

# Mothers' Challenges after Infants' Discharge from Neonatal Intensive Care Unit: A Qualitative Study

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## ABSTRACT

**Background:** Mothers with premature infants face certain challenges such as uncertainty on how to deal with their infant's condition and care for it after discharge from neonatal intensive care unit (NICU).

**Methods:** A qualitative design was used to explain mothers' challenges after their infant's discharge from NICUs in Isfahan, Iran, 2015. Purposive sampling was adopted to interview the mothers who could provide us information about the challenges after their infant's discharge. Data collection was performed by interviewing mothers. Data saturation was reached after conducting 23 in-depth, semi-structured interviews. All the data was analyzed by qualitative content analysis.

**Results:** Four themes and nine categories were identified. The themes were incompetence in breastfeeding, dependence on hospital and nurses, feeding tube as a reason for stress, and constantly worried mothers.

**Conclusion:** Mothers have difficulty in meeting their infants' basic needs after discharge. Supporting these mothers can enable them promote their infant's health.

**Keywords:** Challenges, Discharge, Home care, Mother's, NICU, Qualitative study

## Introduction

Birth of an infant causes critical conditions for families and healthcare systems, and birth of a premature infant exacerbates the situation (1). Many of the problems of premature infants are associated with inadequate compatibility with the extrauterine environment (2). Therefore, these infants should stay in neonatal intensive care unit (NICU) to survive (3). Approximately 9.61% of births worldwide occur before the 37th week of gestation (4).

Annually, four million infants are born in the USA, 12.5% of whom are premature. Iran was reported to have a high rate of preterm delivery (5). An investigation conducted in a city of Iran showed that over half of the hospitalized infants were born premature (6).

Certain complications, such as behavioral, motor, and cognitive disorders, may be observed in premature infants and persist throughout adolescence and even adulthood. It is necessary to hospitalize premature infants in NICU to reduce

these complications, which can put families, especially mothers, under stressful conditions (7). Therefore, one of the best and most efficient approaches to prevent adverse effects due to infants' hospitalization is engaging parents in their infant's care (8). This promotes parents' ability to facilitate the development of their infant during hospital stay and after discharge and reduces the duration of hospitalization. Long-term separation and adaptation to NICU are two tensions that the parents with premature infants have to deal with. These tensions make parents request for their infant's discharge. However, as they take the responsibility to care for their infant, they may develop depression and anxiety (9). Therefore, inattention to mothers as the most early partner in caring for the infants causes anxiety and worry in them, which may affect the quality of care and the process of development and growth in the infant (10).

Uncertainty about infant's condition and the

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need for knowledge about neonatal care are some of the problems of mothers with premature infants (11). A study with the aim of participating parents in life-and-death decisions concerning their very premature and/or critically-ill infants in NICUs found that these mothers were unable to make decisions and uncertain about how to care for their infant after discharge because of having no relevant knowledge (12). Although parents are expected to celebrate the infant's arrival home, they experience stress and anxiety (13).

Mothers may spend many hours caring for their infant, and they are likely to do so through trial and error and practicing care activities because of having stress and anxiety (12). A study by Griffen demonstrated that premature infants' transfer from hospital to home intensified parents' stress for caring for their infant. Certain factors such as experience of caring for an infant alone and struggling to cope with a new role confirm the existence of stress in mothers after discharge (14).

Mothers' lack of knowledge on how to care for their infant and discharging infants without consideration of their needs may cause great levels of anxiety and worry for mothers, the most significant caregivers of the infants, which can affect quality of life of infants (10).

Since the studies conducted in Iran have focused mainly on problems of parents with preterm infants in NICUs, and parents have a plethora of unanswered questions about how to care for their infant after discharge, qualitative studies should be conducted to comprehensively investigate the relevant challenges in Iranian culture. The aim of this qualitative study was to investigate the challenges that mothers encounter after their infants' discharge to gain comprehensive and in-depth knowledge on this issue.

## Methods

This study was conducted to investigate mothers' challenges after their infant's discharge using qualitative content analysis. For this purpose, the relevant approvals were obtained from the Research and Ethics Committee of Isfahan University of Medical Sciences. Besides that, a letter of introduction was presented to the officials of Al-Zahra and Shahid Beheshti hospitals of Isfahan and their consent was attained to conduct the study. In total, 23 mothers were enrolled in this study in 2015.

