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Research Article

Addressing the Needs of Mothers with Infants in the Neonatal Intensive Care Unit: A Qualitative Secondary Analysis

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ABSTRACT

Purpose: Mothers of infants hospitalized in neonatal intensive care units (NICUs) need to be recognized as essential partners of the care team as their presence and involvement are key to infants' health and developmental outcomes. Addressing mothers' perceived needs is beneficial for the improvement of supportive nursing care; however, little qualitative research on their unmet needs has been conducted in South Korea. This study assessed mothers' perspectives on their NICU experiences and their unmet needs within the South Korean cultural context.

Method: A cross-sectional, multicentered, secondary analysis study was conducted using the written responses to an open-ended questionnaire. Of the 344 NICU-experienced mothers, 232 throughout South Korea (seven cities and five provinces) voluntarily completed the questionnaire via smartphone-based or web-based surveys. Their narrative responses were analyzed using thematic content analysis guided by the critical incident technique.

Results: Four themes emerged. NICU-experienced mothers of preterm infants referred to the "family-friendly environment" (16.4%) as a positive experience. The greatest unmet need was "relationship-based support" (58.2%), followed by "information and education-based support" (20.0%) and "system-level challenges" (5.4%).

Conclusion: The importance of creating a family-friendly NICU environment should be emphasized by ensuring 24-hour unrestricted access and encouraging active parental involvement in infant care, as well as actively supporting NICU families through supportive words and actions. The assurance of anti-infection management and better staffing levels should be fundamentally guaranteed to NICU staff.

Introduction

The current annual global rate of preterm births is estimated to be between 5.0% and 18.0%, and it has become a high-priority public health issue worldwide [1]. The South Korean preterm birth rate has increased from 5.2% to 7.6% over the last decade, while the fertility rate (the average number of children born per woman) hit a record low of 0.96 in 2018 [2]. The incidence of multiple births in South Korea has increased, with 4.2% owing to increased maternal age and the development of assisted reproductive technology, and approximately, 64% of twins are born before 37 weeks of gestation [2]. While the rates of survival for preterm and high-risk infants have risen (i.e., 87.9% of low-birth-weight infants in 2015) in the last three decades, one of four Korean mothers of high-risk infants developed symptoms of posttraumatic stress disorder after their infants' neonatal intensive care unit (NICU) hospitalization [3]. Moreover, the detrimental neurodevelopmental outcomes or abnormalities (e.g., cognitive, language, sensory, visual perceptual, attention, and learning disabilities) that occur more frequently with these infants are still unsolved [4]. Therefore, these infants' mothers require additional care to help them cope with their ongoing challenges, such as increased mental health problems and parenting burdens during their infants' NICU stay, which could continue for years after the preterm birth [5,6].

Mothers of preterm infants admitted to the NICU face difficulties adapting to the role of motherhood and bonding with their babies, and their therapeutic caregiving is critical to their infants' optimal growth and development after discharge [7–9]. However, mothers

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may hesitate to voice their opinions to not interfere with the medical staff rather than expressing their complaints regarding their babies' care [7]. In Korea, where parents rarely have 24-hour access to infants in the NICU and are required to follow a restricted visitation policy [8–10], previous qualitative research [11] found that the mothers voluntarily maintained a subordinate position to avoid being a nuisance to the staff throughout their infants' treatment, believing that just following the staff would be better for their babies' health outcomes. In fact, in most South Korean hospitals, including leading medical centers located in metropolitan areas, parents are given access to their infants 2–3 times a day (e.g., dawn, afternoon, and evening) for a limited period of 30–60 minutes. Furthermore, these visits are restricted to biological parents and grandparents (e.g., two persons at one visit, only hospitalized mother for visitation during the morning), and a meeting with the physician is not always possible (e.g., once a day during the day). In this context in South Korea, without a means for exploring and meeting their needs, increasing the family's involvement that is essential for long-lasting positive effects on the holistic health and development of their babies might not be feasible [7,12,13].

Nurses have a guiding role in addressing those family members who are emotionally distressed owing to their infants' NICU hospitalization after birth, which has been recognized by family-centered development care (FCDC) [14]. FCDC is a holistic care philosophy that recognizes the family as being vital partners of the NICU caregiving team, who provide developmentally supportive care to infants with the aim of fostering the mother–infant attachment relationship [12,15,16]. Consistency of the "maternal presence" and their "active participation in infants' care" and "shared decision-making" in the NICU are essential components of FCDC and improve both early and later developmental outcomes in preterm infants [16–19]. However, the gap between FCDC goals and actual practice remains unclear, as there is considerable heterogeneity among NICUs within and between countries worldwide [4,12]. Limited descriptive research has been conducted with Korean NICU mothers using the FCDC perspective. Prior findings were generally favorable toward the implementation of FCDC components; for example, the number of parent visits and the average visit length were negatively correlated with stress levels in a flexible parenting visiting system [10].

Mothers' partnership with nurses is associated with mothers' readiness for discharge from the NICU [20]. However, these prior studies involved participants from a single institution and provided insufficient evidence to establish new hospital ward policies or alter the NICU environment (e.g., eliminating barriers contributing to the open visiting policy) to improve FCDC [10,20]. While an integrative review indicated the necessity of tailored interventions for South Korean mothers [21], our qualitative study lays the groundwork for the development and refinement of family interventions in the South Korean context.

