

# Home-based Care Needs of Preterm Infants Discharged Early from the Neonatal Intensive Care Unit: A Descriptive Qualitative Study

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## ABSTRACT

**Background:** Prematurity could result in the long admission of the neonate to the Neonatal Intensive Care Unit (NICU) and development of some complications for both mother and newborn. The early discharge programs make the neonatal transference to home much easier and are beneficial to both parents and newborns. However, there are limited studies investigating the real needs of the preterm neonates discharged early. Therefore, the identification of the post-discharge needs of these newborns could help the nurses, as the most important health care members, to consider these needs and mitigate the complications affecting the neonates.

This study aimed to describe the care needs of the preterm infants with early discharge from the NICU.

**Methods:** The present study was conducted on 25 participants (i.e., 10 mothers, 3 physicians, and 12 nurses) selected by purposive sampling technique. Data collection was performed by Observer as participant and in-depth interviews by qualitative content analysis for analysis.

**Results:** Data analysis led to the emergence of four categories, namely need to follow nasogastric tube feeding, need for oxygen level monitoring, need to obtain sufficient information about medication, and need to acquire skill for daily care delivery.

**Conclusion:** The enhancement of the nurses' knowledge about the needs of the preterm neonates with early discharge would result in the improvement of their abilities in the relevant domain. Accordingly, these nurses could help the mothers to prevent the incidence of several complications in the neonates, such as readmissions to the NICU. More importantly, these measures could prevent from the consequences of failure to fulfil these needs emerging in the later stages of life.

**Keywords:** Descriptive qualitative method, Early discharge, Home care, NICU

## Introduction

Preterm births comprise 8-10% of the whole births and are the leading cause of mortality and morbidity in the neonates without congenital anomalies across the world (1). According to the American Academy of Paediatrics and the American College of Obstetricians and Gynaecologists, preterm birth is defined as the time when the birth of any neonate occurs before the end of the last day of the 37<sup>th</sup> week of gestation. The Centre for Disease Control and Prevention states that prematurity is the most important reason of neonatal mortality (2).

The preterm neonates are at higher risk of such

disorders as jaundice, temperature imbalance, hypoglycaemia, failure to thrive, and respiratory problems, compared to their full term peers (3). Therefore, these newborns must be hospitalized in the NICUs for long periods of time to have higher chance of survival (4). Accordingly, this group are prone to various health problems in the NICU, such as feeding problems, growth failure, ophthalmic conditions, and neurodevelopmental disabilities (5).

Apart from these complications, other conditions, like noisy environments, absence of bright light, and unclear day-night cycling, could

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lead to the emergence of developmental issues in the newborns. In addition, the susceptibility to nosocomial infection and the emergence of multidrug-resistant pathogens are other problems that should be considered in this group of the neonates (6). Moreover, the prolonged hospitalization in the NICUs leads to the separation of the neonates from their parents, which in turn brings about some other consequences.

This issue highlights the importance of early neonatal discharge following physiological stabilization to prevent other complications and consequences (7). The early discharge programs primarily focus on shortening the length of hospital stay in order to prevent the possible risks of prolonged hospitalization (8). The results of a recent meta-analysis revealed that early discharge programs might improve the short- and long-term motor and cognitive outcomes in the preterm neonates (9).

However, the discharge of the preterm newborns does not mean that they do not need future cares (6). The majority of the preterm neonates need post-discharge and follow-up cares after leaving hospitals since they are often affected by complications, the management of which at home requires their exact identification. Following the NICU discharge, the preterm neonate must continue to receive treatments, such as tube feedings, oxygen therapy, medication administration, and home apnoea monitoring (7). Therefore, the implementation of the follow-up measures by the healthcare team, particularly nurses, could contribute to the reduction of the readmission rate and improvement of the neonatal health status after discharge (10).

