

In addition to wanting to actively care for their infant, parents expressed the need to learn how to care for their premature infant. Parents described learning about clinical aspects of prematurity as well as becoming skilled and comfortable performing basic infant care tasks in the specialized environment of the NICU. Caregiving tasks such as changing diapers required knowledge of risks and signs of infant distress and could not be done independently at the outset.

Similarly, holding the infant required assistance from a professional, and skin-to-skin care required even more time and assistance. Breastfeeding may be delayed because of the infant's condition and therefore involved learning to pump, transport, and store milk. Parents expressed how mFICare group classes helped them acquire new knowledge and skills in a supportive group setting that they could actively apply to their baby's care. One parent described learning from other mothers, in addition to the nurse, in classes discussing respiratory issues for preterm infants:

"Our babies had similar problems, like [need for] CPAP [continuous positive airway pressure] and breathing and all of the different oxygen levels. Some moms know more than others and they would help too with the [respiratory] class."

A first-time parent recounted taking classes that helped them learn the nuances of breastfeeding a preterm infant:

"They [the classes] had shown different positions and stuff like that, on ways to breastfeed them, and then how to get, like different ways to get him to latch or like the accessories that you can have now to help you if they don't latch."

Many parents also credited classes with helping them learn about future caregiving circumstances and the next steps in their NICU journey:

"…We were talking about…arranging, for going home - getting ready for leaving. I don't know, just a lot of the logistical stuff that we hadn't really thought about yet, and… it was starting to look like we would be able to go home in the next few weeks. So, it was stuff that I had been thinking about that lined up really well."

Parents understood they were in a transitional space and that at some point, their infants would be discharged home. Peer parent mentors were noted as valuable resources, offering their experiences, lessons learned, and advice. Peer mentors were relatable and helped parents learn how to think about identifying resources outside of the NICU:

"[the peer mentor] is really helpful. She told us the ways around the hospital, how to put the resources together to make the supporting team, to
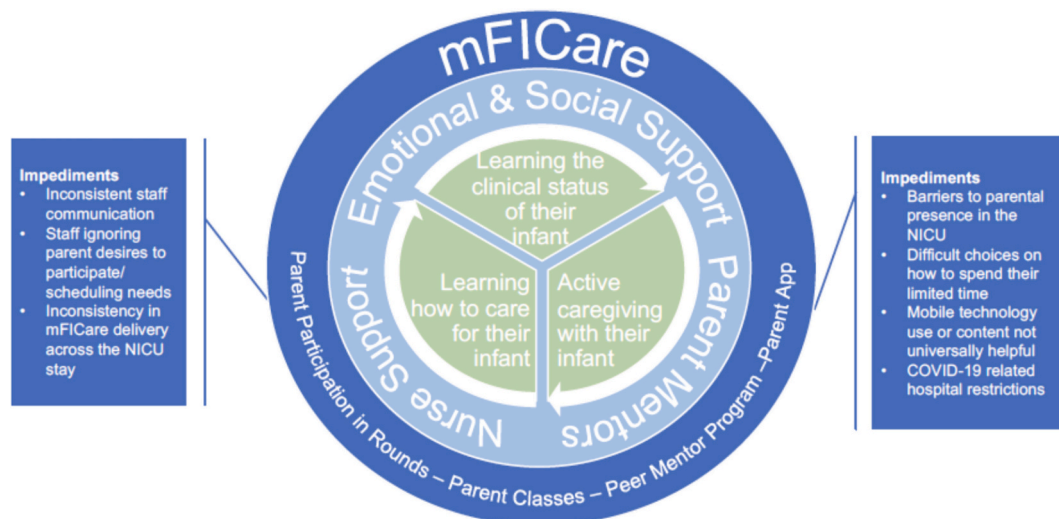
Fig. 1. Themes and subthemes. Inner circle - parent priorities and goals); middle circle – sources of emotional and social support; outer circle – mFICare and its components; Boxes – impediments to culture of NICU clinical team – parent partnership and mFICare implementation.

help the coordinators to come together for the baby, what we see after we've been discharged, and then what type of therapy is out there, what kind of support out there that we can take advantage of [Laughs]. Those are all very informative and very, very good."