Thus, mothers of high-risk infants can cope more effectively with stress when their opinions are recognized by medical staff [22] in a friendly environment [23]. As family advocates, healthcare providers should make efforts to design favorable environments and provide support to families by addressing and accommodating their changeable needs within the complexity of their NICU experiences [24,25]. Understanding mothers' perceived needs would extend the field's knowledge regarding strategies for effective partnerships with NICU families, which are crucial FCDC components [16]. However, few recent qualitative studies have been conducted regarding positive and negative perceptions or unmet needs of NICU-experienced mothers in multiregions in Korea. In this study, the perceived needs of mothers with preterm or low birthweight in NICUs from multicenters were explored by classifying and analyzing their narrative responses to an open-ended questionnaire. In particular, mothers were queried regarding *what is working* and *what should be improved to fulfill maternal needs during their infants' hospitalization in the NICU.*

Methods

Study design

This qualitative study was conducted using narrative responses to open-ended questions that were collected during an original survey of multicentered settings in South Korea [8]. A secondary qualitative analysis was used to capture mothers' responses regarding their NICU experiences and unmet needs using thematic content analysis, which was guided by the critical incident technique (CIT) method [26].

Setting and participants

The sample was collected as a part of a survey of mothers with preterm infants in more than 49 tertiary hospitals of South Korea [8] that investigated the associations between FCDC quality, NICU environmental stressors, and maternal postpartum attachment after preterm birth. For the present study, mothers were included if they gave birth to preterm (i.e., born before 37 weeks of gestation) or low-birthweight (i.e., less than 2500 grams) infants, if the infants' admission to South Korean hospital NICU departments lasted at least seven days, and if the infants were born without congenital anomalies and did not require life-prolonging treatment. Given that length of a NICU stay ($\geq$7 days) is a determinant factor for health-related quality of life in children born preterm [27], the length of the infant's hospitalization was considered an important inclusion criterion. Respondents who did not answer the open-ended questionnaire regarding their NICU experiences and unmet needs were excluded.

In the prior survey, eligible mothers who were within 18 months postpartum were recruited through online postings on three community portals that were exclusively and frequently used by the parents of preterm infants. In addition, mothers with preterm or low-birthweight infants who were admitted to four hospitals were recruited in person at the time of NICU discharge. All of the mothers who agreed to participate and gave written informed consent were provided with direct links to access either smartphone-based or web-based surveys. Data were collected throughout South Korea from November 2017 to January 2018.

In the primary survey [8], the author included the open-ended questions at the end of a questionnaire to explore the specific challenges and unmet needs of the mothers of preterm infants during their hospitalization. This method was an effective way to capture mothers' voices. These qualitative data represented NICU mothers' responses to the open-ended items: *What are your needs in relation to your baby's care in the NICU?* and *Feel free to tell us what should be improved in the NICU.* Of the 344 received surveys, 232 mothers (67.4%) throughout the country voluntarily answered the open-ended question freely. Most of these mothers were recruited online (n = 219 from online recruitment; n = 13 from in-person hospital recruitment). Data from these 232 mothers, who were from seven cities and five provinces in South Korea, were included in the final data analysis.

Ethical considerations

Approval by the Hanyang University Institutional Review Board was initially secured for the data collection procedures and sharing of deidentified data in the primary study [8]. This study was

exempted from ethical approval (Approval no. SSWUIRB-2020-018). For the in-person recruitment, the author received cooperation and permission for data collection from the administration and unit managers of the affiliated hospital after sharing our IRB approval letter. The researcher was introduced to eligible participants by the nursing unit managers or medical specialists in the NICUs, and participants were then provided with details regarding the study from the researcher in separate, private consultation rooms. Participants who were recruited from the community portals reviewed online bulletin board notices with information about the study aims, methods, documentation, and storage of data for three years after the study had been completed. All participants could read the study information and would independently decide to participate once connected to the online survey system. In addition, the researcher provided details to all participants regarding anonymity, confidentiality, and the right to withdraw at any time during the survey. When participants clicked on an online banner indicating written consent, a page was provided for them to complete the questionnaire, including the open-ended question. All participants received a 5,000 won (approximately $4 U.S.) gift certificate available for use at affiliated stores, marts, or department stores.

Data analysis

Before data analysis, the raw data from the smartphone and web-based surveys were downloaded into Microsoft Excel 2020 without any identifying information. For this qualitative analysis, the lead researcher extracted the demographic variables and responses to the open questions written by the 232 participants. The qualitative text data were a secondary analysis from the narrative responses to open-ended questions related to mothers' NICU experiences using thematic content analysis guided by the CIT, a powerful inductive qualitative research method developed by Flanagan [26]. The CIT is a feasible and flexible means for studying human behavior [28,29] that identifies realities and values from participants' own words regarding meaningful experiences that have been committed to memory [28]. The CIT was applied to the categorizing process, that is, sorting incidents into categories or dimensions according to similarities among the reported experiences. By identifying and articulating the nature of each similarity, the researcher discerned and labeled each incident category.

First, important keywords from the incidents were selected, extracted, and their frequencies were checked as a preliminary exploration of the mothers' positive (satisfying) or negative (unsatisfying) incidents during the infants' NICU hospitalizations. The selected verbatim items were collated into an electronic spreadsheet from which key points had been summarized, rephrased each response, or integrated responses into a single keyword, for example, "I was really anxious → anxious: maternal psycho-emotional symptoms" and "I felt so sorry for my baby → sorry: maternal psycho-emotional symptoms." Corresponding to the broad recommendations for data analysis [26,30], a frame of reference was determined that generated categories inductively and identified specific behaviors (specificity) and representative behaviors (generality). The incidents within each theme were closely explored and assigned proper labels. The keywords were summarized and counted from a total of 946 incidents (qualitative data) via Microsoft Excel 2020 FIND function, and interrater agreement regarding the validity and reliability of the positive and negative incidents was considered by an external expert, who had qualitative research experience and more than 20 years of NICU expertise. Visualization of this information was performed using the R (R version 3.5.3) package, Wordcloud [31].

