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Mothers' Experiences of Breastfeeding Premature Infants after Discharge from NICU; A Qualitative Study

KEYWORDS: Qualitative study, premature neonate, Breastfeeding, Mothers' experiences

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ABSTRACT *Background: One of the most challenging issues that mothers with premature infants face is the importance of breastfeeding and the ability to initiate and maintain it at the NICU (Neonatal Intensive Care Unit) and after discharge. Breastfeeding a premature infant requires certain skills that differ from a term neonate. Most mother with premature infants experience a new crisis after discharge and despite the confidence they had before discharge, they might not really know how to feed their infants. The aim of this qualitative study is to understand how a mother interprets her premature infant's behavior and understand the importance of such behavior through experience.*

Methods: We enrolled 14 women whose infants were admitted to NICUs of hospitals affiliated to Kurdistan University of Medical Sciences after obtaining their written informed consent. Data were collected mainly through semi-structured in-depth interviews. In this study, initial coding was done using the words of the participants and connotative codes (the researcher's interpretation of the mothers' speech). Meaningful units were extracted from the participants' speech in the form f initial codes. Then the researcher contemplated deeply on the data to find new insight. Therefore, the codes were reviewed several times and similar codes were put into the same category.

Results:Base d on findings yielded, themes emerged from experiences of mothers. The meaning of preterm infant breast feeding after discharge from NICU, was Mothers' worry about breastfeeding at home, interpreting the neonates feeding behavior and Adapting with the current situation.

Conclusion: This study provided insight into the effective factors on the mothers' experience of breastfeeding their premature infants and their coping strategies. Therefore, qualitative and quantitative interventions on training and following such mothers after discharge is of utmost important for the family integrity.

Introduction

Over time, parental relationships, cultural values and norms have changed. After agricultural and industrial revolutions, parenting and child sponsorship adapted with economical and cultural evolutions. This adaptation in turn influenced parenting behavior and feeding, implying that breastfeeding is a behavior dependent on biological and cultural processes (1).

On the other hand, the feeding behavior of a premature neonate is a developmental process which is a positive learning process gained through experience as well as a supportive process leading to the neonate's improved feeding ability from the mother's breast (2). This supportive context is further improved by skin-to-skin contact with the mother (3). The mother also shows how she helps her child maintain a stable sucking position. At the same time, the nurse stays with the mother to observe the mother and neonate's position and to communicate with them and identify their needs. According to the recommendations of the American Academy of Pediatricians, breastfeeding should begin as soon as the neonate is able to suck milk. The mother's milk is rich in essential nutrients and vitamins and guarantees an infant's growth and development better than any other substance (4). However, the important issue is the successful feeding ability of the premature neonates that should be mastered before discharge from NICU (4, 5). Feeding a premature infant requires a set of skills that differs from the abilities of a term neonate. The mothers of these infants should be able to interpret between signs of a hungry or full infant.

These neonates admitted to (NICUs) would be discharged before they reach the 38th gestational week if they can successfully suck milk and gain weight. The time after discharge is a transitional period, the neonate's growth and development continues, and the neonate's feeding ability and patterns will gradually evolve (6-8).

In the NICU, a specific emphasize is put on the duration of oral feeding of premature infants and most mothers are aware of this duration and allocating a longer time than usual worries them(9). Such compounds as, they learn to cooperate with their infant in attaining oral feeding skills and are discharged (10). In these units, oral feeding is initiated for premature neonates who were supposed to be in their 32-34 weeks of gestation. The time of initial feeding is often varied and depends on factors such as gestational age and severity of primary disease. (11& 12).

The post-discharge recovery, the neonate can gain experience regarding oral feeding skills and learn to coordinate between suckle feeding, swallowing, and breathing and try to meet their physiological needs by creating balance. Moreover, the mothers are also gaining insight into their child's condition and how to interpret and recognize signs of hunger, worry, and physiological stress. (10). Lack of knowledge feeding a premature infant and encouragement, and cooperation on the spouse's behalf, dependency of the neonates to specific devices, long NICU stay are among the limitations that delay breastfeeding (13). Most of mothers' experiences a new crisis after their infant has been discharged (14) and despite the self-esteem they had before discharge, they understand that they might not be able to correctly feed their infant. The feeding skills of premature neonates demand the mother's cognitive and observational behavior which includes thinking about frameworks and structures of the mother's performance.