NICU nurses, both at the bedside and in mFICare classes, played a large role in the knowledge, skills and confidence parents developed to care for their infant:

"The other hospital asked me if I were a nurse because I'm doing so well over there and know so much. I know that, yeah, I've learned so much from all the nurses."

"I felt so prepared by the nurses and by all the different healthcare providers to be able to feel like I can manage this, you know, I know all the steps and all the parts of their care."

Nurses reinforced and individualized mFICare class material with parents at the infant's bedside through tips and hands-on demonstrations to help them improve their infant care practices:

"She (nurse) taught me how to try to read my babies (cues), you know. Like if you see them acting this way, try to figure out what it is, be a little detective, check their diaper and see if they may be wet or old, check their temperature."

Parents wanted to learn the specialized care practices involved in caring for their premature newborn. The mFICare program components provided opportunities for parents to gain new knowledge and skills to achieve their goals.

3.2.3. Learning about the clinical status of their infant and partnering in care planning

A third parental goal was to learn about the diagnoses, health care needs, and current and future prognoses for their infants. They talked about how important it was to their role as parents to be able to share their observations and questions with the healthcare team and to feel that they were a partner in making small and large care plans for their infant. The mFICare protocol supported this goal. One parent described how the mFICare program made them feel valued as partners in their infant's caregiving and care planning:

"Well, I guess for me the components of mFICare that I liked the most was that participation in rounds because…the messaging there is, our unit, our hospital system really cares about you as parents and as a family and see

you as caretakers and this is your child…So, keeping parent participation in rounds I think is one of the most valuable things."

Parents noted that once they began understanding the clinical diagnoses and status of their infants, they were able to provide helpful observations and freely share their concerns with the NICU team, which were then taken into consideration when determining next steps:

"We were told that it [rounds] would be important. And then as the time goes [on], we can see the benefit of it. Examples of that, when [baby's name] was changed on CPAP from one level to another, we had raised our concerns to the doctors. We were saying that he's not ready. Two of his prior nurses told us he's not ready yet… And then the doctors respected our decision."

"Whenever we had observations, they definitely listened to us, and definitely they took those inputs into their process as well."

One parent described a specific instance in which a medication was being prescribed to her infant that caused him to gag and shared her experience bringing this concern to the team during rounds:

"They (medical team) were really open. I think it [medication] was something that was prescribed quite some time back and he didn't seem to really need it as much, so when I asked them if it was absolutely required, they were okay with discontinuing it."

Another parent described how understanding their infant's prognosis in more detail allowed her to develop realistic goals for her infant's health:

"…I think it's better to understand what's really involved and what exactly you should be hoping for instead of just a general picture that you want your baby to be well. I was able to say, 'okay, I want my baby to come out of this, I want his pressures to go down because of this pulmonary hypertension, I want the PDA to get smaller at the right time, not too soon, not too late,' and I was able to distinguish between all that only because I was participating in the rounds."

Parents whose infants require NICU care face challenges to actively participating in their infant's care planning. The mFICare program facilitated shared decision-making through opportunities to learn about their infant's health care needs and to participate in clinical rounds. The level of participation and impact grew over time as parents learned and developed confidence that their observations would be heard and valued by the clinical team.

3.2.4. Emotional and social support

Throughout the interviews, parents frequently referred to examples of emotional and social support and they highly valued these experiences. The main sources of emotional and social support cited by parents were nurses and peer mentors. Nurses provided emotional and social support during direct infant caregiving, supporting parents emotionally as they struggled to overcome fear and worry in learning how to care for their fragile infant. Nurses also provided emotional support for parents when they facilitated mFICare classes and supported parent participation in rounds.

Two parents commented on different ways in which nurses fostered parent-to-parent connections during and after the mFICare classes:

"It was a good place for my husband when a lot of times the men kind of just fall through the cracks, you know, in terms of how they're feeling, but the class was good because there were other dads there and the nurses would ask us to sit in a circle and talk about like our greatest fears or what our babies were going through, and it was a time where he could express himself in a safe place."

