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Challenges of Mothers to Care for Premature Infants at Home: A Qualitative Study

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Abstract

Background: After hospital discharge, mothers with premature infants are responsible to care for the infant independently, which makes them face challenges.

Aim: The present study was performed with aim to explain the care challenges of mothers with premature babies at home.

Method: This qualitative content analysis approach study was conducted in Mashhad city. For this purpose, 15 mothers whose babies had a history of NICU hospitalization were selected by purposive sampling. Semi-structured in-depth qualitative interviews were conducted with the participants until data saturation. Lincoln and Guba criteria were used to ensure trustworthiness of the data. The data from the interviews were analyzed in MAX-QD 10 software with Granheim and Lundman's approach.

Results: By analyzing 435 primary codes, finally 12 subcategories and 4 main categories were extracted. The main four themes included infant barriers to motherhood, uncertainty in self-efficacy, support for mother's empowerment, and resilience strategies.

Implications for Practice: The challenges that mothers face are the result of their feeling of inadequacy to manage the special conditions of their baby at home. Therefore, the opportunity for mothers to practice and learn skills during NICU hospitalization and follow up the neonate's condition after discharge can facilitate the process of care at home for mothers.

Keywords: Content analysis, Discharge, Neonatal Intensive Care Unit, Premature, Qualitative research

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Introduction

Premature babies allocate about 11% of live births around the world and 10% of live births in Iran (1,2). Preterm birth is the main cause of infant mortality in developed countries. In recent years, the rate of admission of newborns to neonatal intensive care units (NICU) has grown significantly. The statistics showed the acceptance rate in these departments has increased by 37% from 2008 to 2018 (3). Hospitalization of a premature baby is necessary to reduce complications in adulthood, but it imposes a stressful situation on the mother. In fact, care process in the NICU, such as feeding tube, oxygen therapy, and careful monitoring of the baby's weight disrupt the mother's expectations (4,5). Mothers have to adapt to the conditions of the NICU environment and endure the separation from their babies; therefore, they experience a considerable stress. In addition to reducing mothers' participation in newborn care, this condition forms a weak bond by creating a separation between mother and baby (5,6). The experience of mothers during their newborn's stay in the NICU has been well documented in the literature and has enlightened our understanding of the shock and grief that mothers face during this period (7, 8) But after discharge from NICU, the responsibility of baby medical care falls on the parents. Sometimes babies are discharged with special treatment measures such as oxygen therapy, feeding tube or special drugs, which must be continued by the parents at home (9). Discharge from the hospital is an important and risky transition period for parents (10,11). In fact, parents have to take responsibility for taking care of babies alone, which causes stress, anxiety, and feelings of confusion (5). In their study, Hariati et al. (2021) found that Indonesian mothers did not have enough self-confidence to take care of their babies in the first days after discharge from the hospital, but they find this confidence at the end of the first month (12). It seems that mothers experience different challenges in the second months after discharge. Breivold (2019) et al. found that one of the challenges of mothers of preterm babies after the first month of discharge is breastfeeding; In fact, interviews with mothers in the second and third months after discharge identified different challenges compared to the first month (13). In developing countries such as Russia, mothers believe that the information and training they received during their infants' hospital was useful only in the first month after discharge, and they are worried about their baby's care needs in the coming months (14). While in developed countries, there are written support systems for mothers after discharge from hospitals, but in African and Asian countries where the number of premature births is high, there is no support systems and no comprehensive studies have been published in this regard.

In fact, there is currently no coherent body of knowledge on this topic, and therefore no standards of practice, or not developed enough to provide evidence-based care guidelines for educating parents about what and how to best care for their baby (15). On the other hand, Boykova (2016) in a study in this field found that there are several contradictions in these studies; For example, the role of support groups such as family has been introduced from a source of support to a different and even contradictory source of stress (14), so it is suggested to conduct studies with a qualitative approach in various societies with different income levels in order to better conceptualize and clarify the issue (13). In fact, qualitative approach is a method which can help to comprehensively understand phenomena in their context without the limitations of quantitative research. Qualitative research is a strong and completely systematic research for understanding and studying social structures and processes, and it clarifies the hidden components of human behavior according to the conditions (14). Therefore, the present study was conducted with aim to explain the care challenges of mothers of premature babies in the second months after discharge from NICU by using the content analysis approach.