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Although mothers of premature infants are trained on how to feed their infants in most NICUs in the country as well as in our Sanandaj city the supervision, monitoring, and application of this training after discharge and at home is still impaired. Moreover, few studies have been done on breastfeeding premature infants after discharge, especially on the mother's experience during this period. Therefore, we aimed to study and describe the experiences of mothers on feeding premature infants during the first week after discharge in a content-analysis qualitative study.

Importance of Study: Studies show that the mortality and morbidity rates of neonates who are breastfed is 20% lower than neonates who are fed with other feeding methods because breastfed infants are at a lower risk of contracting infections or suffering from other diseases (15). Breast milk is considered as the primary source of nutrition in neonates and is in fact the first vaccine the neonate receives. When an infant's immune system (especially that of a premature one) is not fully developed to defend the body against different pathogens, the infant receives important antibodies to fight against viruses and bacteria through breastfeeding (16).

Here, the main points that should be mentioned are the immunological benefits of breastfeeding in preventing infectious diseases, the higher mother-child intimacy, and a faster growth and developmental process (17). Moreover, family and spouse support as well as the nurses patience during the transitional phase from feeding with aiding devices to breastfeeding play a key role in the continuation of breastfeeding at home (18).

Subjects and Methods

In order to define the mothers' perception on breastfeeding, we used a qualitative approach and content analysis. In qualitative studies, the totality of human phenomena is studied and therefore, qualitative studies are the most suitable method to study human experiences such as hope, adaptation, attachment, etc (19). Content analysis is specialized method for processing scientific data. The aim of content analysis is to provide knowledge, new insight, and vision of the reality through a systematic categorization and is a guideline and a subjective interpretation of the content of written information (20). In this study, we used the goal-oriented sampling method.

We enrolled 14 women whose infants were admitted to NICUs of hospitals affiliated to Kurdistan University of Medical Sciences after obtaining their written informed consent. The inclusion criteria were tendency to participate, ability to communicate, and a post discharge period of 2-3 weeks. All participants gave their informed consent to participate in the study.

Data were collected mainly through semi-structured in-depth interviews. Moreover, the researcher referred to the medical records of the neonates and recorded the parents' phone numbers and addresses and asked their permission to visit them at home. Then, after obtaining the mothers written and oral consent, the researcher commenced the interview. All interviews were recorded and transcribed immediately after each interview. The interview started with a simple general question about the infant. In asking the questions, the aim of the study was considered and the interview ended with more specific questions. Each interview lasted for 45-60 minutes based on the mother's condition. The participants were reassured that their information would remain confidential and the tape recordings would be erased after data analysis. They were also informed that they could leave the study at any stage if they wished.

Data were analyzed using common content analysis methods. In this study, initial coding was done using the words of the participants and connotative codes (the researcher's interpretation of the mothers' speech). Meaningful units were extracted from the participants' speech in the form f initial codes (21). Then the researcher contemplated deeply on the data to find new insight. Therefore, the codes were reviewed several times and similar codes were put into the same category. Categorization was done by emerging similar codes and continuous review. Ultimately, narrated evidence was extracted from the data for each concept. One of the advantages of this approach is that the results would be directly obtained and extracted from the participants' speech or text data without opinion analysis (22).

To increase the accuracy and acceptability of the results, we used a combination of several methods such as in-depth interview, rechecking with the participants, and simultaneous analysis by the researcher. At least two meetings took place with each participant for data collection, and each participant was interviewed at least once. Daily notes were taken during data collection and the participants were surveyed to make sure the researcher had understood what the participants meant. Moreover, experts in the field of qualitative research analysis were consulted in order to increase the accuracy of data interpretation.