After completing this process, inductive data analysis using thematic content analysis was conducted [32–34]. All answers were entered into NVivo 12 software program (QSR Internationl 2020) to create a topic by grouping codes that reflected the mothers' NICU experiences and the meaning of their infant care needs. This process involved iteratively reading and rereading the responses, immersing ourselves in the data, and exploring individuals' experiences and unmet needs. Individual mothers' similar and divergent opinions were compared and contrasted to identify meaningful concepts in the samples and to break statements into manageable keywords. For example, the researcher sought to determine what occurred during the birth process, infants' subsequent NICU admission, and the transition from hospital to home. Using the hierarchical categorization procedure proposed by Flanagan [26], themes and subthemes were identified and organized through a process of consensus among the lead researcher and the external auditor. Preliminary coding books were developed by the lead researcher and reviewed by the external auditor, and the final coding books were agreed upon by both individuals after ongoing discussions. This analytic process helped to refine the core themes and subthemes to more closely reflect our data.

Results

A total of 232 mothers of preterm or low-birthweight babies responded to the open-ended question (Table 1). In total, 110 keywords (from 946 incidents) were extracted from the 232 participants. Of the 42 positive incidents, all but four were identically categorized, resulting in a 90.4% interrater agreement. Of the 904 negative incidents, 860 were classified through consensus (95.1%); the incidents (e.g., expenditures, infants' birth weight) that were redundant or irrelevant to NICU experiences or the mothers' unmet needs were disregarded and then confirmed by the external audit. The word cloud in Figure 1 visualizes the initially derived keywords based on their occurrences. The top 10% of the keywords included "my baby," "cure," "NICU," "mother of preemies," "visiting," "preemies," "nurse," "discharge," "kangaroo care," "education," and "condition."

As shown in Table 2, the thematic content analysis identified four themes that were related to mothers' expressed experiences or unmet needs in NICUs: family-friendly environment (16.4%), relationship-based support (58.2%), information and education-based support (20.0%), and system-level challenges (5.4%). The themes and subthemes are described in detail in the following paragraphs, and detailed examples of quotes from the responses are provided in Table 3.

Theme 1: Family-friendly environment

This theme emerged as a positive (satisfying) incident. The mothers described nurses' thoughtful efforts and kindness when sharing information and education. A few mothers who experienced 24-hour unrestricted access to the NICU regarded the visiting policy as being beneficial for their infants' health and maternal–infant bonding. The establishment of a family-friendly NICU environment where the mothers felt comfortable, welcome, and relieved could help with their adaptation and transition to motherhood.

1-1) Supportive attitudes of health-care providers

I was too awkward at feeding and burping my baby and even changing her diaper because it was the first baby in my life. The nurses taught me in a kind and gentle way; so I could rely on them.

Table 1 *Characteristics of the Mothers and Their Infants.*

Characteristics	Categories	n (%) or M ± SD
Characteristics of mothers		
Maternal age (yrs)		34.19 ± 4.29
Marital status	Married	229 (98.7)
	Single or divorced	3 (1.3)
Occupation	Yes	81 (34.9)
	No	151 (65.1)
Academic background	High school	36 (15.5)
	Junior college	69 (29.7)
	University	95 (40.9)
	Graduate school	28 (12.1)
	Others	4 (1.7)
Religion	Having a religion	98 (42.2)
	No religion affiliation	134 (57.8)
Monthly household income (10,000 won/m)	<100	2 (0.9)
	100-299	94 (40.5)
	300-499	90 (38.8)
	500-699	32 (13.8)
	≧700	14 (6.0)
Family system type	Nuclear family	201 (86.6)
	With her own parents	6 (2.6)
	With parents-in-law	19 (8.2)
	Others	6 (2.6)
Pregnancy intention	Yes	140 (60.3)
	No	92 (39.7)
Delivery mode	Cesarean	162 (69.8)
	Vaginal	70 (30.2)
Used assisted reproductive technology	Yes	42 (18.1)
	No	190 (81.9)
Multiple pregnancy	No (singleton)	199 (85.8)
	Yes (multiplet)	33 (14.2)
Experiences of breastfeeding in the NICU	Yes	138 (59.5)
	No	94 (40.5)
Experiences of kangaroo care (skin-to-skin contact) in the NICU	Yes	114 (49.1)
	No	118 (50.9)
Average number of visitations (days/week)		5.73 ± 1.95
Average number of visitations (times/day)		0.63 ± 0.58
Characteristics of children born preterm		
Child's age (yrs)		1.52 ± 1.12
Gestational age (weeks)		30.44 ± 3.97
Birthweight (gms)		1523.00 ± 634.02
Gender	boy	135 (58.2)
	girl	94 (41.8)
Hospitalization in the NICU (days)		62.97 ± 69.11

Note. M = mean; NICU = neonatal intensive care unit; SD = standard deviation; yrs = years.