The results of a study indicated the necessity of post-discharge apnoea monitoring at home and pointed out that failure to control this condition could increase the risk of sudden infant death syndrome (11). In addition, in another study, it was shown that the neonatal feeding, especially gavage feeding, must be controlled after discharge and performed just the same as it was implemented in the hospital by the nurses and physicians (12). According to Jefferies et al., following the discharge, the preterm newborn should be checked at home for cardiorespiratory disorders, which develop as a result of uncoordinated sucking, swallowing, and respiration (6).

In addition, based on the results of a study conducted by McCormick, since the intake of vitamins, in particular vitamin D and Iron, is crucial for the preterm neonates, it is important to

make sure that these newborns receive these supplements sufficiently following their discharge (13). Considering the importance of the above-mentioned points, the in-depth identification of the care requirements of the preterm neonates with early discharge is crucial for the improvement of the follow-up measures of the healthcare team. This is because despite the relative improvement of the neonatal health status and the relative stabilization of their conditions, they have unstable conditions at home and experience post-discharge complications (14). This point highlights the importance of performing a qualitative study to comprehensively capture these needs (15).

This study facilitates the creation of a complete and comprehensive account of the present needs to launch a home-based care program by the nurses. It could act as a beneficial help to the parents of the preterm neonates both during their admission to the NICUs and at home. This study is part of a PhD dissertation, aimed to describe the care needs of the preterm neonates with early discharge from the NICUs.

## Methods

### Study design

The current study was conducted to describe the post-discharge needs of the preterm neonates using a descriptive exploratory design. The qualitative descriptive studies are carried out to present a thorough summarization of an everyday event. These studies are less interpretive, compared to other qualitative approaches. The phenomenology or grounded theory can be mentioned as the examples of such studies (16). Data analysis was performed using the conventional content analysis method. Content analysis mainly focuses on the identification of important themes or categories within content and yields a rich description of the social reality (17).

### Study population

The participants were selected from two large Iranian university hospitals located in Isfahan. These hospitals are considered as the main referral centres for the infants who need special care and treatment in the central and southern parts of Iran. The study population corresponded to a group of physicians (n=3) and nurses (n=12) with over two years of NICU working experience and mothers of preterm neonates (n=10) with no congenital anomalies, who had Iranian nationality and expressed willingness to participate in the study. Demographic characteristics are presented in Table 1. The sampling took place within January

**Table 1.** Demographic characteristics of the study population

Demographic characteristics of participants	Age (year)	Education level	Job status	Occupational experience (year)
Mother	20-29:6	High school: 6	Housewife: 8	3-10:10
Nurse	30-39:4	Academic degree: 4	Employee: 2	11-15:2
Physician	27-35:8	Bachelor's: 9	Nurse: 10	5:1
	36-45:4	Master's: 3	Head nurse: 2	15:2
	35-55:3	Specialist: 3	Neonatologist:3	

**Table 2.** Samples of interview questions

Nurse and Physician
<ul style="list-style-type: none"> <li>• What are the post-discharge challenges faced by the preterm neonates?</li> <li>• What are the care demands of the preterm neonates at home?</li> </ul>
Mother
<ul style="list-style-type: none"> <li>• How do you spend the days after discharge?</li> <li>• How was your neonate's condition after discharge?</li> <li>• What needs did arise for your neonate after discharge?</li> </ul>

to May of 2015 via purposive sampling method.

During the sampling process, the researchers gave special attention to two criteria, namely the alignment of the subjects' experience with research questions and the feature of being a 'good informant' (18). The inclusion criteria for the mothers was delivery before the 37<sup>th</sup> week of gestation, NICU admission duration of 10-45 days, and early discharge as prescribed by the physician. The researcher had interviews at the hospital with the mothers whose neonates had been discharged early according to the physician's prescription.

In addition, since the needs of these newborns become evident after their transference to home, the researcher visited the parents at their homes the day after the discharge and interviewed them again. In addition, the parents who referred to the paediatric hospital 3-5 days after the discharge of their neonates were interviewed. The research settings included the NICUs, neonatal clinics, and houses of the parents whose preterm children had been discharged early.

