# Factors affecting infant's transition from neonatal intensive care unit to home: A qualitative study

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## ABSTRACT

**Background:** The infants, hospitalized in the neonatal intensive care unit (NICU), engage with problems from admission to discharge, exploring of which ensures their safe transition. The purpose of this study was to identify the factors that influence infant's transition from the NICU to home.

**Materials and Methods:** A qualitative study was used for identifying the factors that affect infant's transition. Data were gathered by interviewing 16 nurses and physicians in NICUs of university hospitals in Iran; and were analyzed by qualitative content analysis method. MAXQDA, MAX Qualitative Data Analysis, is a software which has been developed in Berlin, Germany. software, the qualitative data analysis package, was used for coding and categorizing.

**Results:** There are 10 categories that affect infant's transition, as revealed in data analysis. These categories were delineated into three themes: Cognition of infant's needs, effectiveness of trainings, and organizational context.

**Conclusion:** The results of this study further disclosed the factors that facilitate or hinder infant's transition from the NICU to home. The aspects of correct cognition along with more effective trainings must be fully introduced to the staff to meet infant's needs. Also, authorities are better to make policies to decrease organizational barriers. Therefore, it is suggested that applying developmental care can ease infant's transition.

Key words: Content analysis, infant's need, neonatal intensive care unit

#### INTRODUCTION

The ultimate goal of health professional is to transit the infant from neonatal intensive care unit (NICU) to home safely. To achieve that, a holistic view to the infant's needs can be helpful. All health care providers try to put their knowledge into practice to provide a continuous care, facilitate the transition process, and improve the outcomes for both the infant and the family.<sup>[1]</sup>

There are many reasons proving that the infant requires a neonatal intensive care during hospitalization and also proceeding of the discharge programs should be focused on. Numerous NICU infants remain vulnerable to respiratory and gastrointestinal infections through infancy.<sup>[2,3]</sup> Furthermore, the major concern in the NICU and after discharge is breastfeeding, as a source of nutrition and growth agent. A qualitative study provided some information about the barriers to breastfeeding. Low milk

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Address for correspondence: Dr. Mahboobeh Namnabati, Departments of Child and Family Health, Tabriz University of Medical Sciences, Tabriz, Iran. E-mail: namnabat@nm.mui.ac.ir content was the greatest breastfeeding barrier at the time of discharge from NICU. The maternal perception of the physical status of the infant was also identified as the most consistent and prevalent barrier to breastfeeding within the first 3 months after discharge.<sup>[4]</sup>

Re-hospitalization of infants may occur after their discharge. The studies have shown that these infants have used the most services from the second week after birth to the 3<sup>rd</sup> year of age.<sup>[5,6]</sup> These infants were hospitalized for short-term (e.g., hypothermia, respiratory and cardiovascular disease, and infection) or long-term (e.g., neurodevelopment disability) complications. The risk of complications increases with the prematurity.<sup>[2]</sup> NICU infants have higher risk of mortality and morbidity. Being discharged, 2-5% of these infants die from medical complications related to their preterm birth within 2 years. It is reported that the post-discharge mortality rate was 7.5 per 1,000 in very low birth weight (VLBW) infants.<sup>[7]</sup> In Iran, about 7% of infants are low birth weight.<sup>[8]</sup> A 3-year survey, done in an Iranian NICU, has indicated that 7% of hospitalized infants were returned to a university hospital.<sup>[9]</sup>

The problems such as breastfeeding barriers, re-hospitalization, morbidity, and mortality reveal the risk factors that accompany infants during their transfer from NICU to home specially in the sensitive period of early infancy. On the other hand, improvement in nursing and medical care has increased survival rates of NICU infants. Family-centered care, kangaroo mother care, and early discharge program are all intended to reduce the total length of hospital stay for the premature infants as well as their morbidity.<sup>[10]</sup> In addition, the impact of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) on development and behavior of the child and on the mother-child interaction appears to have certain positive long-term effects.<sup>[11]</sup> Furthermore, NIDCAP-based care for VLBW infants improved short- and long-term outcomes significantly.<sup>[12]</sup> Therefore, it seems that there are factors that affect nursing intervention and infants' developmental outcomes. Thus, it necessitates recognizing the factors that affect the infant's transition from NICU to the home. A qualitative study can help obtaining comprehensive and rich description about the existing background and real situation of dominated process of infant's transition because it is believed that qualitative study yields broad and deep information that may not be achieved through quantitative study. The qualitative research can improve the body of knowledge of nursing that is useful in nursing practice. Nurse plays a crucial role in working with infants and their families to create a facilitated transition.<sup>[13]</sup> Therefore, the focus on given descriptions and the experiences of nurses and physicians can determine the effective factors of transition. Thus, the aim of this study was to identify the factors that can affect infant's transition from NICU to home.