[Omitted] *They told me to feel free to call them if I had any difficulties, and then, sometimes, I made a phone call to the nurses in the NICU to ask a question. It was very helpful.* (P140)

1-2) 24-hour open-access visiting policy

*After my preemie transferred to the *** medical center, I could meet him anytime. He was getting stable, thanks to the open visiting policy, I think.* (P19)

Theme 2: Relationship-based support

Most mothers shared their negative (unsatisfying) experiences surrounding interpersonal difficulties, including problems with health-care providers (e.g., medical doctors, nurses) or the inability to bond with their infants. Therefore, the need for supportive actions to build positive relationships with mothers and help reestablish the mother–infant relationship arose. First, the described incidents covered a variety of mothers' emotional reactions evoked by their infants' admission to the NICU after birth. For instance, the extracted keywords that participants used to describe their feelings included "overwhelm," "difficulties," "guilt," "grief," "uneasiness," "misery," "anxiety," "sadness," and "fear." These emotions or feelings that were related to the traumatic event of an unanticipated NICU experience rendered the parents susceptible to the NICU professionals' words and actions. The mothers preferred empathic concern and warmer (hopeful) words from the staff, even when delivering negative news.

2-1) Lack of empathetic communication skills

I heard only extremely frustrating stories from a neonatal doctor at a first meeting. I felt bitter toward the staff … they used overly negative words to mothers who were very fragile after the preterm birth. (P108)

Right after I had my baby, I could never feed my baby … even I could not hold him in my arms and hold his hands … [omitted] *There was nothing I could do as his parent; it made me sad. I wish the nurses and physicians understand and comfort me.* (P72).

Most premature infants are immediately separated from their mothers after birth, especially in South Korea. This early and prolonged separation from their infant after the unexpected preterm birth overwhelmed mothers with negative emotions and exacerbated their psychosocial distress. This distress was amplified by mothers' feelings of awkwardness, doubt, disappointment, or helplessness regarding the disrupted mother–infant attachment relationship during hospitalization. Participants' narratives reflected this experience.

2-2) Separation and detachment from the infant

I was away from my baby immediately after I had the baby. It was too hard for me, as a mother. [omitted] *Leaving her alone in the NICU, I felt too disheartened, and it was very, very hard.* (P64)

I really don't know why I had no affection toward my baby, I thought it was because of the emergent cesarean I had or … what if I could hold him in my arms after birth. (P33).

Figure 1. Extraction of keywords from response data. Figure 1 visualizes the initially derived keywords with a word cloud based on the occurrences of the keywords.

Table 2 *Categorization Results for Positive and Negative Incidents of NICU-experienced Mothers.*

Step 1 Keyword extraction	Step 2 Subcategories	Step 3 Categories (subthemes)	Step 4 Theme
Positive (satisfying)			
18	6	Supportive attitudes of health-care providers 24-hour open-access visiting policy	Family-friendly environment (16.4%)
Negative (unsatisfying)			
64	14	Lack of empathetic communication skills Separation and detachment from the infant Limited opportunities for kangaroo care and infant care	Relationship-based support (58.2%)
22	10	Inconsistent guidance on infant care Need for development of educational contents for parents	Information and education-based support (20.0%)
6	4	Concerns about infection control Improving NICU facilities/equipment and rectifying staff shortages	System-level challenges (5.4%)
Total 110	34	9	4

Note. NICU = neonatal intensive care unit. A total of 110 keywords were selectively extracted from positive and negative incidents through a process of consensus. In total, 4 themes and 9 subthemes were identified by the thematic content analysis.

Participants reported that they were eager to participate in baby care and interact with their preterm infants (e.g., holding, hugging, touching, skin-to-skin care) in the NICU. They appeared to have learned from the Internet, friends, and news that increased interaction with their babies was necessary to build a secure attachment relationship. However, some identified gaps between their desire and reality or the possibility of kangaroo care, and others wished they had opportunities to provide kangaroo care. Many mothers felt frustrated when they were not allowed to have this level of physical contact without being given specific reasons.

2-3) Limited opportunities for kangaroo care and infant care

During the hospitalization, I wish they would give us time and allow mothers to provide kangaroo care or to do things such as feeding their babies and being close to the babies. (P51)

I traveled to the hospital from my province, taking 4-5 hours by public transportation … but I was allowed only 30 minutes to hold my baby in my arms, and that made me too sad. She seemed to wait for me for a long time, saying "welcome, mommy. I was missing you." (P42)

Theme 3: Information and education-based support

Developing proper guidance and information on infant care based on the educational needs of NICU mothers was needed. Participants commented upon their satisfaction with the neonatal care for their preterm infants and reported the lack of consistent practice and guidance for caring for babies with special needs offered by nurses from day to day while their infants were hospitalized in the NICU. Some mothers shared complaints about inexperienced nurses or unfriendly staff who taught them how to care for their premature infants.

3-1) Inconsistent guidance on infant care

It was confusing when the nurses taught me baby care in different ways. For example, one nurse taught me I had to pat my baby on the back a little harder and faster to burp her … The other said I needed to pet her on her back slowly, not pat hard. (P24)

Some participants suggested that the education provided to NICU families did not meet their practical needs and that they required greater educational support than they received. They also expressed difficulties with education and practices regarding the "parental role," "breastfeeding," "growth and development," "rehabilitation," and "infant care" while their babies were hospitalized. Participants expressed more childcare difficulties in the home setting because the "discharge program" was lacking. They mentioned the need for consistency in discharge education to manage the challenges of providing therapeutic care for their preterm or low-birthweight children in a home environment.

3-2) Need for the development of educational content for parents

I wish to receive education and training on the rehabilitation of preemies … Also, I'd like to learn how to deal with expected situations about my baby after leaving the NICU. (P92).

I think there is little parental education about the development of preemies … I didn't know anything until my child was one month old. I used to search for cases like mine via the "Mom's Holic" [an online community portal for mothers] site to find information about preemies. (P111).