The inclusion criteria for the mothers were 1) willingness to participate in the study, 2) gestational age of at least 27 weeks, and 3) NICU

admission for at least five days. The data was gathered through in-depth and semi-structured interviews with mothers. The duration of each interview session was 1-2 hours. For this purpose, the researcher was always present in the NICU to interview the mothers before their infant's discharge by physician's order.

According to the researcher's experience, many mothers with their preterm infant admitted to NICU insist that their infant stay in NICU for a longer period of time. Therefore, it is essential to interview these mothers to understand their challenges at discharge. In addition, since most challenges are encountered after discharge, the researcher presented to neonatal clinic and interviewed the mothers who referred to the clinic for their infants' examination of growth and development after discharge and the mothers whose infants were readmitted to the NICU few days after discharge.

Purposive sampling was adopted to interview the mothers who could provide us information regarding the challenges they faced after their infant's discharge. The interviews were continued until reaching data saturation and the statements were reiterated, such that no new codes were obtained from the last three interview sessions. The interview questions were as follows: *How do you spend the days after discharge? And how was the condition of your infant after discharge?*

Analysis of the data was carried out shortly after their generation by conventional content analysis. Conventional content analysis was used to subjectively interpret the content of the textual data. In the first phase, the researcher read the whole text to familiarize with the data. The researcher was immersed into the data to gain the ideas of the content, and wrote down the drawn data from interviews with frequent review of the data. Secondly, the text was read line by line, and the phrases or words related to the concepts of interest were underlined.

After the extracting the basic codes, the conceptually similar codes were generated. Then, they were assigned to a single cluster and semantically related clusters were assigned to a class. Then, similar classes were consolidated. The credibility, dependability, fittingness, and conformability are the considered criteria of scientific rigor in qualitative research (15). One of the best approaches to increase the reliability of the data is long-term involvement with the research subject, and since the researcher was constantly interacting with the participants before and during the study, the reliability of the data increased. The researcher also did member check.

In so doing, the generated codes and classes were reviewed by experienced lecturers. They also commented on the rectitude of codes and classes. The maximum attainable diversity in sampling (drawing the interviewees from all age groups and interviewing in different settings) enhanced the fitness and generalizability of the data.

For ethical considerations, ethical approval was issued by the Research and Technology Deputy of Isfahan University of Medical Science and the relevant authorities. During the whole study process, ethical considerations, such as oral informed consent, were observed to ensure anonymity, confidentiality of information, discontinuation of participation at any time, and the provision of ethical obligations.

## Results

Overall, 23 mothers participated in this study. The mean age of the mothers was 28 years and their mean educational level was higher than secondary education. In general, 80% of the infants were boys. From the interviews, four themes and nine categories emerged regarding the mothers' challenges after their infant's discharge (Table 1).

### Incompetence in breastfeeding

Mothers should have the necessary qualifications to care for their infants at home after NICU discharge. After infants' discharge, competence in breastfeeding is the most important competence a mother should have. Therefore, mothers' incompetence, especially in breastfeeding, lowers their self-confidence, and consequently, delays growth and development of their infants. Regarding this, a mother stated: "At home, fear of it is a bad thing, sometimes you don't know how to breastfeed [and] a problem happens to the child, there's no one to help you."

Or another mother said: "I'm afraid of breastfeeding my child because at home I have no confidence even in myself."

Since feeding premature infants is different and needs more time, mothers' lack of knowledge

about their infant's behaviors throughout feeding may exacerbate their stress and anxiety. In this regard, a mother confirmed: "Since the time I took my child to home and have him take my breast, his jaw shakes and gets red, I'm afraid something happens to him, I can't breastfeed him."

### Dependence on hospital and nurses

Transferring infant from hospital to home may be considered a challenge for parents because they do not have adequate experience in caring for their infant. Relevantly, a mother stated: "In hospital, you are relaxed if something happens, there are nurses and physicians that help you, but at home you're all alone."

