


Alberta Family Integrated Care™ and Standard Care: A Qualitative Study of Mothers' Experiences of their Journeying to Home from the Neonatal Intensive Care Unit

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Abstract

Globally, one in ten infants is born preterm. Most preterm infants require care in a level II Neonatal Intensive Care Unit (NICU), which are highly technological critical care environments that can be overwhelming for parents. Alberta Family Integrated Care (AB-FICare™) is an approach to care that provides strategies to integrate parents into their infant's care team. This sub-study is the first to compare mothers' experiences in the context of AB-FICare™ and standard care. Semi-structured interviews with mothers from AB-FICare™ ($n=14$) and standard care ($n=12$) NICUs were analyzed using interpretive description informed by grounded theory methods. We identified a major theme of Journeying to Home with six categories: Recovering from Birth, Adapting to the NICU, Caring for Baby, Coping with Daily Disruption, Seeing Progress, and Supporting Parenting. Mothers in the AB-FICare™ group identified an enhancement to standard care related to building reciprocal trust with healthcare providers that accelerated Journeying to Home.

Keywords

neonatal intensive care unit, family integrated care, family-centered care, mothers' experiences, preterm infants, qualitative methods, Canada

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Introduction

Globally, the estimated preterm (<37 weeks gestation) birth rate in 2014 was 10.6% (Chawanpaiboon et al., 2019). Compared to their full-term counterparts, preterm infants are at a higher risk of short- and longer-term morbidities attributed to physiological immaturity (Natarajan & Shankaran, 2016). Preterm infants born at <32 weeks gestation are the most immature and require care in a level III Neonatal Intensive Care Unit (NICU; Committee on Fetus and Newborn, 2012). However, the majority (~80%) of preterm infants are born 4 to 8 weeks early, or between 32 weeks and 0 days [32⁰] and 36⁶ weeks gestation and require intensive care in a level II NICU. NICUs are highly technological critical care environments and parents report that sounding alarms, extensive technology, and monitoring systems can be overwhelming during an already stressful time (Fernández Medina et al., 2018; Stefana et al., 2018; Treherne et al., 2017).

Mothers of preterm infants experience emotional distress related to the admission of their infant to the NICU (Feeley et al., 2016; Ionio et al., 2016; Lotterman et al., 2019). Parents experience fear and anxiety related to the uncertainty of their infant's survival (Gibbs et al., 2015; Pineda et al., 2018; Stefana et al., 2018) and disrupted parent-infant attachment (Dall'Oglio et al., 2019; Feeley et al., 2016). Parents have described emotionally disconnecting as an attempt to cope with their infant's ongoing medical instability and potential to deteriorate (O'Donovan & Nixon, 2019). The highly technological and fast-paced environment of the NICU may also limit opportunities for parents to be actively

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involved in the care of their preterm infant (Finlayson et al., 2014; Pineda et al., 2018).

Family-centered care is a philosophy of care that emphasizes respect and responsiveness toward families' needs and values (Institute for Patient- and Family-Centered Care, n.d.). Family-centered care supports the belief that optimal health outcomes are achieved when families collaborate with the healthcare team and play an active role in decision-making (Institute for Patient- and Family-Centered Care, n.d.). Although healthcare systems espouse family-centered care, its fundamental concepts remain poorly understood and are broadly interpreted by healthcare providers and parents (Harrison, 2010; Kuo et al., 2012). This leads to difficulty implementing family-centered care and variability in operationalization across NICUs (Foster et al., 2010; Franck & O'Brien, 2019; Kuo et al., 2012; Mikkelsen & Frederiksen, 2011; Smith, 2018). In studies of parental experiences with family-centered care, parents expressed (a) dissatisfaction with communication (Finlayson et al., 2014; Foster et al., 2010) and information sharing (Butler et al., 2014; Foster et al., 2010; Hill et al., 2018), (b) inconsistency of information from healthcare providers (Butler et al., 2014; Finlayson et al., 2014), and (c) difficulty negotiating parent-healthcare provider roles (Butler et al., 2014; Coyne, 2015; Foster et al., 2010). Parents described (a) a lack of emotional support (Foster et al., 2010; Raiskila et al., 2016), (b) lack of opportunities for fathers' participation (Raiskila et al., 2016; Sigurdson et al., 2020), (c) not feeling valued as a member of their infant's care team (Sigurdson et al., 2020), and (d) being unable to participate in decisions about their infant's care (Hill et al., 2018; Raiskila et al., 2016). Additionally, studies of healthcare provider experiences with family-centered care have reported (a) an expectation that parents provide basic care because of busy workloads and staff shortages (Coyne, 2015; Foster et al., 2010), (b) lack of shared decision making (Benzies et al., 2019; Mirlashari et al., 2020), (c) inconsistent practices related to parental involvement (Benzies et al., 2019; Butler et al., 2014), and (d) safety risks for the infant (Benzies et al., 2019). Complex and intertwined health system issues challenge healthcare providers' ability to operationalize family-centered care (Benzies et al., 2019; Foster et al., 2010) to improve outcomes.