Findings

We included 14 mothers with ages ranging from 20-41 years with various educational levels. Codes were extracted from the interviews from which 12 categories and three themes were obtained. The extracted themes were the mothers' worry about breastfeeding at home, interpreting the infants' feeding habits, and adapting with the current situation.

A) Mothers' worry about breastfeeding at home: This theme was the first extracted theme. This theme consisted of codes such as the mother's lack of knowledge about the higher or lower volume of milk and eliminating some feeding periods, the mother's feelings and experiences about caring for the baby at home, mother's young age and inexperience, and the mother's inability to breastfeed in a suitable position.

With respect to as the mother's lack of knowledge about the higher or lower volume of milk, one of the mothers (No4) stated that: "*I really don't know how much I should feed my infant. When I'm breastfeeding, I sometimes feel he wants to keep eating, but I don't continue fearing he would bloat. I don't know whether I could increase the duration of feeding or not? My house is by far different from the NICU. At the hospital the mother was not in charge really, but at home, I have to decide and it's heavy responsibility.*"

Mother(No 1) stated: "*You know what my biggest worry is? It's when my baby can't swallow the milk sucks and would suffocate…and I wouldn't know what to do then.*"

The mothers of preterm neonates, who had stayed at the NICU during the hospitalization of their child, were constantly in contact with their child and had suitable opportunities for breastfeeding and prepared themselves for feeding at home. In this regard, mother 3 mentioned: *"I was sick myself and sometimes left my child and my mother was with the baby."*

Mother (No 2) whose preterm neonate was actually her first child stated: *"I can't hold my baby easily or even breast feed in a proper position. The nurses helped me and my baby at the hospital and held the baby so I could breastfeed better. Now I can't do everything alone and this worries me…My other worry is feeding in a crowd, especially when friends and relatives come round and I have to find somewhere to go and breastfeed."*

Another mother (No 5) said: *"If I was older and had other kids and was not this clumsy, I could have fed my baby better because I would have had some experience and would have heard about breastfeeding from others."*

Ultimately, mother 3 stated: *"It takes a long time to feed my*

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baby and to hold him correctly. I sometimes sweat so much that I prefer to put him on the mattress besides for some time and then try again. So I'm constantly thinking that he's hungry and doesn't suck milk and gain weight. I'm worried about him being hungry and not being fed well."

B) Interpreting the neonates feeding behavior: The second theme of this study was interpreting the infant's behavior during breastfeeding at home after discharge. In fact, this theme includes understanding and identifying the infant's readiness to be fed as well as recognizing the signs of hunger and fullness. Awareness of feeding also includes the mother's regulation of the infant's actions and behavior before feeding according to the neonate's level of consciousness and alertness. The sings of hunger and fullness included the mentioned statements of the mothers but several mothers described behavior that signaled the infant's readiness for feeding.

One of the mothers (No 11) exclaimed: *"My baby was always awake before feeding…She would open her eyes and was awake and I knew it was time to feed her."*

Mother (No 5) stated: *"The signs of readiness was so weak in my baby that I didn't know exactly what they meant and what my baby wanted."*

In this study, the infants' readiness for feeding was often described in the form of lip movements towards the nipple. Mother (No**8)** said: *"when I hug my baby and stick her cheek to my breast she searcher for my nipple with her lips."*

With respect to hunger, the mothers' explanations were clearer and the signs consisted of codes such as crying, weeping, and search reflection. Of course, other behavior such as finger sucking and making sounds while sucking. However, they claimed that identifying these signs was hard and frustrating.

Mother(No 4) said: *"I have to wake my baby for feeding and force him to eat…And this is very hard for me because he can't sleep and can't eat well."*

Mother (No10) mentioned:*"My baby moans during sucking…That why I am sometimes tempted to bottle feed him because I think he doesn't receive enough nutrients this way, and thinking that I have to feed him with formula worries me even more."*

Mother(No 3) also stated: "My child wakes up whenever she's hungry but falls asleep again before being fed and I often stimulate him by caressing, talking and massaging him… Then he wakes a little and I feed him."