# MATERIALS AND METHODS

The purpose of this qualitative study was deeply to describe the effective factors that affect infant's transition from NICU to home. Qualitative content analysis was used for describing phenomenon. The goal of content analysis is to provide knowledge and understand the under study phenomenon.<sup>[14]</sup> In this study, conventional approach was used in which coding and categorizing are derived directly and inductively from the raw data.<sup>[15]</sup> The advantage of the conventional approach to content analysis is gaining direct information from study participants without imposing pre-conceived categories or theoretical perspectives. One characteristic of qualitative content analysis is its focus on the subject and context, and emphasis on differences and similarities within codes and categories. This approach deals with manifestation as well as latent content in a text. The manifest content, that is, what the text says, is often presented in categories, while themes are seen as expressions of the latent content, that is, what the text is talking about.<sup>[15]</sup>

Purposive sampling was used to select 16 participants as rich informative cases.<sup>[16]</sup> The participants included

fourphysicians and twelvenurses aged from 28 to 55 years and had 3-15 years of work experience. All of them had a background in pediatric and neonatal units. All the professionals were experienced at three levels of NICUs. In level 3, infants are complicated cases and require intensive care; level 2 completes maternity and neonatal cares for uncomplicated and most high-risk infants; and in level 1, complicated cases that do not require intensive care and infants are under supervision to be provided with some facilities to discharge from NICU. The setting for this study was three NICUs of university hospitals in Tabriz and Esfahan cities, Iran, in 2011.

The study was approved by the ethics committee of Tabriz and Isfahan Universities of Medical Sciences. A written consent was obtained from each participant and they were informed about the aim of the study. The participants were asked to attend as they wished. The interview could be cancelled if the interviewee would request.

Data were gathered during 6 months through in-depth interviews. Interviews lasted from 20 min to 3 h. Each interview commenced with an opening question such as "what do you do for infants from the beginning of the hospitalization to the moment of discharge from the NICU?" and then, they were asked to describe their experiences in discharging infants and to explain situations and factors which affect infant's transition tohome.

Content analysis was conducted to analyze the data. Interviews were transcribed and coded. The qualitative data analysis package MAXQDA10 was used for the initial stages of coding. MAXQDA10 is a software for text analysis that helps making codes, categorization, and link research notes to the codes. However, the software is only an aid for organizing the material and is not an interpretive software itself.

In this study, each interview was reviewed line by line and coded, then similar codes were grouped into a category and then similar and appropriate categories were constructed into themes. Zhang and Wildemuth (2009)emphasized that categories must be generated inductively from the data. Constant comparative method not only enables us to stimulate original insights but also to distinguish the differences between categories and creating themes in a way to link the underlying meanings together in categories.<sup>[15]</sup>

Various aspects of trustworthiness have been considered in the study. Credibility was established through prolonged engagement in the NICU. In addition, member checking was used for accuracy of the qualitative findings through the process as well as expert informants who considered the transcripts in relation to the analysis developed by the primary researcher. Dependability of findings was assured by data triangulation which involved the collection of data from multiple sources for the same study. The intent is to use data from one source to make the data valid and reliable for another source.<sup>[16]</sup> With regard to clear and precise description of coding, categorizing, and formation of themes of raw data, the conformability was revealed.

## RESULTS

Three themes were identified from the data analysis: Cognition of infant's needs, effectiveness of trainings, and organizational context. Themes, categories, and codes are shown in Table 1.

## **Cognition of infant's needs**

The cognition of infant's needs affects facilitating the infant's transition from NICU to home. The health professionals know, understand, and notice the infant's needs. They also assess to what extend those needs are met. In fact, the health providers could recognize these needs from different aspects. Perfect cognition can lead to meeting these needs and facilitate the infant's transition from NICU to home. Deficit cognition leads to leaving the needs unmet and is a barrier to transition.