Family Integrated Care (FICare) is an approach to care, based on the philosophy of family-centered care, designed to integrate parents into their infant's care team from the time of admission. With FICare, parents are empowered and supported to develop the knowledge, skills, and confidence to care for their infant. In level III NICUs, a pilot study (O'Brien et al., 2013) and 25-site international cluster randomized controlled trial (cRCT) (O'Brien et al., 2018) of FICare demonstrated increased infant weight gain during a 21-day window during hospitalization and decreased maternal stress (as measured by the Parenting Stress Scale NICU [PSS:NICU]; Miles et al., 1993) and anxiety (as measured by the State-Trait Anxiety Scale [STAI]; Spielberg et al., 1970), but no reduction in hospital length of stay. A similar model, Close

Collaboration with Parents, was evaluated in nine NICUs in Finland and reported increased maternal and paternal presence in the NICU and skin-to-skin care (He et al., 2021), and increased perceptions of family-centered care (Toivonen et al., 2021).

With advice from Alberta healthcare providers, FICare for level III NICUs was adapted for level II NICUs, and evaluated in a 10-site cRCT (Benzies et al., 2020). Although differences were not statistically significant, compared to the standard care group, mothers in the Alberta FICare™ (AB-FICare™) group experienced less stress (as measured by the PSS:NICU; Miles et al., 1993), anxiety (as measured by the STAI; Spielberg et al., 1970), and depressive symptoms (as measured by the Edinburgh Postnatal Depression Scale [EPDS]; Cox et al., 1987), and were more confident (as measured by the Perceived Maternal Parenting Self-Efficacy [PMP S-E] tool; Barnes & Adamson-Macedo, 2007) in caring for their infant (Benzies et al., 2020). Compared to the standard care group, infants in the AB-FICare™ group were discharged home 2.55 days sooner, without concomitant increases in emergency department visits or readmissions. However, there was limited understanding of mothers' experiences with AB-FICare™. The purpose of this sub-study was to describe mothers' experiences parenting their preterm infant in a level II NICU. A qualitative approach using interpretive description (Thorne, 2017) informed by grounded theory methods (Corbin & Strauss, 2008) enabled an exploration of mothers' socially constructed experiences of the context of care (AB-FICare™ and standard care). The research questions were: How do mothers describe their experiences of parenting a moderate or late preterm infant in a level II NICU? Are mothers' descriptions of their experiences different depending on the context for care (AB-FICare™ and standard care)?

Philosophical Underpinnings

The philosophical underpinnings of this sub-study were pragmatism and symbolic interactionism (Corbin, 2021). Pragmatism is useful because the intent of this research was to use mothers' experiences to effect action and change in practice to value, respect, and integrate parents of critically ill preterm infants into the NICU care team (Strauss, 1993). Interactionism is aligned with one of the key components of AB-FICare™, Relational Communication, and guided the researchers to be sensitive to mothers' experiences with healthcare providers and interpretation of meaning. Attention to context (AB-FICare™ and standard care) enabled the researchers to interpret and describe how mothers' experiences were influenced by different approaches to care.