"They're (nurses) really good in a way where the education is one component. Another really important thing is she [nurse] will locate other parents who are going through the same thing and how they react to the education, how they express their concerns… It's like a group therapy. At the same time, it's an educational session. It's really enjoyable."

Another parent highlighted the importance of the emotional support aspect of the mFICare classes and how it helped her realize that she needed care while her infant was in the NICU:

"A lot of things that are geared towards the parent are really good because I feel like all the attention is for the patient and not for yourself, and so realizing that you also need a lot of care during this time is really important."

Some parents spoke about the emotional and social support received from their peer mentors:

"At that time when she [mentor] started coming around, my life was… because I'm so busy I was not making time to go chat with a friend, just to sit down, have a coffee, and then to tell them like, 'Hey, this happened today.' So that gave me an opportunity to do that, to just have a friend, someone that says, 'Hey, I've already been through this,' and outside of just meeting up at the hospital, I felt like I can text someone and just have support."

Another parent described the special relationship with their peer mentor:

"[Parent mentor] was probably one of the best parts of FICare because it was somebody who had actually been in my shoes with twins and really well-versed with the whole nine yards, and I was able to connect with her, I don't know, four or five times and we still stay in touch."

Support from nurses and peer mentors contributed to positive emotional and social experiences for parents and supported their desire to learn how to best care for their infants.

3.2.5. The role of app technology in mFICare

The We3health app was proposed and designed by former NICU parents to provide a tool for parents to track their participation, skills, view the current class schedules, and receive informational videos and resources. The app was also a research tool, delivering study surveys to parents, acquiring data and sending reminders. Some parents had positive views of the app:

"I think, as you know, that time is relatively monotonous and relatively timeless, and so, the app not only kind of forced you to keep track of those activities because they're important but it also made you feel like you were doing something or accomplishing something every day."

Others recognized its potential but felt that the beta (test) version used in the study required further improvement, specifically regarding the user interface and navigation:

"I know for a long time it was hard for me to remember how to change her weight. And I kind of just gave up on that because how it is on the app, it's kind of hard to do."

Some parents commented about negative feelings that arose with some of the content, leading them to stop using the app:

"The first question it (app) asks is how much time we were able to spend in the hospital yesterday… and if you are not able to go to the hospital that day for any reason, it might feel like the app is asking you, okay, were you being a good parent, how much time did you spend in the hospital yesterday?… When I opened the app and that was the first question, I used to feel really bad about it and then I would just close the app."

Parents clearly valued emotional support they received from nurses and peer mentors. Insights from parents on app features that were more or less useful inform future iterations and may help improve user uptake of the app.

3.2.6. Impediments to mFICare delivery and meeting parental priorities

Throughout the interviews, parents provided examples where individual, program or NICU team practices impeded family-integrated and family-centered care delivery for parents and infants, thus thwarting parents from achieving their priorities and goals on a consistent and predictable basis throughout the infant's NICU stay.

These situations occurred because of miscommunication, lack of communication or inconsistent communication with individual or groups of healthcare professionals. For example, one parent described instances of communication barriers between her and her NICU team, or team workflow priorities taking precedence, leading her to miss out on opportunities to be actively involved in her infant's caregiving and shared decision-making:

"There were a couple times where I really wanted to be part of the FICare briefings [rounds] in the mornings and it would just get started earlier than normal or they wouldn't call me on the phone. Or the breastfeeding, like they kept telling me how important breastfeeding was and then I would call and say, "I'll be there at 9 so don't do a bottle feeding or a tube feeding because I'll be there at a certain time," and then I'm literally like five minutes late and I call and say, "I'm five minutes late, I'm on the bridge," I get there and they're like, "Yeah, we already fed the baby, we just had to move on.""

Some parents needed more support to become comfortable with participating in rounds and additional support afterwards to help with understanding and emotionally coping with the information they learned about their infant's clinical status, as illustrated in the following quotes:

"There are some good and bad [experiences in rounds]. I mean, they give me some good news and then the next day they switch it to bad news. And it really is confusing for me because I don't understand everything. They say one good thing and then the next day they say something bad."