**Data collection**

The data were collected through participant observation and semi-structured in-depth interviews. All participants were interviewed at NICUs, neonatal clinics, and parents' homes. The time and place of the interviews were determined by the participants. Each interview session lasted 60-90 min. To ensure the confidentiality of the interviewees' personal information, all of the interviews were coded, and the participants were assigned pseudonyms in all of the reports of the study.

In addition, the researchers completed their information by means of participant observation and attending NICUs for six months. The researchers' contributions to some of the nursing tasks, such as neonatal feeding and other care

procedures, facilitated the establishment of a closer relationship between the researchers and the participants and affected the maternal behaviour at the time of discharge.

Most of the observation sessions lasted about 2-3 h. Field notes were taken during the observation and typed in detail immediately after the session. Data collection was terminated upon reaching the saturation point (19). A written consent was obtained from every interviewee before each interview. The interview sessions began with general questions to establish a close, trust-based relationship between the interviewer and the interviewee, followed by more detailed questions based on the initial responses.

Examples of the interview questions are provided in Table 2.

**Data analysis**

The data were analysed through the conventional content analysis method with an inductive approach (20). To this end, semantic units were identified in form of sentences or paragraphs in the transcribed interviews, and primary codes or open codes were extracted. Subsequently, the main categories and subcategories were derived. In the next step, the first transcriptions as well as primary and final categories were reviewed for several times. Afterwards, the required changes were made in the number, content, and name of the categories in each review before the finalization of the primary categories, main categories, and subcategories.

**Trustworthiness**

The credibility, dependability, confirmability, and transferability were addressed as the precision criteria of the qualitative studies (21). The credibility of the study was assessed via two strategies, including clarification of the issues for

the participants at the end of every interview and crosscheck of the codes and themes obtained by the research team.

Furthermore, the dependability of the study was examined through the adoption of a decision trail throughout the data collection, data analysis, and data interpretation procedures, adherence to interpretive study when developing the interview guide, codification of the data, as well as theme presentation and analysis. Confirmability was enhanced by taking comprehensive field notes and team debriefing during coding, data interpretation, and theme development. In addition, the transferability was improved by providing detailed descriptions of the research methods.

### **Ethical considerations**

This study was approved by the Ethics Committee of Isfahan University of Medical Sciences (No: 394172). Verbal consent was obtained from all the participants. All necessary measures were taken to maintain the confidentiality of the participants' identity. The participants were also provided with key information about the aim of the study, both in oral and written forms, and assured that they were free to withdraw from the study at any point.

## **Results**

The results of the analysis led to the emergence of four categories, including need to follow nasogastric tube feeding, need for oxygen level monitoring, need to obtain sufficient information about medication, and need to acquire skill for daily care delivery. The categories and subcategories are presented in Table 3.

### **Need to follow nasogastric tube feeding**

#### **Maternal insufficient information about tube feeding**

Early discharge and nasogastric tube feeding require sufficient knowledge on the side of

parents. According to the participants, the parents lack the required knowledge about the proper feeding method of the newborns.

"Since the newborns are fed via nasogastric tube, they are at high risk of pulmonary aspiration. This is avoided if mother knows how to feed the newborn properly" (Physician 2).

The parental insufficient knowledge about the feeding and its involvement in the development of a number of complications, such as pulmonary aspiration, in the newborns and their readmissions to NICU was clearly reflected in the statements of the participants.

"A newborn who was tube fed got discharged two days ago, but he has been readmitted due to aspiration caused by the improper feeding method" (Nurse 1).

### **Fears associated with tube feeding**

The early discharge of the newborns receiving tube feeding could aggravate the mothers' fear of tube movement and/or removal. Even in some cases, fear of tube removal prompted some mothers to refuse the early discharge of the neonate.