Methods and Analysis

Study Design

As a sub-study of the primary AB-FICare™ cRCT (Benzies et al., 2020), this interpretive descriptive study (Thorne,

2017) informed by grounded theory methods (Corbin & Strauss, 2008) was designed to qualitatively describe mothers' experiences in the context of different approaches to neonatal intensive care (Corbin, 2021). The University of Calgary, Conjoint Health Research Ethics Board (CHREB ID 15-0067), University of Alberta, Health Research Ethics Board (Pro00060324), and Covenant Health Research Centre, Health Research Ethics Board (ID 1762) approved this study. We applied the COnsolidated criteria for REporting Qualitative research (COREQ) (Tong et al., 2007) for transparent and accurate reporting of health research.

Setting

Between October 2016 and September 2018, this sub-study was conducted in 10 level II NICUs (five AB-FICare™ and five standard care sites) in Alberta, Canada (Benzies et al., 2020). There was a similar distribution of open ward and single-family room NICUs. The majority of NICUs had lockers or bedside storage to store belongings; most had a parent lounge with a microwave to heat food. In this jurisdiction, health services are delivered to a demographically diverse population of approximately four million people (Government of Alberta, 2019) through one publicly funded, integrated healthcare system, which espouses a philosophy of family-centered care. Although newly hired nurses receive specialized training and orientation to work in the NICU, in general, healthcare providers do not receive additional training to provide family-centered care.

Participants

Mothers of preterm infants born between 32^{0/7} and 34^{6/7} weeks gestation who were enrolled in the AB-FICare™ cRCT (Benzies et al., 2020) and consented to participate in follow-up studies were invited to participate in this sub-study. Of the 129 invited, mothers were purposively sampled to include participants from urban and regional sites. Except for one regional standard care site with no participants, between one and five mothers from each NICU participated, with similar numbers in the AB-FICare™ and standard care groups.

Context for Level II NICU Care

For this sub-study, the context for mothers' experiences was two approaches to care in level II NICUs: AB-FICare™ and standard care. In the standard care approach, infants and parents received NICU care as usual. AB-FICare™ is a theoretically driven, psychoeducational enhancement to care that provides actionable strategies and practical tools for healthcare providers to integrate parents into their infant's NICU care team. There are three components: Relational Communication, Parent Education, and Parent Support. Relational Communication, based on family systems theory (Wright & Leahey, 2013), uses circular pattern diagrams to

encourage healthcare providers to think interactionally and use circular questioning and commendations to negotiate roles as parents are integrated in the care team, including participation in daily bedside rounds. Parent Education is based on adult learning (Knowles, 1973) and self-efficacy (Bandura, 1997) theories to provide consistent and evidence-informed education to parents. Parent education was delivered through multiple modalities including sequenced information in a parent education pathway, individual bedside teaching, group parent education sessions, and Life's Little Love app (© 2015 Alexiatek). Parent Support is based on stress and coping theory (Lazarus, 1966; Lazarus & Folkman, 1984). As part of the AB-FICare™ cRCT, all participating mothers were screened for depressive symptoms using the EPDS (Cox et al., 1987). Mothers who scored in the clinical range (≥ 13) were referred to a social worker for psychological support. Family mentors, who had previous experience with a preterm infant in NICU, provided informal support. Families in both groups received a parent journal to provide data for the cRCT. For both groups, these data included information about how much families spent out-of-pocket while their infant was in NICU. The AB-FICare™ group journal had additional pages to record their infant's gestational age, weight (including gain or loss), feeding, participation in education sessions, questions to ask the healthcare team during bedside rounds, and an invitation to record their thoughts and experiences each day. Families in the AB-FICare™ group received a parking pass to facilitate their presence in NICU.

Data Collection

Mothers provided written informed consent to participate in the cRCT and possibly an interview. At the 2-month follow-up (all infant ages were corrected for prematurity), mothers were invited by a female research assistant to participate in a one-on-one interview via telephone. Scheduling interviews with mothers caring for a preterm infant was challenging. A female research assistant with qualitative interviewing experience scheduled telephone interviews when infants were between 2- and 7-months old. Interviews were semi-structured to allow participants freedom in their responses and lasted between 30 and 90 minutes. See supplemental documentation for the semi-structured interview guide. There was no previous relationship between the interviewer and participants. Interviews were digitally audio-recorded, de-identified, and transcribed verbatim by a professional transcriptionist. The first author (RD) verified the accuracy of the transcripts.