Mother (No9) exclaimed: *"My baby searches for the feeding source when he gets hungry and I feed him and this makes me happy."*

The signs of hunger and fullness that were described by the mothers included lack of sucking, biting the nipple, drooping, falling asleep, vomiting, drooling, turning the head as a sign of fullness. Another mother (No 12) did not know when and under what conditions her infant stopped suckle feeding. While mother (No14) stated: *"I understand my baby is full when she brings up"*, and another mother (No 8) mentioned:*"My baby doesn't get tired when he's suckle feeding and sucks well."* Two other mothers (No 11 and 7) said: "*My baby brings up the milk through his nose when he's full*" and "*after she's full she turns over and falls asleep*", respectively.

C) Adapting with the current situation: The codes extracted from this theme were the infant's suckle feeding skill, meeting the infant's nutritional needs, understanding the successful interaction between the neonate's feeding and other activities and household chores (such as routine shopping, cooking, washing clothes, and caring for other children), and also, managing anxiety and cultural issues related to breastfeeding.

Mother (No13) said: "*When we came home from the NICU), breastfeeding took most of my time and I couldn't attend to my chores, children, and husband. But now I successfully juggle feeding my baby (with much difficulty) and doing my chores somehow."*

Mother 6 explained: *"at first my baby would shut her mouth firmly and resisted being fed and I had to force her mouth open with my fingers. Now she sucks easily."*

Other mothers (No **8** and 13) explained that their infants did not need chin support, rest for breathing, or in general feeding balance (sucking, swallowing, and breathing). In contrast, several mothers reported problems such as suffocation, mouth fullness, and lack of breathing. In this regard, mother(No 14) said: *"my baby breathed heavily and needed to take his breath often between sucking…But now he's better. Now my daughter helps me when I'm breastfeeding."*

One of the other codes of adapting with the feeding process was anxiety and stress management. In this regard, one of the mothers (No13) mentioned: "*When I was initially discharged from the hospital, I constantly got frustrated with breastfeeding…and my husband would tell me to bottle feed or get help from another person to feed our child if I couldn't handle breastfeeding. I would tell him we couldn't afford to bottle feed with formula and that he had better help so that I could cope with this situation."*

Discussion

We found that the mothers' experiences of feeding their premature infants included their worries about their infant's feeding, interpreting the neonate's feeding behavior, and the mother's adaptation with breastfeeding. The mother's worry about the infant's feeding ability included subcategories such as uncertainties, lack of knowledge, the mother's inexperience, young age, clumsiness, problems in holding the infant, and problems in regulating the volume of milk. Young mothers and those who had become a mother for the first time and had give birth to a premature infant should become capable of breastfeeding at home and might have little experience about dealing and feeding their infant. In this regard, other researchers found that becoming a mother and feeding a premature infant is a mutual bond. However, they found that this was interpreted as losing the infant, emotional chaos, and separation. At the beginning of breastfeeding, these mothers felt out of control, powerless, confused, emotionally unstable, afraid, guilty, and insecure (23).

The mother's anxiety and worry about the volume of milk her premature infant receives is a natural reaction. In a study by Kavanaugh and colleagues,1995 on the mothers' concerns on breastfeeding after discharge, the researchers found that these concerns included whether the infant received enough amounts of milk and could compensate feeding, concerns with tools used for feeding the infants, and the mothers' identified strategies for reducing their concerns (24). Their findings are consistent with our study.

We found that one of the mothers other concern was shame and embarrassment from breastfeeding in a crowd. In this regard, other researchers have stated that breastfeeding might be considered as panache in some cultures; therefore, many mothers try to seek a private quiet place to maintain their privacy and be able to breastfeed without stress (25).