This issue was evident in the statements of a nurse, saying "The mother is scared. The mothers are instructed about the way of gavage feeding. But, they do not know what they should do in case the tube is removed" (Nurse 4).

Accordingly, a mother said, "I don't want my newborn to get discharged. I don't know how to tube feed him at home, I am scared" (Mother 2).

Furthermore, the researcher observed that a mother whose child had been hospitalized for 20 days and was about to be discharged based on the order of a physician started to cry and stubbornly refused to take the newborn home because she was afraid of the tube feeding complications at home". According to the participants, tube feeding could serve as a "chamber of horrors" and made the mothers much more fearful of tube feeding at home.

**Table 3.** Categories and subcategories emerged in this study

Categories	Subcategories
Need to follow nasogastric tube feeding	*Maternal insufficient information about tube feeding *Fears associated with tube feeding *Need for control of tube feeding by skilful practitioners
Need for oxygen level monitoring	*Parental insufficient knowledge about delivering oxygen therapy to the neonates *Parental insufficient skill for looking after the neonates receiving oxygen therapy
Need to obtain sufficient information about medication	*Insufficient information on medication *Asking frequent questions from the healthcare team
Need to acquire skill for daily care delivery	*Safe bathing *Proper massaging *Inappropriate physical environment

### ***Need for control of tube feeding by skilful practitioners***

Parental frequent visits to the healthcare team after neonatal discharge to check the place of tube feeding and also feeling insecure about how the neonates are fed were other points made by the participants. The parents demanded assistance from the healthcare team, nurses in particular, to assess the position of the tube to see if it was properly inserted.

"We regularly replace the tube in the morning. But, they take the kid here even before night and say the tube has come out of the position and ask us to check it again" (Nurse 4).

### ***Need for oxygen level monitoring Parental insufficient knowledge about delivering oxygen therapy to the neonates***

Discharging the neonates receiving oxygen therapy and continuing home-based cares could raise multiple questions in mothers about the oxygen quantity and delivery of proper care during oxygen therapy. As acknowledged by the participants, parental insufficient knowledge in this regard results in their frequent referrals and calls to the neonatal units of the hospitals.

"When a newborn is discharged, mothers call us immediately and ask how much oxygen they should administer or how to adjust the pulse" (Nurse 4).

Moreover, the insufficient knowledge of the parents about oxygen therapy could instil fears in the parents. Accordingly, one of the mothers stated, "I was not sure how much oxygen I should administer; I was afraid.... this made me call them immediately and inquire about it" (Mother 6).

### ***Parental insufficient skill of looking after neonate receiving oxygen therapy***

The parental skills in oxygen therapy are crucial. As stated by the participants, the parents' poor skills in delivering cares to the neonates could lead to the commission of errors during oxygen therapy or even bring about health complications for the newborns.

"I was not sure how to give the oxygen to my baby. Once, I even read the number of pulse oximeter in a wrong way" (Mother 4).

In addition, the participants cited the mothers' poor skills and inadequate abilities in delivering oxygen therapy as the primary reason for their disagreement with neonatal discharge from the NICU. The researcher observed the insistence of a mother on keeping her newborn in the NICU as she argued, "I don't know how to give the oxygen. I don't know what to do if the skin of my child

goes black. I don't want my child to get sick again".

### ***Need to obtain sufficient information about medication***

#### ***Insufficient information on medication***

According to the participants, discharging the neonates receiving multiple drugs poses the parents to multiple questions about the way of administering these drugs at home and makes them fearful about the early discharge of their newborn. Furthermore, the parents' poor knowledge of the drug side effects makes them to associate the neonate's restlessness with the drugs taken.

"The newborns are prescribed with a lot of drugs after discharge, but mothers don't know much about the drugs and administer wrong dosage" (Nurse 5).

"Whenever I give the prescribed drugs to my child, she either sleeps excessively or gets listless. I am afraid this may be due to the drugs" (Mother 4).