Data Analysis

NVivo version 12 (QSR International, Doncaster, AUS) was used to manage the qualitative data. Informed by Corbin and Strauss (2008) constant comparative analysis, after reading

each transcript individually, open coding was used to break down the data, examine it closely, and develop conceptual names based on participants' implied meaning of their NICU experience. Coding was interpretive with weekly interactions between two researchers (RD [undergraduate researcher] and KB [principal investigator]) and the data to check and recheck concepts and meaning. RD wrote memos in the software to track tentative meaning along with properties and dimension of the concepts, and potential connections to other emerging concepts. Open codes of each interview were constantly compared to identify similarities and differences across participants and the two contexts for NICU care (i.e., AB-FICare™ and standard care). Similar concepts were labeled and grouped around major themes or categories. RD and KB repeated this step twice to ensure identification of all concepts and amend errors, and to search for contradictions when the data did not fit the analysis. When meaning of data was not evident, even after making careful comparisons and asking questions about the meaning of the data, another expert in qualitative research was consulted, which resulted in greater clarity about one category (Supporting Parenting). After review of the emerging categories by two experts (JK and PZ) in AB-FICare™, connections were identified between categories and sub-categories. We linked categories with their properties and dimensions to describe a major theme. All categories were saturated. We used IBM SPSS version 25 (IBM Corp, Armonk, NJ) to describe sample characteristics.

Findings

Characteristics of Mothers and their Infants

In the AB-FICare™ ($n = 14$) and standard care ($n = 12$) groups, the mean maternal age was 31 (range 24 - 38) versus 33 (range 24–39) years, respectively. By group, most mothers completed post-secondary education (64% vs. 50%), were married (86 % vs. 75%), born in Canada (93% vs. 83%), Caucasian (86% vs. 92%), and reported a household income over CAD \$80,000 (79% vs. 67%). In the AB-FICare™ ($n = 15$) group, 67% of infants were male versus 88% in the standard care ($n = 16$) group. In the AB-FICare™ group, the mean gestational age of infants was 33^{3/7} (range 32^{0/7}–34^{4/7}) weeks versus 34^{2/7} (range 33^{4/7}–34^{6/7}) weeks in standard care group.

Major Categories

Within the context of NICU care approach (i.e., AB-FICare™ and standard care), a major theme of Journeying to Home was revealed with six major categories: (1) Recovering from Birth, (2) Adapting to the NICU (with sub-categories Physical Environment, Technology is Overwhelming, and Continuity and Consistency in Care), (3) Caring for Baby (with sub-category Participating in Bedside Rounds), (4) Coping with Daily Disruption, (5) Seeing Progress, and (6)

Supporting Parenting. Quotes were identified by participant ID and context of care. For the major categories of Adapting to the NICU, Coping with Daily Disruption, and Seeing Progress, the experiences of mothers were similar regardless of the context for care. However, context influenced the categories of Recovering from Birth, Caring for Baby, and Supporting Parenting. For these three categories, similarities and differences in the context of mothers' experiences were compared and contrasted.

Recovering From Birth

All mothers described their unique experiences of giving birth to a preterm infant. Mothers in the standard care group emphasized the physical and emotional challenges they faced during their recovery from birth while their infant was admitted to the NICU. Specifically, recovering from a cesarean section and being treated for health complications were difficulties mothers faced as patients. Ultimately, these complications led to the interference of parent-infant closeness at birth. Mothers spoke about being unable to see their infant for up to 12 hours after giving birth, which resulted in concerns about bonding with their infant. They described challenges of being with their infant because the NICU and postpartum unit were on different floors.

When I had the C-section and I was in recovery on the 5th floor and he was in the NICU, on the 3rd floor. . . One time I was down seeing him and I came back up and I realized that the doctor had come by to see me so I missed that visit. So it just wasn't really in my view, very conducive to one – me bonding and spending time with my son, but also me recovering and getting the care that I needed as well, just because we're so far away from each other. (ID 202 Standard Care)

In comparison, mothers in the AB-FICare™ group were overall less preoccupied with the challenges of their recovery. These mothers highlighted the need to take care of their own mental health by getting more sleep or taking a break from the hospital.

I had spent 5 days there [the hospital] prior to my C-section so then it was another week on top of that. I just had not actually physically set foot out of the hospital and gotten fresh air so it was just nice to go out for lunch and get a break from the hospital. (ID 602 AB-FICare™)

At the same time as recovering from birth, mothers were learning to adapt to the expected and unfamiliar environment of the NICU.