"In the beginning it was kind of intimidating because, you know, they have all these short forms and these acronyms that you don't really follow, but we started asking about those to the nurses after the rounds, [we] tried to understand what exactly they're looking for."

Unfortunately, disrespectful interactions were also noted on occasion, such as for this encounter with a resident doctor regarding medical terminology when the parent shared an observation about her infant's bowel function:

"It was just that one time, and it was the new resident… I was talking about how [baby's name] hadn't pooped in a long time, and it was causing

her pain because she was popping out her hernia. So… in front of rounds, he said, 'You should use more formal words in a formal setting,' in front of the entire group of people. And I just thought that was kind of a little crass, rude. If you think I should talk a certain way, at least pull me aside like after rounds. Not do that. And plus, not everyone uses the word stool."

Finally, there were communication challenges between parents and staff related to hospital imposed COVID-19 precautions that negatively impacted parental participation in mFICare rounds, such as when clinical rounds transitioned to a hybrid manner with a smaller in-person team and additional team members and parents joining virtually through video-conferencing or telephone. Virtual rounds provided more opportunities for parents to join rounds by video or phone during the COVID-19 pandemic, and simultaneously created logistical challenges:

"Like on the phone, it's so different because I don't know who's talking. And I get confused, like they say something and I don't get it. And when I'm in person it's like a whole different thing because, I know who they are."

Factors beyond the NICU affected parents' ability to participate in their infant's direct care and care planning, such as limited transportation, care for other children and employment obligations. Lack of communication from the NICU team added to parental stress in these circumstances:

"[Hospital distance] just added to my stress level of not being able to be there at all times, like a couple times there was some testing that was done on the babies where I just wasn't there where they did it like maybe at 3 AM and I was really upset because I wanted them to call me before, like they did a lumbar puncture on [infant] for bacterial meningitis to check for that, and I was really angry and upset that they didn't call me."

For some parents, mFICare class timing conflicted with parent work schedules or with the parental goal to spend as much time with their baby as possible. Although parents saw value in the classes, some parents felt they sometimes had to choose between going to classes or caring for their infant:

"I wanted to be able to hold both the babies for some time while I was there, and I had a very limited time so I guess I didn't really try to make time to participate in those [classes]. I was trying to fit a lot of things in those couple of hours that I was there. I had to hold both the babies, pump, and then just eat if there was a mealtime in between. It used to be, just really hectic, even while I was there. The one class I did participate, it became more like them just chatting with me, asking how I was doing and stuff like that, which was pretty good."

4. Discussion and conclusion

4.1. Discussion

The findings of this study shed light on parents' experiences of caregiving in a NICU during a trial of the mFICare model. As part of the trial, the FICare model was newly introduced to US NICUs with innovations including nursing-led implementation and a parent-designed app. We found that the majority of parents described their experiences in the mFICare program as generally positive, similar to the few reports of parent views about FICare from other countries [14-17]. Parents in our study described three common priorities of actively participating in their infant's direct caregiving, learning how to care for their preterm infant, and learning about the clinical status of their infant so they could fully partner with the clinical team in care planning. Similar priorities have been noted in other qualitative studies with NICU parents [18,19]. mFICare provided structured yet flexible programming to address parent priorities and assist them in meeting their parenting goals. When implemented well, parents viewed the mFICare components favorably

and were able to articulate the direct benefits they received from participating in the program.

FICare components of parental participation in clinical rounds, the parent group classes, and the parent peer mentor program were all valued and supported parental priorities. These findings are consistent with prior FICare research in Canada [9,20] and a subsequent US FICare implementation study [21]. Parents in our study had mixed reviews about the added value of the app technology, mostly related to the limitations in the beta version of the app. Other studies have shown positive views of parent app technology to support FICare [21,22]. The app used in our study was designed in partnership with parents and had several new interactive features, rather than solely passive content. The features that did not meet the needs of all parents need further testing of both content and user interface, including assessment of comprehension and health literacy requirements. Another explanation for parents' mixed reviews is that the app focused on the early phase of the infant's NICU admission whereas most of the parents interviewed had enrolled in the study more than three weeks after their infant's admission and thus some app content may have had less relevance. Future design of app content for parents should continue to be developed in full partnership with parents, using common platforms and undergo iterative user testing with diverse NICU parents.