Therefore, the poor knowledge of the proper drug dose and administration could confuse the parents and create some problems in the neonates as a result of "over or under-dosing".

### ***Making frequent questions from the healthcare team***

The participants highlighted the importance of training the parents about administering the drugs and pointed to the frequent post-discharge referrals and calls of the parents, in particular to the nurses.

"Before the discharge, we take a syringe and show the parents how to give the drugs. But they again call us and ask about the drug dosage and the way of its administration" (Nurse 2).

"Before discharging my child, they instructed me on medication. But I would call the nurses again to be sure" (Mother 9).

The provision of the parents with insufficient knowledge during their neonate's hospital stay, along with their nagging doubts about administering drugs, prompts them to make frequent calls to the healthcare team. Mothers talk about the "peace of mind" after checking each issue with nurses.

### ***Need to acquire skill in daily care delivery Safe bathing***

As recurrently mentioned, prematurity, low weight, and slipperiness of the neonates during bathing and subsequent challenges were some of the important reasons for the parents' reluctance to bathe their newborns.

"I am worried about bathing my baby, he is so

tiny and may slip out of my fingers at any moment" (Mother 8).

Furthermore, parental poor knowledge about proper bathing of the neonates was another issue that discouraged the mothers from this practice. Some of them admitted that they had not bathed their newborns even two weeks after the discharge.

"Mothers don't have enough information about bathing their newborns, and this is why they refuse to do so for a while" (Nurse 7).

### ***Need to proper massaging***

The provision of the preterm neonates with massaging is an issue of significant importance. However, the parents are required to acquire knowledge about the massaging methods and oil types.

"Mothers keep asking us about the type of massage oil" (Nurse 8).

"After discharge, many mothers have contacted us to enquire about the type of massage oil to apply" (Nurse 1).

In addition, the condition of the preterm newborn, combined with maternal poor knowledge about proper massaging, induces fears in mothers and discourages massaging. Even some mothers admitted to "be afraid of fracture".

### ***Inappropriate physical environment***

The participants mentioned early discharge, busy environment, and excessive exposure to light as stimulants, which could cause restlessness in the preterm newborns.

"Parents don't know they should not place newborns in the crowded environments. Noise and crowded places are not good for the infants" (Nurse 3).

"Most of the times when parents inform us that their newborns are restless, we inquire for more information only to find out that home is warm and the newborn is ok" (Nurse 4).

Furthermore, according to the researcher's observation during the home visits, excessive light, television noise, and placement of the newborn's bed next to the fireplace or heater created less than desirable conditions.

## **Discussion**

This study aimed to perform an in-depth investigation of the needs of the preterm neonates who were discharged early from the NICU. If these newborns are discharged sooner, they will suffer from less complications that are caused by long hospital stay (2). Accordingly, these newborns

need some home-based cares, the improper provision of which could result in more serious complications and increase the risk of readmission to the NICU (22). Therefore, it is essential to follow up the neonatal status to ensure the fulfillment of post-discharge requirements, such as tube-feeding.

According to Hummel et al., it is crucial to closely monitor the neonates in need of technological supports, such as nasogastric tube for faster transition to oral feeding (23). The mothers' lack of experience in feeding the newborn with nasogastric tube and their concerns over the removal or movement of the tube were highlighted by the participants. Therefore, the provision of the neonate with the post-discharge supports by health teams could accelerate the process of transition to oral feeding, which in turn reduces the parental anxiety (24).

In a study performed by Rafferay et al., it was shown that discharging the newborns with nasogastric tube created the fear of apnoea development during feeding in mothers, while the inexperienced, young mothers expressed more serious concerns in this regard (25). Following the discharge, mothers frequently refer to the healthcare teams due to the lack of confidence and do not feel secure about feeding their neonates. Consequently, the healthcare teams should enhance the mothers knowledge and skills to feed the preterm newborns with special care demands (26).