Methods

This study used conventional content analysis approach which is a suitable choice for examining the daily experiences of human emotions and feelings (16). The present study was reported according to the Consolidated Criteria for Reporting Qualitative Studies (17).The participants included 15 mothers with premature babies who were selected through purposive sampling. The mothers who more than a month has passed since their discharge from the hospital were selected. Satisfaction with sharing experiences was considered among their other characteristics. Maximum diversity (age, gender, place of residence, education and marital status) was used to select participants. Sampling was done among mothers whose babies were hospitalized in the NICU of Imam Reza and Ghaem hospitals in the

northeast of Iran. The first author who was in the NICU as a trainer of nursing students and had skill in qualitative research cconducted the interviews.

The first author explained the objectives of the study to the participants; So that none of the mothers refused to participate in the interview. The face-to-face, in-depth and semi-structured interviews by field notes were done. Each session lasted about 65-105 minutes. Also, to get more information, two participants were invited to the second round of interviews. The time and place of the interviews were chosen by the participants. They were interviewed separately to minimize the interaction effects. The first author conducted initial interviews with two mothers to develop the themes presented in the interview guide. Finally, these two interviews were analyzed after completion. The interviews started with the general question "Why your baby was born early?" and gradually focused on specific issues with questions such as "What did you do and how did you feel when you heard that your baby is discharged from the NICU?" Or "Tell me about your life after discharge" or "Tell me about a day in your baby's life after discharge?". If necessary, ask probing questions were used such as "Can you explain more" "What makes you feel this way?". More probing questions such as "Please elaborate on that," "What's on your mind?" were asked if needed. In each session, the interview ended with two questions: "Do you have anything else to say?" or "Do you have a question for me?". Sampling continued until reaching data saturation (18).

In this study, Granheim and Lundman qualitative content analysis method (19) was used to analyze the handwritten text of all participants. All textual data were read several times by the first and second researcher to obtain a complete understanding of the issue. Next, the text related to the purpose of the study was extracted and grouped into meaningful units. Each unit was coded and then the codes were compared based on differences and similarities and categorized into subcategories. Then, the subcategories were classified into broader categories that constituted the manifest content. Finally, the categories were linked by their underlying meaning and grouped into themes. During the analysis process, two researchers (first and second) independently performed each step. Differences between the two researchers were identified and discussed until agreement was reached. Handwritten notes were taken to facilitate conceptual comparison. The MAXQDA10 software was used during the coding process.

Four methods (credibility, confirmability, transferability, and dependability) were used to ensure the reliability of the data. To ensure credibility, the interview text and the extracted codes were presented to the participants to confirm their credibility. Also, the full texts of all the interviews along with coding and primary classes were presented to two experts in qualitative studies to confirm their credibility. Moreover, in order to increase the credibility of the findings, the researcher used reflexivity to ensure the transparency and quality of qualitative research. In order to provide confirmability, the steps of conducting the study from data collection, analysis and formation of classes and themes have been presented in detail. Also, the process of the work was given to two experts in qualitative studies to confirm the accuracy of the research. In order to ensure transferability, the researchers provided a clear description of the context, selection and characteristics of the participants, data collection and analysis process so that the reader can judge the applicability of the findings in other situations. Also, an attempt was made to increase transferability by presenting rich and detailed findings with appropriate quotations. In order to provide dependability, continuous comparative analysis of data and analysis of negative cases were used.

Ethical Consideration

The sudy was approved by the ethics committee of Mashhad University of Medical Sciences (ethical code: IR.MUMS.NURSE.REC.1399.036). The researcher collected data after receiving permission and presenting a letter of introduction to the officials of the research field. It should be noted that the place of the interview was determined by the participants. Before interviewing the participants, the objectives of the research and their voluntary participation and voice recording were first explained and they were asked to sign the informed consent form.