Theme 4: System-level challenges

The mothers identified system-level needs in the NICU settings to be assured of the best care for their infants. For a few participants, the greatest concern was an infection-free environment for their fragile infants. They were always worried about ensuring safety and hygiene regarding medical procedures for the infants in the NICU. However, participants tended not to discuss this with the NICU health providers and not to disclose complaints related to antiinfection management or guidelines. The mothers seemed concerned that their complaints would be viewed as hassles to the health providers and would ultimately influence their babies' care.

4-1) Concerns about infection control

I'd like NICU nurses and doctors to be more careful about disinfection, and I hope I can trust the hospital with having a reliable anti-infection guideline. (P 203).

I want the staff to consider cleanliness and hygiene a little more. [omitted] *I am her mother, and I put my preemie in the NICU⋯ I could never complain to the nurses, or doctors; what if she were to be disliked by them because of me.* (P99)

Other mothers noted that a national support policy or a uniform hospital policy is needed to address the regional differences surrounding advances in medical equipment, facilities, and staff

Table 3 *Examples of Quotes from the Participants' Responses.*

Theme	Subtheme	Direct quotes
Family-friendly environment	Supportive attitudes of health-care providers	*I was too awkward at feeding and burping my baby and even changing her diaper because it was the first baby in my life. The nurses taught me in a kind and gentle way, so I could rely on them. I really appreciated it. Of course, there were some who were relatively unkind. It would have been hard to care for my preemie in my case but for the discharge education program at the NICU. It was incredibly helpful. They told me to feel free to call them if I had any difficulties, and then, sometimes, I made a phone call to the nurses in the NICU to ask a question. It was very helpful.* (P140) *The physicians and nurses were very kind, friendly … (P228).*
	24-hour open-access visiting policy	*After my preemie transferred to the *** medical center, I could meet him anytime. He was getting stable, thanks to the open visiting policy, I think.* (P19)
Relationship-based support	Lack of empathetic communication skills	*I gave birth to a baby with sudden pain without any prior signs, and then … I heard extremely frustrating stories from a neonatal physician at a first meeting, without any hopeful words at all. I know that other mothers of preterm babies had heard only the worst scenario or were in a situation just like me. I felt bitter toward the staff … who used overly negative words to mothers who were very fragile due to the preterm birth. This type of thing should be improved … I think.* (P108) *Right after I had my baby, I could never feed my baby … you know that even I could not hold him in my arms, and hold his hands … Under the endotracheal intubation, he couldn't make any sounds, but he spoke with his own facial expressions … At that time, there was nothing I could do as his parent, it made me sad and distressed. I wish there were programs to understand and comfort me in these situations …* (P72) *Trust seems to be the most important thing … because I can see my baby only during visiting hours … The only thing I can do is just trust them completely, and I really need their help and a single good word from them …* (P41) *… I hope doctors explain difficult medical terms more easily to parents, because they are poor at medical terms.* (P230)
	Separation and detachment from the infant	*I was away from my baby immediately after I had the baby. It was too hard for me, as a mother. [omitted] Leaving her alone in the NICU, I felt too disheartened, and it was very, very hard.* (P64) *I really don't know why I had no affection toward my baby, I thought it was because of the emergent cesarean I had or … what if I could hold him in my arms after birth.* (P33) *Of course, I understand we (NICU families) have no choice but to follow the hospital ward policies, such as visiting hours, the allowed numbers of visits, restricted physical contact … and I know it's all for my baby, to protect her from infections. However, you know … I am worried about my baby being separated from me, lying down in an incubator, surrounded by all kinds of medical equipment … She must be anxious too. I cannot even see her all day long … but it may be heartbreaking for me to watch over some emergent events around her as well. Please understand that parents have nothing to do except to be worried about everything related to the baby.* (P111)
	Limited opportunities for kangaroo care and infant care	*During the hospitalization, I wish they would give us time and allow mothers to provide kangaroo care or to do things such as feeding their babies and being close to the babies.* (P51) *When I took my baby out of the incubator and provided kangaroo care, I felt numerous emotions. At first, she couldn't eat well … but after she was being in my arms, and heard my heartbeat, she seemed to handle breast milk well, and to sleep well … I traveled to the hospital from my province, taking 4-5 hours by public transportation … but I was allowed only 30 minutes to hold my baby in my arms, and that made me too sad. She seemed to wait for me for a long time, and to say 'welcome, mommy. I was missing you, mommy.' Thinking back, tears are filling my eyes … It was unavoidable, but it was too bad* (P42) *In my case, I touched my baby's hand when he was 50 days of age, for the first time … and then he could receive first kangaroo care at two months of age. I heard kangaroo care helped to improve preterm babies' conditions and establish a bond between the mothers and their children … It was a shame kangaroo care was not provided until the babies were stable. (P154)* *I cannot hug or touch my baby. I am so sad. Even if nurses care for him well, I feel miserable, because they touched him with vinyl gloves. (P224)* *I wish to have more time to give kangaroo care to my baby … and I'd like to have various experiences of baby care. (P92)*
Information and education-based support	Inconsistent guidance on infant care	*It was confusing when the nurses taught me baby care in different ways. For example, one nurse taught me I had to pat my baby on the back a little harder and faster to burp her … The other said I needed to pet her on her back slowly, not pat hard.* (P24) *I feel they care for babies slightly differently. So, I would like to say that the care must be same to improve this situation …* (P195) *I wish that they (NICU professionals) would strengthen the standard discharge instructions for parents of NICU infants before we leave the hospital. The program should consist of providing detailed information about directions for caring for preemies, not healthy babies, for example, whether swaddling my baby often is needed, how to massage my baby for her sensory development, and so on …. I feel sorry for her because what I did was wrong, or I didn't know how to do it well, and didn't know what I should do in the right way … Most people around me used to teach me about baby care based on normal (healthy) babies.* (P50).
	Need for development of educational contents for parents	*I wish to receive education and training on the rehabilitation of preemies … Also, I'd like to learn how to deal with expected situations about my baby after leaving the NICU.* (P92)