Adapting to the NICU

In the major category of Adapting to the NICU, there were three sub-categories: Physical Environment, Technology is Overwhelming, and Continuity and Consistency in Care.

Physical environment. The physical environment and layout of the NICU played an overwhelmingly important role in mothers' experiences adapting to the NICU. In both groups, mothers described that the physical environment in the NICU was generally welcoming and comfortable. However, many mothers said they would have preferred a private room instead of a shared space with other families. Mothers mentioned opportunities to stay overnight with their infant.

I liked to be able to sleep next to my baby once I finally was able to stay overnight in the hospital so that I could hear what was going on and be a part of the feedings. I think if I wasn't able to stay in the room it would have taken a lot longer to go home because if you're not in the room, then you can't necessarily be there for the feedings and things like that. . . (ID 595 AB-FICare™)

Technology is overwhelming. Mothers in both groups described that sounding alarms, monitors, cables, and tubes were barriers to providing care for their infant. Often, infants had multiple different attachments that parents felt uncomfortable navigating without support and monitoring by nursing staff. Some mothers highlighted that they were unable to hold their infant for many days because of the attachments and fragility of their infant. Mothers felt constantly on edge when alarms sounded for their own and other infants. Over time, the constant alarms began to take a toll on their mental health, leaving mothers feeling anxious, sad, and scared. When nursing staff supported and educated parents to understand the alarms, they felt more involved and comfortable in the care of their infant.

Obviously if you stay there overnight, the monitors don't turn off, they keep going every night. So for me I think it was important to go home, get a little bit of a break to rest and recover myself, however, every time I left my emotions were very high because I felt as if I was leaving my baby. (ID 202 Standard Care)

Continuity and consistency of care. Continuity and consistency of care contributed to maternal adaptation to the NICU in both groups. Having the same nurse for consecutive days helped build a mutually trusting relationship and facilitated consistency of care. Mothers found it difficult when nursing assignments changed frequently as they felt like they were starting again with a new nurse.

The one thing we found that was a little bit hard was when there would be a new nurse, it was like starting again from scratch. They would assume our knowledge was very low and would repeat a lot of the same thing or try to tell us the same thing. . . So the more they could keep the same person [nurse] with us, the easier it was and more beneficial it was for us. (ID 225 AB-FICare™)

As they worked with different nurses, parents identified minor discrepancies in care and found it hard to learn about the best way to care for their infant.

With one nurse I did a tight swaddle on my baby and then I'd come back from lunch and she'd be in a loose swaddle. So then I'd be like "Oh I guess I'm supposed to loose swaddle my baby.." And then I'd go for dinner and I'd come back and it's a different nurse and my baby would be in a tight swaddle. It seemed no matter what I did that day, not that either was right or wrong, but I took it personally on how to swaddle my baby. (ID 595 AB-FICare™)

As mothers spent time with their infant in NICU, they learned to navigate healthcare provider shift schedules and recognize different approaches to good quality care. In approaches of NICU care where mothers felt welcomed and supported to do so, they began to engage in caring for their infant.

Caring for Baby

Mothers in both groups described in depth the care they provided to their infants. Depending on parental comfort, the care varied from providing skin-to-skin with complete assistance from nursing staff to parents managing all aspects of non-medical care with supervision only. Mothers mentioned that changing diapers, providing baths, feeding, and temperature checks was their contribution to the healthcare team. In the AB-FICare™ group, mothers felt more involved in the care of their infant because the nurses had consistently emphasized parental presence and involvement. Increased parental involvement also made parents feel like their contribution to the healthcare team was easing the staff's workload so nurses could spend time with infants who did not have parents at the bedside.

I was expecting to be just sitting there watching him you know, in the incubator with all the wires and everything, but I ended up being more involved. So, the nurses, they emphasized the involvement of my presence. . . like them just telling me to get involved instead of just telling me, "Oh step aside while I do this tube feed". Instead of doing that, they kind of came and said, "Hey do you want a syringe to feed your baby on the side?". Those little things made my day so much better. (ID 731 AB-FICare™)

In this category, the sub-category of Participating in Bedside Rounds emerged for the AB-FICare™ group.