Results

The participants in this study included 15 mothers who had the experience of admitting a newborn in the neonatal intensive care unit. The age range of the mothers was 18 to 36 years, 5 mothers had educational level less than diploma and others had more than diploma. The mothers' gestational

age was between 28 and 33 weeks, the average duration of the newborn's hospitalization in the intensive care unit was 24 days. After analyzing the rich and deep descriptions of the participants, 435 primary codes were extracted. After reviewing several times, the codes were summarized and classified based on similarity and appropriateness. Through analysis, comparison and inner meaning, main theme was "A chain of I can and I can't", which has been abstracted into 4 categories and 12 subcategories. The first category was “Barriers to motherhood”, with three subcategories, including: Infant's physical appearance, Breastfeeding problems and Fear of harming the baby. The second category was “Uncertainty in self-efficacy” with four subcategories, including: Hypersensitivity to infant symptoms, Inability to distinguish between low-risk and high risk symptoms, not knowing the meaning of infant behavior, and Inability to treat the child's symptoms. There was another category “Support for empowering the mothers” with two subcategories, including: Receive psychological support from peers and Informational support of medical staff. The last category was” Resilience strategies” which had three subcategories, including: Influenced by religious beliefs, Imagination for the baby's future and Improving the growth process of the baby (Table 1).

Table 1. Categories and subcategories of care challenges in mothers of NICU admitted newborns

Theme	Category	Subcategory
A chain of I can and I can't	Barriers to motherhood	Infant's physical appearance
		Breastfeeding problems
		Fear of harming the baby
	Uncertainty in self-efficacy	Hypersensitivity to infant symptoms
		Inability to distinguish between low-risk and high-risk symptoms
		Not knowing the meaning of infant behavior
		Inability to treat the child's symptoms
	Support for empowering the mothers	Receive psychological support from peers
		Informational support of medical staff
	Resilience strategies	Influenced by religious beliefs
		Imagination for the baby's future
		Improving the growth process of the baby

The theme extracted in this study was 'A chain of I can and I can't". This theme reflects the doubts of mothers regarding abilities to care for their infants; in fact, they experience uncertainty about their capabilities to manage the conditions of their premature infants when confronted with the challenges and difficulties of caregiving.

Barriers to motherhood

This category represents the distortion of interactions between mother and premature baby, which limits the opportunity for the formation of attachment between them. Mothers believe that the small size of the baby and limited connections with the baby at the time of discharge, such as feeding tubes, are the obstacles for mothers to communicate with the baby. In fact, the fear of harming the baby due to its different physical appearance causes stress in mothers, so they try to limit their physical contact with the baby in order to deal with this stress, and as a result, the physical contact between the mother and the baby is reduced. In this regard, one of the mothers said:

"…My child was very small, his appearance was terrible, I tried not to hug him too much and not to move him so that he would not get hurt" (Participant No. 5)

Breastfeeding is a golden opportunity for mother-baby communication in full-term newborns. Problems arising from breastfeeding, such as the baby's weak jaw for feeding, aspiration during breastfeeding, the need to use a tube for feeding and consuming formula reduce the opportunity for communication between mother and premature baby. In fact, with the occurrence of these problems, mothers felt that they lacked enough self-confidence to breastfeed their babies. In this regard, one of the mothers said:

"…His jaw was weak, he could not empty the breast and feed well, that's why my milk dried up, and so I feed him with formula. I always wanted my baby to drink my own milk because nothing can replace mother's milk. I always say that the problems of the baby's prematurity caused that I couldn't find the feeling of being a mother." (Participant No. 3)

Uncertainty in self-efficacy

This category represents mothers' lack of belief in their abilities to take care of a premature baby with unique physical characteristics. In fact, mothers believe that despite the training provided to them and observing the type of care and treatment during NICU stay, they are still unable to take care of their babies at home. Mothers' inability to distinguish low-risk and high-risk symptoms and inability to treat symptoms has made mothers doubt about their ability to take care of the baby. The mothers believe that following the discharge and accepting the responsibility of the baby care alone caused them to show excessive sensitivity to the symptoms of the baby. The symptoms which are normal in a full-term baby are considered as a dangerous sign by these mothers, so they cannot perform effectively in controlling and managing the baby. In this regard, one of the participants expressed her experience:

"…Once, while feeding, the baby became lethargic and black, I couldn't do anything; after taking him to the hospital, the nurse gave him oxygen and he got better. The nurse said it was nothing, just because he drank too much milk, it jumped in his throat. I was very confused at that moment. I felt that the problem was very serious and there was nothing I could do". (Participant No. 8)

Support for empowering the mother

This category represents empowering the mother to take care of the baby after interacting with the medical staff and other people supporting the mother. In fact, the mother of premature baby is supported when she is hospitalized in the NICU, which includes not only the family and relatives of the mother and the baby, but also the medical staff and other mothers who had NICU admitted babies. Medical staff try to help mothers overcome their fears by providing information and answering their questions. One of the participants said in this regard:

"…In the first days, I was worried about my baby because he was premature and had to breathe with oxygen; I was not afraid because in the hospital, they had taught me everything to take care of my baby, for example, they told me how to deal with the baby's problems" (Participant No. 2)

Mothers with premature babies believe that the baby's grandmothers cannot help in taking care of the premature baby, but other mothers who have experienced similar situations can provide psychological support foe these mothers, help them psychologically to overcome their fears and empower them to take care of the baby. In this regard, one of the mothers said:

"…I think mothers with premature babies experience more stress than those with normal children; for example, I get annoyed and upset when I compare my child with normal children, but I feel better when I compare with children similar to him. That's why mothers with similar conditions of babies' can better understand and support each other." (Participant No. 4)

Resilience strategies

This category represents mothers' positive reinforcements that lead to mother's resilience against her concerns for the baby. Religious belief is one of the most frequent positive reinforcers among mothers with premature babies. In fact, believing in God's superior power makes mothers protect themselves from their worries for the future of the baby and consider the hope of a bright future as the cause of God's favor for the baby. In this regard, one of the mothers said:

"…When I think about the condition of my child, I say that it was God's destiny that the child born at this time. God always wants the best of events for his servants." (Participant No. 6)

Some mothers hope for a bright future by observing the Improving in the growth process of the baby and in fact, it made the mother resilient in the face of problems. Another strategy of mothers to be resilient against newborn problems is to fantasize about the child's future. In this regard, one of the mothers expressed:

"…When he was just born, he had to breathe with a machine, I thought he was going to die, this child wouldn't survive. But to deal with these thoughts, I always thought of him growing up and going to school, and I felt better." (Participant No. 7).

Discussion

The present study explained the challenges of mothers with premature babies to care them at home. The present study indicate the physical conditions of premature babies and their special care needs and the special care challenges for mothers who try to overcome their fears by using different approaches. After the discharge form hospital, they still haven't reached the necessary stability to take care of their baby. In fact, they evaluate their abilities as sufficient and insufficient in a back-and-forth process. The results of the present study indicate that the condition of the premature baby and mother's fears after discharge from the hospital are considered as the obstacles to create a safe attachment between mother and baby. In line with the current study, Yang et al. (2019) also found that the connections with the premature baby and the complicated conditions of the baby after hospitalization are the obstacles to the communication between mother and baby to the point where these mothers deny their maternal role (20). Indonesian mothers also stated that the physical condition of the baby, such as the small size, causes psychological stress in the parents, which has become an obstacle for them to fulfill their parental role (12).

As the results of the present study showed, breastfeeding is disturbed in premature babies. Along with the present study, Palmer et al. (2019) in the follow-up of mothers one year after discharge from the hospital found that mothers are facing serious challenges to breastfeed these babies, and they must find unique solutions according to their own baby's conditions to promote breastfeeding (21). Mother-baby attachment starts early in pregnancy and is essential for the baby's development in the future (22). It seems that mothers consider the relationship with the baby and taking care of it after birth as a way to form this attachment, but the physical conditions of the premature baby disrupts the process.