Ignoring mothers, the most important early partner in caring for infants when they are hospitalized in NICU, leads to their dependence on nurses and physicians and incompetence in caring for their infant after discharge. A mother asserted: "My child was under a physician's supervision in hospital, therefore, I was ensured that if sometime a problem happens to him, there's a physician."

Mothers' inadequate experience in caring for their infant and insufficient training about infant's condition, symptoms, and behaviors and how to care for it cause a decline in their confidence and competence. For example, a mother stated: "[When] you go home, you have confidence in none of your works. Now, he may take too much oxygen, why his lips are shaking ... it's too hard." Another mother reported: "[During] the first days at home, I put the pulse for my child, I misread its figure, immediately I called the ward and asked, they told me you've misdialled."

### Feeding tube as a reason for stress

Discharging an infant does not necessarily mean that his/her health and developmental problems have been resolved. Parents are likely to face certain problems after discharge including those related to pharmacotherapy, feeding tube, or respiratory support. Parents, the primary caregivers, should be supported and empowered

**Table 1.** Themes and categories regarding mothers' challenges after their infant's discharge

Themes	Categories
Incompetence in breastfeeding	Mothers' poor self-confidence, fear, and stress
Dependence on hospital and nurses	Dependence on nurses Lack of empowerment of mothers
Feeding tube as reason for stress	Parents' fear of taking out the tube Feeding with anxiety Parents' worry about others' attitude
Constantly worried mothers	Others' inadequate support for mothers Premature infants in need of intensive care Intensified worry because of relatives' interference

to provide intensive care for their infant at home, as lack of support for these parents might exacerbate their fear and stress in caring for their infant. In this regard, a mother asserted: *"My husband and I were feared. When he cried and got red, we thought that his tube might be displaced, [therefore], we breastfed him, he cried so much."*

Or another mother stated: *"Constantly both nights and days, my husband and I are careful that sometime [the infant] doesn't take out the tube with his hand. My husband is more stressed than me."*

Feeding tube not only causes the parents to develop stress, but also it intensifies their stress because of their relatives' lack of familiarity with this type of feeding and misconceptions regarding the conditions of an infant with feeding tube. In this respect, a mother told us: *"Both my husband and I let no one come to visit, because when someone sees [the infant], [he/she] says that he has a bad illness, [then] you should explain for one hour that I give him milk with this tube."*

### **Constantly worried mothers**

Lack of relatives' sufficient support for mother to care for the infant can lower mother's self-confidence and therefore, she refuses to have the hospital discharge her infant. A mother said: *"I didn't like my child to be discharged soon, because I had no one to help me."*

As caring for a premature infant is different from caring for a normal one, a family supporter who is experienced in caring for premature infants can play a significant role in enhancing mothers' self-confidence. Another mother stated: *"I like to have someone experienced and if a question comes up to me, I can ask."*

Prematurity, small body, and low weight increase inexperienced mothers' fear of caring for their premature infant. Relevantly, a mother said: *"... They are so weak like recently hatched sparrows, you should be very much careful when caring for them."*

Mother's fear of caring for her infant increases relatives' interference. In this regard, a mother acknowledged: *"[When] relatives came and any one advised something. One said it's better to eat this, another one told me never discontinue oxygen and always put it for him, in this way, I got confused and didn't know who says the right thing."* Another mother told us: *"My family helped me very much, but they did everything they knew since old days and thought it was correct, so I got more worried that maybe they guide me wrongly."*

## **Discussion**

The aim of this study was to carry out an in-

depth investigation of mothers' challenges after their premature infant's discharge from NICU. In this study, four themes of incompetence in breastfeeding, dependence on hospital and nurses, feeding tube as a reason for stress, and constantly worried mothers were identified.

An infant should be appropriately breastfed to remain healthy. Breast milk is the best choice for an infant's normal growth and development and is the most natural and valuable food, which can be conveniently provided for infants (1). Mothers are required to be competent to supply this complete food for their infant. However, poor self-confidence disturbs this natural process after discharge, which can be easily inferred from the mothers' statements.