Participating in bedside rounds. In the standard care group, few mothers spoke about participating in bedside rounds. Mothers who had the opportunity mentioned being present and able to ask questions of the medical team. In comparison, mothers in the AB-FICare™ group were encouraged to participate by sharing information about their baby in a way that was meaningful to them, at the start of bedside rounds. These mothers spoke about how consistently being part of bedside rounds was motivation for them to be in the NICU every day. In addition, mothers described appreciating the support that medical staff provided by explaining their infant's condition and needs in layman's terms.

It kind of takes me back to one of the doctors that was doing rounds one morning and he asked me how it was going. I think it was one of the first days I participated in rounds and I went to go rattle off all the numbers that the nurse had told me. You know, how much weight she had gained overnight or lost overnight, how many episodes she's had, how much food she's getting. The doctor stopped me and said, "No. Mom, how is she doing?" He really made me think that even though the nurses are there for 12 hour shifts and looking after our little ones, I knew better how she was doing. (ID 586 AB-FICare™)

Regardless of increasing confidence and competence in the care of their infant, all mothers dealt with daily disruptions associated with parenting their infant in the NICU.

Coping with Daily Disruption

Although parents were grateful to spend time with their infant in the NICU, many mothers mentioned the disruption to their daily routines. One of the main disruptions for mothers in the standard care group was organizing the travel between home and the NICU. Not only was this a barrier to spending more time with their infant, mothers also felt the emotional toll of having to leave their infant in the NICU overnight. Financially, mothers described needing to navigate the added expense of parking at the hospital.

Most mothers in the AB-FICare™ group described being separated from their partners, other children, and home community as a major disruption. Similar to mothers in the standard care group, this separation was described as a barrier to spending more time in the NICU because mothers had to balance their time between the NICU and their home life.

Being away from my husband and my son was one of my biggest challenges. . . I talked to my husband every day but it's not the same. . . It was harder not to have his support physically than just on the phone or through text message. (ID 679 AB-FICare™)

Mothers in both groups acknowledged that family members stepped in to provide childcare while they spent time in the NICU.

Seeing Progress

Mothers identified that one of their greatest joys in the NICU was seeing their infant make progress. A good day was described as their infant taking all their feeds, gaining weight, monitors removed as they were no longer needed, and getting validation about their infant's progress from the healthcare team during bedside rounds. Mothers noted these as milestones that led them one step closer to being discharged from the NICU.

The biggest joy was seeing how quickly my son was able to overcome the obstacles of being preterm. He was able to start eating a lot better under their [nurses'] supervision and as a

result he got stronger. That was a great joy to see him get so much stronger so fast under their care. (ID 152 Standard Care)

In comparison, when infants had significant weight loss or needed more medical intervention, mothers felt like their infant regressed. Mothers described this as a bad day because the regressions coincided with being unable to be involved in the care of their infant and further from discharge.

A bad day would have been showing up and he had reverted. One day we got there, and he needed to have the oxygen put back on because he might have caught a little cold or something. . . But that was a bad day because then you feel like you're that much further from going home again. (ID 325 AB-FICare™)

Although seeing progress was common for mothers of infants receiving both approaches to care, mother described the support they received for parenting very differently in each group.

Supporting Parenting

In both the AB-FICare™ and standard care groups, mothers emphasized the large role that healthcare providers played in supporting parenting in preparation for their infant's discharge. Mothers identified that education from nurses, lactation consultants, social workers, and physicians made them more confident in caring for their infant. Nurses played a large role in providing emotional support to mothers when they felt most vulnerable. Many mothers emphasized how intimidating it was to have an infant in the NICU, but simply having the support of nurses by their side made a difference in their experiences. When mothers were alone in the NICU without family supports, nurses stepped in to provide support. Mothers mentioned that simple, tangible actions such as providing a nipple shield or a glass of water were supportive. Mothers in the AB-FICare™ group highlighted that financial support, such as a hospital parking pass, enabled parents to spend more time with their infant.

Mothers in the standard care group observed that healthcare providers focused more on the care of their infant rather than the circumstances surrounding their lives. Some families felt uninformed and unsupported as healthcare providers provided minimal support to help them understand what was happening to their infant. Although the care provided by healthcare providers was generally good, mothers identified the lack of communication and limited understanding of their life circumstances as problematic.