In the present study, mothers believed that they do not have the necessary abilities to manage the conditions of premature babies. It has been emphasized in the literature that mothers need time to adapt to the conditions of their premature baby so that they can take care of a premature baby as a new situation, which may vary from a few days to a few weeks (23). Along with the current study, Garfield et al.'s (2014) study also found that parents considered uncertainty in transferring the baby to the home. They believed that facing the baby's symptoms, they are worried about doing a wrong intervention that would endanger the baby's life (24). Contrary to the present study, in the study of Breviold et al. (2019), mothers coped well with the transfer of their premature baby from the hospital to home and were able to manage the baby's condition (13). It seems that these differences are affected by the professional support of mothers. In developed countries such as the United States, there is a written program for the follow-up of premature babies after discharge from the hospital, and trained nurses visit the baby at home and provide training based on the needs of mother and baby; while in the current study, the follow-ups and training of the treatment staff were limited to the time when the baby was admitted to the hospital or periodic visits of the baby to the doctor's office. Therefore, the mother's responsibilities of the baby at home without access to a trained support system such as a medical staff leads to a feeling of incompetence in the mother.

In the current study, one of the resources to improve the ability of mothers to take care of a premature baby at home was the informational support provided by the medical staff, which helped mothers to take care of the baby. Along with the current study, Hariati et al. (2021) also found that Indonesian mothers felt competent in care due to the training given in the NICU to care for the baby and considered it as the beginning of independent motherhood (12). Although the information provided by the staff is considered as a source for empowering mothers, in the present study, receiving information and psychological support from peer mothers who had similar condition of premature babies was also helpful. In consistent with the present study, Rossman et al. (2015) identified the most effective support provided to mothers with premature babies as informational and emotional support provided by peers (25). The noteworthy point in this study is that, unlike the studies conducted in Asian countries, in which mothers identify receiving support from their mothers and other women in the family as an important source of care for the baby (12, 26), this type of support did not play a role in the present study. These differences appear to be due to the unique needs of these infants. In fact, a premature baby which requires unique experience and knowledge for care, and the shared experiences of other family members do not meet the needs of these babies, so only people who have similar conditions or sufficient knowledge have can help in taking care of these babies.

In the present study, the most important coping strategies for mothers to care for premature baby at home were religious approaches. While in the literature, the most important approaches of mothers

were social support and mental adaptations (24). Folkman believes that a person first identifies the meaning of a stressor and then evaluates its threat or challenge. Following this interpretation, the person determines whether the available resources and options are sufficient to face the situation or not (27). Therefore, it seems that the differences in the coping strategies arise from the religious background of the society. In religious countries like Iran, people try to get hope and peace with the help of God to deal with critical and stressful situations. They connect themselves to the infinite source of power to benefit from the support of this source of power. This study, like any other studies, had some limitations. The most important limitation was the lack of access to the fathers of these babies to identify the challenges from their point of view. On the other hand, the information of mothers hospitalized in one of the big hospitals in the east of the country was used to collect data. Some of the participants were outside the city and in neighboring cities, which the researchers were limited to access them. It is suggested that in future studies, the challenges of other family members and people involved in the care of these babies should be taken into consideration in order to reach a comprehensive perspective for a care plan for this group of mothers.

Implications for practice

This study contributes to the nurses in knowledge of caring for mothers with babies with a history of hospitalization in the NICU. In fact, the results of this study can help in designing comprehensive educational programs to improve the knowledge and skills of mothers by nurses to prepare these mothers for discharge from the neonatal unit and improve the quality of care for these infants. On the other hand, providing these trainings and preparing mothers according to the challenges they experience at home can be helpful in improving the competencies of mothers and reducing their fears and worries regarding the care of premature babies.

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Conflicts of interest

The authors declared no conflict of interest.

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Authors' Contributions

Naghmeh Razaghi and Elahe Ghayebie Motlagh: Conception and designing, Zahra kariznoee: Acquisition of data, Elahe Ghayebie Motlagh: Analysis and interpretation of data and drafting the article. All authors have agreed final version of manuscript.

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