Mothers' inexperience and lack of knowledge about feeding techniques and infants' behavioral feeding symptoms bring about stress. This stress is deleterious for both mothers and their infants. Therefore, providing practical opportunities for mothers enhances their competence in caring for their infant after discharge (16) and relieves their fear and anxiety in this regard (17). Satisfying mothers' needs during their infant's hospital stay promotes their self-confidence and helps them take full responsibility for infant care, particularly in feeding (18). A study by Valizadeh et al. in 2014 confirmed that poor self-confidence of a high proportion of mothers was due to lack of knowledge (19). Another study demonstrated that mothers experienced high levels of stress while breastfeeding at home because of poor self-confidence (20).

Based on the findings of our study, feeding behaviors, such as color changing and jaw vibration while breastfeeding, increased mothers' stress at home. Relevantly, Ross reported that infants' feeding behaviors, including reddening in breastfeeding, caused stress in the mothers at home because of not having adequate knowledge about premature infants' feeding behaviors (21).

According to the findings of a former study, mothers' dependence on healthcare team to care for their infant in hospital and no support for them after the infant's discharge decrease their confidence in their abilities to care for their infant at home. Thus, empowering mothers should be initiated since the infant's admission to NICU. Mother's full-time presence to engage in her infant's care enhances her abilities, confidence, and competence after her infant's discharge (22). Overall, although some attempts are currently being made to prepare mothers to care for their infant after discharge while their infants are

hospitalized, many additional attempts are required to reach to a favorable status. For this purpose, it is necessary to involve mothers in infant care under the healthcare team's supervision in hospital to enhance mothers' self-confidence and care abilities.

The third generated theme, feeding tube, is a reason for parents' anxiety. Discharging a premature infant with feeding tube and parents' inadequate experience in infants' feeding increase parents' stress and lead to growth restriction of their infant.

Raffray et al. conducted a study to investigate the barriers and facilitators to preparing families with premature infants for discharge home from NICU. They demonstrated that diapering, bathing, cord care, infant feeding, skin-to-skin care, recognition of newborn's cries, as well as specialized care for infants with specific medical needs (e.g., medication administration, oxygen therapy, and gastrostomy/colostomy care) were the most important challenges mothers face from health care providers' perspective (23). Similarly, these challenges emerged from the mothers' statements in the present study. Therefore, supporting parents in caring for their infant after discharge is highly important.

Moreover, infant's prolonged tube feeding after discharge to reach the desired weight, inadequate knowledge, and relatives' misconceptions about feeding with tube cause an increase in parents' stress. Therefore, healthcare team's support for mothers in feeding their infant to reach the desired weight after discharge helps discontinue feeding tube sooner and relieve parents' stress (24). Exchange of information and family-oriented interventions after discharge can contribute to increasing mothers' efficiency and competence to care for their infant (16).

A study indicated that post-discharge follow-up was critically important because despite partial recovery, infants' conditions were not stable at home and they might experience post-discharge complications (25).

Mothers are always worried about their infant's health. This condition becomes more critical if the infant is premature and is admitted to NICU. Premature infants' small body and need for intensive care after discharge intensify parents' fear. Similarly, Lopez et al. demonstrated that parents were unable to care for their infant at home because of infant's small body (26).

Another study found that parents of premature infants were constantly worried about their knowledge and skills for changing diapers, bathing, umbilical cord care, nutrition, and skin care. Besides,

parents of infants with special needs reported to be constantly worried about oxygen therapy and medical attention (18). Inadequate support for mothers after infants' discharge and their inadequate knowledge lead to relatives' greater interference with infant care. This may deteriorate infant's condition. Relevantly, a study reported that relatives supporting mothers can play a dual role. On the one hand, they help mothers in caring for their infant, and on the other, they may harm the infant by making harmful interferences (27).

Findings of a qualitative study are unique to that study and cannot be generalized to a large population. However, understanding the meaning of a phenomenon in a particular situation is useful for understanding a similar phenomenon in the same situation. Our findings are specific to two hospitals in Isfahan, Iran, and may not be generalizable to other neonatal units.

## Conclusion

Regarding the findings of this study, we can argue that mothers' presence in NICU to engage in infant care and healthcare team's support for these mothers after discharge might lower their stress and promote their self-confidence and care abilities, which in turn, lead to infants' growth and development, as well as reduction in their NICU readmission.

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## Conflicts of interests

No Conflict.

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