The infants' feeding manner was the second theme extracted from this study and included the infants' prolonged hospital admission, not drinking well, lack of sufficient sucking, not being able to suck milk. Several studies have been done on the afflictions experience by mothers of premature infants in

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breastfeeding at home after a prolonged hospital stay. In an ethnographic study, Hurst found that the biggest sources of stress among these mothers were interruptions in the milk flow because of inadequate sucking or swallowing, fear of the infant's survival with respect to the infant's inability to feed (26). On the other hand, for families that longed for a child with a facial complexion reflective of their own to be able to nurture and most importantly be feed with breast milk during pregnancy, the birth of a premature infant that cannot be breastfed is considered as a crisis (27). Mothers are often happy when their infant is discharged, but experience anxiety and depression when they have to take the full responsibility of caring for their infant. Be that as it may, the adaptive strategies vary depending on the mother's personality (28). The mothers of preterm infants have more concerns about the infant's attachment, health, and growth compared to mothers of term neonates (29).

In our study, interpreting the infants' feeding manner included the infant's readiness to be fed and signs of hunger and fullness. In fact, recognizing the infant's readiness to be fed was based on the mother's consideration of the infant's behavior before feeding, the infant's awareness and alertness, and moving the lips towards the nipple (30). Ross & Brown 2002, suggested that the home environment should be supportive of the infant and the parents should be trained on how to meet the infant's nutritional needs. Also, the information provided to the family should be coordinated based on the infant sleep/awake patterns and mood (31). In another study, the researchers also believed that it should be a main principle to train and inform mothers about breastfeeding before discharge. In the mentioned study, the mothers received theoretical and practical training frequently. The researchers also added that the NICUs did not consider enough space and trained personnel for training such mothers (32).

With respect to understanding and interpreting the signs of hunger and fullness, we found that the mothers were capable of identifying these signs and they did not consider signs such as over drinking and inability to coordinate sucking, swallowing, and breathing, and bringing milk up through the nose problematic. Moreover, what the mother perceives might not be indicative of what is really happening. Some suggestions have been presented for mothers in this regard. Therefore, these signs could be trained by giving scenarios of realities of humans life (33).

The adaptation with the feeding process experienced by the mothers was mostly related to cultural and physical problems. Moreover, the birth of a premature infant puts an excess financial burden on families. On the other hand, separations from the infant and cultural limitations of breastfeeding are factors that interfere with the mother-child attachment process, suitable feeding, and the growth and development of the neonate. Brand and co-workers believe that paying special attention to ethnic issues in breastfeeding as well as cultural issues are of utmost importance.

A study done in Sweden showed that mother-child separation during the first weeks of life exerted severe mental pressure on the mother and could interfere with the breastfeeding process, even if the infant is not at risk of severe health problems (34). However, elimination of breast feeding creates anxiety and reduces self-esteem (35) and creates a bad feeling of "motherhood" (33).

With respect to the mothers' adaptation with breastfeeding, we found that the subcategories of this theme were increasing the infant's suckle feeding skills, meeting the infant's nutritional needs, and creating balance between breastfeeding and other household chores, anxiety, and cultural issues. In this study the mothers stated that their infant's condition is improving and they can manage the feeding process, coordinate between breathing and sucking swallowing milk. They were capable of managing breastfeeding and other tasks by using specific strategies and with the help of their spouse and other children. As mentioned in a previous study, the relationships between family members and their support are among the important factors for adaptation and creating balance (31).

After discharge from hospital, mothers create balance between their current condition and their motherhood role and persevere in handling household responsibilities; which is indicative of the mothers' awareness of her responsibilities. Mother generally have more self-esteem when they provide their child's needs themselves. They feel that they will become more familiar with their infant's behavior and believe that they can independently nurture their child.

This study also had some limitations. Since it was a qualitative study and it such studies data collection stops when data is saturated and therefore, the sample size is limited. Hence, the findings cannot be generalized to other mothers with premature infants. Also, since the infants had a good general health condition after and were able to suckle feed after discharge, the results cannot be generalized to the mothers of infants that were not discharged.

Conclusion

This study provided insight into the effective factors on the mothers' experience of breastfeeding their premature infants and their coping strategies. As a whole, these strategies provides a common language and concrete feeding plan orienting feeding to the quality of the mothers' experiences and long-term feeding success. Therefore, qualitative and quantitative interventions on training and following such mothers after discharge are of utmost important for the family integrity. By building common goals for feeding, a common knowledge base and a common skill set for mothers, the breast feeding supports the infant's physical growth.

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