			I think there is little parental education about the development of preemies … I didn't know anything until my child was one month old. I used to search for cases like mine via the 'Mom's Holic' [an online community portal for mothers] site to find information about preemies. (P111)
			I am really afraid and anxious during my everyday life … I feel it's one disaster after another. What if my preemie is different from other babies? I feel so sorry for my baby going through a bunch of tests and examinations … I hope you share enough information on how my baby can live life just as other children do. (P26)
System-level challenges	Concerns about infection control		*I'd like NICU nurses and doctors to be more careful about disinfection, and I hope I can trust the hospital with having a reliable anti-infection guideline. There are many parents who haven't said any words, offensive or unpleasant to the ear … As a parent who left a baby to NICU professionals, we could not help but feel afraid the babies were disadvantaged in receiving care due to our negative words. Therefore, whenever I went to visit my baby in the NICU, I tried not to offend the caregivers. All of the nurses I met were kind, but regarding the NICU environment, I hope every hospital has clean and pleasant NICUs for preterm babies.* (P 203)
	Improving NICU facilities/equipment and rectifying staff shortages		*I want the staff to consider cleanliness and hygiene a little more. [omitted] I am her mother, and I put my preemie in the NICU… I could never complain to the nurses, or doctors; what if she were to be disliked by them because of me.* (P99)
			I often feel there is a shortage of medical staff working in the NICU. It may be or must be too hard for one nurse to care for several babies properly at once. I think it made it hard for her to meet me … and that's why I could hardly ask any important questions whenever I visited the hospital. Even when I just met the nurse at the end of the visitation, she was running out of time and had only a few seconds to answer my questions. I believe in their love and devotion to preemies, but it would be better if they have more time for each baby. (P30)
			I sincerely wish any hospitals other than the 'BIG 3' will provide reliable and safe facilities. If so, there would be many places where parents can leave preemies without fear and can count on NICU professionals. (P88)
			The physicians and nurses were very kind, friendly, but the hospital facilities and medical equipment seemed to be poor. (P228)

Note. NICU = neonatal intensive care unit.

shortage problems in NICUs. They recognized that these challenges could directly affect their babies' lives.

4-2) Improving NICU facilities/equipment and rectifying staff shortages

I often feel there is a shortage of medical staff working in the NICU. It may be or must be too hard for one nurse to care for several babies properly at once. (P30)

I sincerely wish any hospitals other than the "BIG 3" [The several "Big" hospitals dominate patient care in the Korean health system] will provide reliable and safe facilities. If so, there would be many places where parents can leave preemies without fear and can count on NICU professionals. (P88)

Discussion

This qualitative study examined mothers' perspectives on their experiences and unmet needs during their preterm or low-birthweight infants' NICU hospitalization. The narrative responses to the open-ended questions collected from the original multicentered survey were secondarily analyzed using thematic content analysis guided by the CIT method. Four synthesized themes related to their expressed experiences and unmet needs were finally aggregated from the initial 946 incidents and 110 keywords: one positive (satisfying) and three negative (unsatisfying) incidents were revealed.

The mothers revealed that their utmost need was for support from the NICU health-care providers related to the relationship with their infants. The need for supportive actions that lead to the development of consistent guidance on infant care and educational content and improvements in the unfavorable staffing levels was identified. In addition, mothers sought assurances regarding the quality of equipment or facilities and infection control management, although a limited, family-friendly environment emerged as the only positive experience in NICUs where they could feel welcome 24 hours a day and assured by their health-care providers.

First, this study found many mothers' unmet needs surrounding the desire for active interactions with their infants after the traumatic separation from the infants in the NICU. A growing body of research has identified that maternal engagement in all caregiving, mother–infant attachment, and the assurance of the close proximity and open access to their infant can positively influence infants' neurological, psychosocial, cognitive, and physical development [16,17,19]. Unfortunately, our findings suggested a discrepancy between actual practices and ideal practices based on the FCDC perspectives in Korean health facilities. Mothers believed or heard that kangaroo care and breastfeeding their infants born very early could promote maternal attachment to their infants. They felt a sense of ownership toward their infants from the experience of contact, which has been reported earlier by Choi and Lee [11]; however, in this study, less than 60.0% of mothers were allowed to breastfeed and less than 50.0% engaged in kangaroo care (skin-to-skin contact) with their infants. When mothers were not allowed to use kangaroo care without convincing reasons, their frustration increased, and some expressed increased feelings of guilt regarding their deprived maternal role. Mothers who feel detached from their maternal role are likely to see themselves as "NICU moms" or "part-time mothers" and to have problems with nurses over ownership and control [35]. The participants in this study reported that the traumatic experiences related to their early separation from their infants disrupted the attachment relationship, and they expressed a strong desire to participate in caregiving

in the NICU. Given that maternal attachment to a preterm infant is key to developing the maternal role after NICU discharge [9], interventions that support attachment and involve NICU families as vital partners in their infant's care are strongly recommended and should not be overlooked.