Parents highly valued the emotional and social support provided, most often by nurses and parent mentors. It is well known that nursing emotional and social support reduces parental stress during a NICU stay [23,24]. The mFICare program extended how nursing support was provided beyond the infant's bedside to group parent classes and in modeling and supporting parents' participation in clinical rounds. Parents valued having these expanded opportunities for support. Consistent with previous literature [25], parents in this study highly valued peer support from former NICU parents and group social support received through shared learning and empathetic contact with NICU parents during the mFICare classes.

The supportive relationships and activities described by parents could only exist within a unit culture that valued partnership between the NICU clinical team and parents (Fig. 1). Consistent with FCC principles, for successful delivery of mFICare interventions, there must be an underlying culture of mutual trust and power-sharing such that parents are welcomed as full partners in their infant's care planning and caregiving [5].

Parents also described impediments to engaging with the mFICare program. These were related to inconsistencies in NICU operations and team dynamics and difficulties in interpersonal communication with NICU healthcare professionals. Health professional- or organizationally-centered care delivery is unfortunately well-documented in the literature and exacerbates parental stress and trauma [6,26,27]. mFICare is designed to provide a framework to create greater consistency and accountability in delivery of parent partnered NICU care. Adherence to the model may not be consistent across the unit and parents may be exposed to care that is inconsistent with FICare. Further research is needed on unit-wide FICare implementation and sustainment to determine if overall parental exposure to unsupportive care practices is reduced. In our study, impediments to parental participation also arose from socio-economic and other constraints on families that made it difficult for them to participate in the mFICare activities. While flexibility in timing and modality of delivery of mFICare components may help, hospital and community resources are also needed to support parental participation in caregiving and care planning [27].

Although there was robust support for the themes and subthemes from the interview data, a limitation of the study was closure of the parent study prior to recruitment of additional participants for interviews, which precluded confirmation of thematic saturation or member checking. Further research is needed on parental views of FICare, with and without mobile app support, when FICare is implemented as the unit-wide model of care for the NICU. Further research is also needed to explore the views of fathers participating in mFICare.

4.2. Innovation

This study demonstrates several noteworthy innovations. First, despite growing adoption of the FICare model worldwide, there has been surprisingly little update in the US. Thus, this research is innovative in that it provides the first data on the views of US parents participating in an implementation trial of FICare in an academic medical center NICU in the US. Second, the study included a parent-designed app to support parent engagement in all the components of the FICare model. The app served a further purpose of providing a secure and efficient platform for research survey administration and data collection. As noted above, content and user interface improvments were suggested by parents and further research will be needed to determine the added value of apps for FICare as well as for research participation. Third, the nursing-led study brought an innovative disciplinary lens to the research that may contribute to greater sustainability and scalability of the model that is so highly dependent on the central role of nurses at all levels of NICU care delivery and organizational function.

4.3. Conclusions

The findings from this study provide an in-depth understanding of parental views of participation in the novel mFICare program in a single NICU as part of a US clinical trial. Overall, parents valued the additional supports and modalities of support delivery provided by the mFICare program and recommended its continued and expanded use to support successful parenting for preterm infants.

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Ethical approval

Ethical approval was provided by the Institutional Review Board of the University of California San Francisco in advance of implementation. Written informed consent was obtained from the parents/guardians.

CRediT authorship contribution statement

Linda S. Franck: Writing – original draft, Validation, Supervision, Software, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Jazzelle Magaña:** Writing – review & editing, Writing – original draft, Visualization, Software, Formal analysis, Conceptualization. **Robin Bisgaard:** Writing – review & editing, Methodology, Investigation, Data curation. **Brittany Lothe:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Yao Sun:** Writing – review & editing, Methodology, Conceptualization. **Christine H. Morton:** Writing – review & editing, Validation, Supervision, Software, Formal analysis.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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