For them [the nurses] to be maybe a little more understanding of what the families are going through. Just in terms of like the loudness and chattiness. Even when we first would want to hold them [the babies] and sometimes you felt like they [the nurses] didn't understand as much what you were going through. They could maybe improve on that (ID 377 Standard Care)

In contrast, mothers in the AB-FICare™ group emphasized that healthcare providers showed awareness and understanding of circumstances surrounding their lives outside of their infant's NICU hospitalization. This awareness led to parents feeling valued, respected, and supported. Healthcare providers advocated for families during moments when parents felt they did not have a voice and were always present for parents during moments of vulnerability. Through this support, parents developed confidence in caring for their infant. Ultimately, healthcare providers and parents developed a strong relationship built on the foundation of reciprocal trust surrounding the infant's care.

I would say that the nurses definitely were caregiver focused. They were thinking about the babies, but they [the nurses] were also thinking about us. Helping us with different things, answering our questions. They would ask us, "How are you feeling about this?" I felt like they were really thinking about the babies first because that's the most important, but then also how can we make this easiest and the most beneficial for the babies through making it easier for the caregivers and the parents. (ID 225 AB-FICare™)

In summary, mothers in the AB-FICare™ group highlighted how they felt valued, respected, and supported through relationships with healthcare providers built on reciprocal trust. This trust was reflected in mothers' caring for their infant as they felt confident and empowered. In comparison, mothers in the standard care group did not describe the same feelings of support as mothers in the AB-FICare™ group. Although care was described as generally good, parents in the standard care group wanted more information about their infant's progress and better preparation for discharge.

Journeying to Home

We linked categories with their properties and dimensions around a major theme, Journeying to Home. Given the unexpected preterm birth of their infant and the need for care in the NICU, mothers' descriptions focused on working toward discharge. Although mothers in both groups articulated many similarities in Journeying to Home, there were many differences that depended on the context of care. The differences suggested that with AB-FICare™, mothers felt encouraged and supported to be involved in their infant's care in the NICU. With this involvement, mothers became more confident and felt they were working together with the care team to support their infant in Journeying to Home. With strong relationships between mothers and healthcare providers built on understanding and reciprocal trust, Journeying to Home was less circuitous for mothers in the AB-FICare™ group than mothers in the standard care group. Evidence-informed parent education and basic psychosocial support helped parents to build confidence and focus on discharge.

Discussion

In this qualitative study, we explored similarities and differences in the experiences of mothers of moderate and late preterm infants in the context of two approaches to NICU care (AB-FICare™ and standard care). We identified six major categories of mothers' experiences: (1) Recovering from Birth, (2) Adapting to the NICU, (3) Caring for Baby, (4) Coping with Daily Disruption, (5) Seeing Progress, and (6) Supporting Parenting. These major categories were linked around a major theme, Journeying to Home. To our knowledge, this is the first qualitative study exploring mothers' experiences in the context of AB-FICare™ and standard care.

With regards to recovering from birth (first major category), past studies support our finding that mothers experience great emotional challenges, which can include anger, anxiety, and depression, during their recovery from birth of a preterm infant (Ionio et al., 2016; Klawetter et al., 2019; Lotterman et al., 2019; Trumello et al., 2018). However, there has been little research considering the physical challenges that mothers experience after giving birth to a preterm infant. This study revealed that mothers faced many physical challenges, in addition to the emotional challenges, during their recovery from preterm birth, all while wanting to care for their infant in the NICU.

Mothers in this study described in detail the barriers they encountered while adapting to the NICU (second major category). The overwhelming technology and lack of continuity and consistency in care contributed to stress. These findings align with literature outlining how mothers must overcome stress (Al Maghaireh et al., 2016) and a multitude of challenges as they familiarize themselves with the NICU (Fernández Medina et al., 2018; Klawetter et al., 2019; Stefana et al., 2018; Treherne et al., 2017). As mothers in this study adapted to the NICU environment, they spoke at length about the care they provided to their infant (third major category). In the AB-FICare™ group, mothers felt more involved in the care of their infant as nurses emphasized parental presence and involvement. This finding is supported by recent studies conducted in both level II and III NICUs (Bradford-Duarte & Gbinigie, 2020; Broom et al., 2017). As in the Level III NICU model of care (O'Brien et al., 2018), parents in the AB-FICare™ group were supported and encouraged to participate in bedside rounds actively and consistently. This had a positive influence on mothers' experience of parenting their infant in NICU.