Although creating a partnership by encouraging ongoing bidirectional communication between the care team and the mothers is key to FCDC [18], mothers' perspectives of the empathetic communication skills of their health-care providers were generally unfavorable. Those who were sensitive to the NICU staff's words and actions tended to be ambivalent about their care team and expressed having negative feelings when hearing unwanted and hopeless information about their infants; however, they had a strong desire to be well informed and supported. Our results are consistent with previous studies that explored parental perceptions of the NICU experiences and found that NICU parents worldwide experienced an emotional rollercoaster [36] and mental health problems [37]. In other countries, the need for comprehensible and honest assurance and information were more important than support and comfort [13,38,39]; however, this qualitative study suggested that empathic concern and warmer, kind and comforting words even when delivering negative news might be preferable for mothers in South Korea. Interestingly, most mothers who gave birth to premature or low-birthweight children tended to call the babies "ireundungi"—a Korean word for refined (a premature baby who starts his/her life earlier as a fast starter created by the Dasomi Project, a Korean social enterprise)—rather than "misuka"—which implies a negative connotation related to social stigma regarding the preterm infant. Using the word "ireundungi" or the infant's name in a respectful tone and avoiding the word "misuka" might be effective when NICU staff are communicating with the emotionally vulnerable mothers, so as not to foster guilt. Thus, while every mother who gave birth to a preterm or high-risk infant might have similar experiences regardless of their cultural context, the strategies to support them should be tailored according to the families' specific cultural context.

Second, in the theme, "information and education-based support," participants described the lack of practical educational sessions and content to increase their readiness for motherhood and the inconsistent practices for caring preterm infants in the NICU as being unsatisfying experiences. There have been some previous studies regarding the informational and educational needs of Korean mothers. In a qualitative study of mothers' experiences regarding attachment toward their low-birthweight infants in a follow-up program, mothers identified that receiving limited information was a major barrier for forming attachments to their infants [11]. Knowledge of child development by the mothers of premature infants is a significant predictor for maternal confidence [40], while less knowledge on prematurity development than rearing and high educational interest in the development has been examined in a descriptive study in 2013 [41].

A partially improved knowledge gap regarding the unmet educational needs among the mothers in the NICU was found. The participants expressed childcare difficulties in their home because of the insufficient discharge program ($n = 33$) and their interests in specific areas, including the "maternal role" ($n = 50$), "breastfeeding" ($n = 18$), "rehabilitation" ($n = 12$), and "infant care" ($n = 9$) while their infants were hospitalized. Further studies are needed to examine the long-term benefits of a parenting education and training program to improve infants' developmental outcomes and maternal caregiving. Many online community portals have been developed for parents of preterm or low-birthweight babies with the purpose of sharing information and experiences, such as Naver Café and Daum Café in South Korea. Introducing mothers with peer support needs to relevant web pages and facilitating mentoring relationships as well as peer connections between the NICU graduate parents and those whose babies are newly admitted to the NICU is recommended for mothers' improved adaptation to motherhood.

Early interventions that provide parent education from NICU admission to discharge should be led by a specialized nurse and health-care professional in charge (or a certified lactation consultant who specializes in the clinical breastfeeding management) rather than nurses on duty who may vary owing to the shiftwork system to resolve the inconsistent infant care guidelines that were identified by mothers. All the NICU nurses in practice, no matter what hospitals they are working for, should be provided opportunities to take systematic training courses such as human lactation and breastfeeding, infant/childcare, discharge, and the importance of developmentally supportive care. It would be helpful from a long-term perspective to adopt a lecture series related to therapeutic parenting skills and development of prematurity given by a professor as a formal curriculum for nursing college students in a university. Development of the training courses for NICU staff nurses can promote their competence as mentors who can play a key role in providing emotional support and parental education during the transition to motherhood and the transition from the NICU to the home environment.

Some mothers' positive experiences included the supportive attitudes of health professionals and unlimited open access to their infants in a family-friendly NICU environment. It seems that the positive incidents (16.4%) were relatively fewer than the negative ones (83.6%) owing to the NICU culture in South Korea and the unmet need–focused questions of this study. Most domestic NICUs adopt a traditional open-bay NICU system with restricted privacy, and mother–nurse interactions are limited within the time period of visits allowed [8,10], while the quality of nurse–family interactions within a single-family room structure has been reported to be better than in an open-bay unit [42].

Participants expressed the need for support to cope with unfamiliar environmental stressors, such as medical equipment (e.g., ventilator, patient monitoring devices), altered maternal roles, and infants' physical appearance. Empathetic communication from care team members and a home-like environment that is tailored to the families' preferences can help reduce maternal stress and their adaptation to the traumatic NICU environment [25,36,43]. Mothers could feel comfortable depending on their health-care team when having conversations with and being guided by kind nurses. For inexperienced mothers, nurses can serve as facilitators, teachers, and mentors in a learning phase, when answering mothers' questions, sharing information, and guiding families in developing their caregiving abilities [16,18]. Furthermore, as a few mothers mentioned, 24-hour family involvement and an unrestricted open visiting policy should be considered. Despite the advantages (e.g., lower incidence of sepsis and higher rates of exclusive breastfeeding) of the single-family rooms compared with the open-bay units [44], there has been little interest in establishing an open visiting system [10] and a family-friendly environment and culture in Korean NICUs.