Monitoring the oxygen level was another category extracted in this study. Based on the findings, the parental poor knowledge about oxygen therapy could make them apprehensive and lead to the commission of errors during this therapy. The results demonstrated that parents are in a state of uncertainty following the discharge of their neonates (27). This uncertainty will be overcome if the parents receive appropriate information about the safe provision of cares for the newborns (2).

Poor skills in administering oxygen therapy also made the parents scared and justified to disagree with their neonatal discharge. According to the literature, although parents are fearful of administering oxygen therapy at home, they will manage to regain their confidence if they receive the support of the healthcare team and adequate training (28, 29).

In a study conducted by Aliyu et al., a large portion of mothers opposed oxygen therapy since they did not have the knowledge and necessary skills to manage this therapy at home (30). Since a large number of the preterm neonates may be discharged while they are on oxygen therapy,

supporting the parents could contribute to the delivery of a safe neonatal care and alleviation of the associated complications (31).

As reported in a number of studies, some mothers commit mistakes in adjusting the oxygen quantity and reading the pulses due to having insufficient information. Since oxygen provision is a vital issue for these neonates, following up this issue is extremely important. The need for obtaining sufficient information about the medication was another category obtained in the present study. As suggested by the participants, the parents' poor knowledge of the medication side effects and dosage could make them concerned over home administration of these drugs (23).

However, the present study indicated that although the parents were given sufficient training about dosing during the neonatal hospitalization by the nurses, they still became confused after discharge. The results of a similar study revealed that the adequate communication between the mothers and healthcare teams and acquisition of relevant information by parents could allay their fears and uncertainty feelings (32).

The necessity of the regular provision of such daily cares as safe bathing, massaging, and providing an appropriate physical environment was another issue mentioned by the participants. According to the findings, the small body size of the neonates, along with their low weights, discouraged the parents from bathing the newborns following their discharge. Moreover, the poor information of the parents about the bathing method aggravated their reluctance. The results of a similar study showed that the mothers were afraid of bathing their preterm neonates (33). Likewise, in another study, it was reported that the mothers needed information about the sleep and bathing of the newborns following the discharge of their preterm neonates (34).

The participants asserted that the parents required sufficient information about the post-discharge massaging of the newborns. As massaging plays an important role in the growth and development of the preterm neonates, the nurses could provide the parents with necessary information on post-discharge measures in this regard (35). The provision of parents with appropriate type of massage oil could help the parents administer more successful massaging. Since some neonates may be allergic to some types of oil and may show dangerous responses, the application of appropriate oil could promote motor activities and decrease the stress-induced behaviours. In addition, maternal provision with

adequate information to acquire the necessary massaging skills not only positively affects the development of the neonates, but it also allays the maternal stress and anxiety (36).

Access to relevant information about the conditions of the physical environment, such as brightness, temperature, and noise, were also other requirements of taking care of the preterm neonates as asserted by the participants. The preterm newborns with special care demands are in dire need of a calm and non-provocative environment for sound growth and development. However, some parents with insufficient information about the effects of stimulant factors on the development of the neonates may ignore these factors. Accordingly, in a study, it was reported that the parents should be given adequate training to establish an appropriate environment for the sound growth and development of their neonates (23).

### **Limitations of the study**

The participants of the present study were selected from two university hospitals in Isfahan, which may limit the generalizability of the results. However, we tried to partially mitigate the effect of such a limitation by using a purposive sampling method to include the participants of various sociodemographic backgrounds. The number of the participants was appropriate for a qualitative study. Nevertheless, one of the strengths of this study was the inclusion of different groups, namely mothers, physicians, and nurses.

### **Conclusion**

The early discharge of the preterm neonates from the NICU could encounter the parents with a body of unresolved demands regarding the delivery of home-based cares. The failure of the healthcare team to show timely appropriate responses could lead to irrecoverable consequences in the neonates. Therefore, it is essential to follow up the preterm newborns until the improvement of their health status.

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### **Conflicts of interest**

The authors of the present study have declared no conflicts of interest.

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