Mothers in this sub-study spoke about the disruption to their daily lives (fourth major category) of having an infant in the NICU. Organizing travel between home and the NICU and separation from home life were the two main disruptors. This finding is supported by Klawetter et al. (2019) who spoke to these limitations and how they interfered with parental ability to spend time with their infant. In a study of 11 NICUs in six European countries, parental closeness to

their infant was predicted by the ability of parents to stay overnight in the NICU (Raiskila et al., 2017). Amenities such as a reclining chair or bed in the infant's single-family room may reduce disruption.

Mothers in this study highlighted that seeing their infant make progress (fifth major category) in the NICU was one of their greatest joys, as they believed that each milestone their infant achieved was one step closer to going home. However, when the infant needed additional medical intervention, mothers felt like their infant had regressed. There is a paucity of published literature on this finding (Stacey et al., 2015), and future research is needed to understand how to support mothers to understand positive and negative milestones during hospitalization.

The most notable difference between groups was revealed in the last major category, Supporting Parenting. Mothers in the AB-FICare™ group described a strong relationship with healthcare providers built on reciprocal trust. This trust empowered mothers to feel part of their infant's care team and built confidence in providing care on the journey to home. Mothers in the standard care group did not describe the same feelings of support. This perceived lack of support from healthcare providers is consistent with other studies (Hassankhani et al., 2020; Kim, 2020; Sigurdson et al., 2020; Wreesmann et al., 2021) and may place greater responsibility on mothers to navigate on their own a longer and more circuitous journey to home. To improve the quality of care in all NICUs, future research is needed to better understand the components of AB-FICare™ that contribute to reciprocal trust and maternal feelings of support and empowerment in the care of their preterm infant.

The major theme, Journeying to Home, embodied mothers' descriptions of their experiences during their infant's stay in the NICU. While other studies have focused on parents' experiences in the NICU (Al Maghaireh et al., 2016), few studies have considered parents' experiences in different contexts of NICU care. This study provides qualitative findings that mothers experience AB-FICare™ differently from standard care. In a systematic review of studies in pediatric intensive care units and NICUs, Segers et al. (2019) reported high quality evidence of the effect of family-centered care interventions on parent satisfaction and length of stay in the NICU only. It is reassuring that mothers articulated concepts that were aligned with the three components of AB-FICare™ (i.e., Relational Communication, Parent Education, and Parent Support) and these contributed to an accelerated journey to home for infants of mothers in the AB-FICare™ group.

Strengths and Limitations

This study was strengthened by the diverse sample and saturation of categories but limited by inclusion of a select group of mothers who participated in a cRCT of AB-FICare™. Inclusion criteria for the AB-FICare™ group was presence in the NICU for 6 hours per day; thus, these findings may not be

transferable to mothers of preterm infants who are unable to be with their infant in the NICU. This study was conducted in Alberta, which has a single integrated health system with standardized structures and processes; thus, findings may not be transferable to other jurisdictions. Although an attempt was made to recruit participants from each site in the cRCT, we were unable to recruit mothers from one regional site in the standard care group. Finally, the authors of this sub-study were part of the AB-FICare™ cRCT, which may have led to bias toward the AB-FICare™ approach. This was addressed throughout the analysis by constantly questioning the data and seeking advice on categories where mothers' experiences were different depending on the context for care.

Implications for Nursing Practice

Building reciprocal trust with parents of infants admitted to a level II NICU is of critical importance to nursing practice. As revealed in this study, mothers identified that support during their infants' NICU hospitalization accelerated their Journeying to Home. NICU managers may wish to consider embedding AB-FICare™ training in staff orientation with annual updates. AB-FICare™ training modules are brief and delivered asynchronously online to enable all staff to participate. In addition to staff education, policies could be developed and implemented, with input from all stakeholders, to facilitate integration of parents into the NICU care team, as soon as they are ready and willing, after admission (Zanoni et al., 2021).

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Supplemental Material

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