Finally, the mothers thought the restrictive policies regarding parental presence in the NICU might be attributed to system-level challenges of securing state-of-the-art facilities and equipment, qualitative and quantitative improvements of care support, and optimal nurse–patient ratios. The staffing problems included unfavorable patient–nurse ratios, feelings of being burden owing to

excessive overtime, and a relative excess of novice staff nurses with limited experience working with NICU families, which interfered with creating a culture that promoted a family-friendly environment. Korea's Ministry of Health and Welfare announced in July 2018 that NICUs would be supported to provide a stable treatment environment by ensuring an adequate nursing staff [45]. Currently, the South Korean standards for the nurse–infant ratio in the NICUs are higher than those in other countries (e.g., nurse-to-patient ratios; 1:3 for Japan, 1:2 for California in the US), with each staff nurse being in charge of 3.6 babies on average even in tertiary hospitals that are well known for their high standard of care [45]. Because the NICU is characterized by highly specialized and labor-intensive nurses, it is essential to secure sufficient manpower according to the increased number of occupied beds and to reduce the high turnover of nursing staff owing to high levels of stress and burden. This can be accomplished by retaining skilled health-care professionals and optimal nurse–patient ratios. Moreover, consistent, supportive care for a stable treatment environment and high-quality patient care from health providers may not be assured if there are obstacles to providing systematic education and training programs and unfavorable nurse-to-patient ratios [46].

There is an urgent need to secure an adequate NICU infrastructure (e.g., medical facilities or equipment, staffing levels) because it is vital to the prognosis and long-term outcomes of high-risk infants and their families. The current participants recognized the regional gaps across the South Korean hospitals in terms of the infrastructure and medical technology quality in neonatal care. Hence, critically ill infants who need neonatal intensive care treatment are concentrated in the major university hospitals around the country's capital. Maternal–fetal intensive care units, which were intended to provide comprehensive care for high-risk pregnant women and neonates, have been operating extensively in a wide variety of local sites in Korea since 2014. However, it is still necessary to improve the perception of families of high-risk infants regarding community medical resources through a public campaign and to establish substantial strategies for reducing technology gaps between the general hospitals in metropolitan and district regions. The ongoing policymaking process, discussions, and debates about these issues should be led by a panel of leaders in the clinical field (e.g., NICU staff members, health providers, unit managers), families with experiences in the NICU and caring for preterm children, and policymakers.

Concerning participants' concerns about infection control, this may be related to the timing of the survey—from November 2017 to January 2018—when four premature babies at Seoul's Ewha Womans University Medical Center in South Korea died from bacterial sepsis [47]. Although most health-care providers are familiar with infection control strategies, including hand washing and infection control, and offices in most leading hospitals regularly train and monitor the status of hygiene (e.g., practice rate of hand washing, nosocomial infection rate) in Korea, preterm infants in the NICU are vulnerable to infection owing to immature immune systems and thereby might have increased risk of infection while hospitalized. Moreover, children including newborns need a small dose of medication, which might increase risk of contamination during the preparation and administration of intravenous injections. The Korean government has announced a health insurance plan to strengthen compensation for aseptic intravenous medication procedures (e.g., total parenteral nutrition, anticancer agents, antibiotics), which will be used for patients in the NICUs, and a new guideline on pharmaceutical compounding of sterile injectable medicines has been released by the Korean Society of Health-System Pharmacists [45]. It is necessary to secure available pharmacy technicians who are responsible for the sterile compounding process and preparation of compounded sterile injectable products. Neonate-tailored injectable products with low doses (e.g., 50 ml lipid nutrition) should be designed and covered by health insurance.

This study may have limitations regarding generalizability, akin to all qualitative studies, as the sample here consisted of mothers of preterm and low-birthweight babies admitted to diverse NICUs located in different geographical locations (more than 49 institutions) in South Korea with varying levels of quality and infrastructure required for critical and supportive developmental care. The study was designed to focus on unmet, latent needs rather than the satisfying experiences to contribute to the identification of effective/ineffective and existing/absent FCDC practices. Therefore, the quoted findings may somewhat distort some aspects of the South Korean situation, depending on how individuals expressed and exaggerated their views of their experiences while in the NICU. This study focused on mothers' perspectives and needs during their infants' hospitalization because of the postpartum attachment focus in the original survey. Further qualitative studies using in-depth face-to-face interviews are needed to explore both mothers' and fathers' caring experiences and unmet needs during their infants' hospitalization. Despite difficulties recalling and recounting past incidents and actions, the participants might be given enough time for recollection in an anonymous context. The most important strength of this study includes its offer of anonymity and privacy to these emotionally and socially vulnerable mothers from different institutions as they participated in this research to explore positive and negative perspectives.

Conclusions

Our study highlights mothers' perceptions of their experiences during their preterm infants' NICU admissions and specific unmet needs in the Korean cultural context. There remains a discrepancy between actual practices and the ideal goal of FCDC in the NICUs. The findings provided an improved understanding of the barriers to creating a family-friendly NICU environment that is equipped with a 24-hour open visiting policy. Strict unit policies that limit parental visitation must be readjusted to ensure that the NICU families can have 24-hour access to their infants and participate in infant care. The greatest need is for relationship-based supports for interpersonal difficulties (e.g., ineffective communication with health providers, disrupted attachment relationship with the infant). Nurses should be attentive to mothers' emotions with empathic concern and warm words to help with their adaptation to the traumatic NICU environment. System-level challenges include building an infection-free environment and improving the quality of the infrastructures (e.g., NICU facilities, equipment, staff shortage). Finally, it is critical to develop systematic education guidelines on preterm infant care and to provide continuing training and education, which is customized for a variety of learners (e.g., from administration down to the cleaning staff) to improve care consistency. Nurses can be the best advocates for mothers to address their hidden unmet needs during their babies' hospitalization and can facilitate the reconstruction of the deprived maternal role and the mother–infant relationship. Unless the NICU staff are well supported, they will burn out, and the needs of both infants and their families will not be met.

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Conflicts of interest

None declared.

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