## Knowing

The health providers have sufficient knowledge about many needs of the infants. They know that high-risk infants have tremendous problems which require intensive care. For example, infants encounter stressful environment of the NICU. A nurse explained that:

"We know that we disrupt the baby's peace and sleep by blood sampling, vital sign controlling and other painful procedures."

Although experienced professionals know necessitation of a quiet environment for infants, they are not able to provide a calm atmosphere for infants.

#### Noting

Considering the physiological needs of infants, the staff noted that the application of some procedures results in physiological stability. A nurse emphasized that:

"We are alert to temperature instability. We do some interventions and we will inform the doctor to order."

In addition, infants would undergo aggressive medical interventions in the NICUs which adversely affect their growth and development. Professionals are well aware of these effects and closely monitor them. A nurse noted that:

"An infant was grunting, so the nurses tried to perform vein puncture. It took place several times with no success. The baby went cold and cyanotic...."

Physicians also believed that the preterm infant's hospitalization is not without damage. Sometimes, they are hospitalized for prematurity and taking prophylactic

Table 1: Identified factors affecting infant's transition from neonatal intensive care unit to home: Themes, categories and codes

Themes	Categories	Codes
Cognition of infant's needs	Knowing	Having information about infants being in a stressful environment, being knowledgeable onnutritious needs, making the least changes in position, arranging an individual care plan,Kangaroo mother care, Familiarity with the medication
	Noting	Being alert to physiologic instability, considering effects of painful procedures, paying attention to the side effects of intubation, noticing hypoxemic.
	Perceiving	Understanding the need of prenatal care, detecting the need to effective resuscitation, having experience about infant's problems and needs
	Reasoning	Assess reasons for gaining weight, evaluating the effects of invasive interventions on infant's health, formation of idea about unsuccessful breastfeeding
Effectiveness of trainings	Attempts to train	Holding workshops, conferences and skilled professionals rounds, supervising novice staff, planning special neonatal courses
	Perceiving	Deficit knowledge of the staff, ineffective trainings uncoordinated teaching of mothers, useless continuous teaching, lack of evaluation of education
	Deterioration of education	Following routines and traditions,working without thinking about it, do not considering evidence-based practices, lack of protocols, practicing out of standards
Organizational context	Inadequate equipments	Ineffective phototherapy devices, inadequate pulse oximetry, insufficiency of some devices in NICU
	Shortage of staff	Low staffing ratios, shortage of nurse on holidays, lack of specialists on holidays
	Uncoordinated programs	Unavailable protocols and regulations in NICUs,Unclear duties, lack of team working, being in pressured university hospitals

antibiotics. Consequently, they got worse because of nosocomial infection and other side effects of medical and nursing interventions.

# Perceiving

Knowing and noting lead to perceive infant's needs. Health care providers continuously face complicated cases which have special needs. They have experienced problems of preterm infants which is a reflection of their maternal background. Various events made the health providers to better understand the problems that may occur during pregnancy, delivery, or even neonatal period and raise some special needs for infants. One neonatologist explained that:

"Infants' background affects their fate. Preterm infants encounter main problems that stem from maternal diseases for which they were forced to perform a cesareansection. For instance, a pregnant woman with hypertension will deliver a baby with intrauterine growth retardation (IUGR). Therefore, it is crucial to have a link between obstetric and neonatal services. The more control on the mothers and prenatal care, the better the health of infants will be."

Moreover, the staff detected infant's needs based on their experiences about effective resuscitation. Another physician emphasized on respiratory care:

"Improper infant resuscitation would cause a lot of problems; such as 1respiratory infection and neurodevelopmental disability. For this, all healthcare providers must know resuscitation principles correctly and use proper equipments, i.e., a very accurate respiratory management is needed which represents a skillful nursing."

## Reasoning

Professionals must be able to assess infant's health state for meeting their needs and preparing them for discharge. Gaining weight is considered an important feedback of the effectiveness of medical and nursing care. A nurse claimed that:

"A baby who is under ventilation or has had several blood samplings or invasive procedure cannot gain weight."

Another nurse mentioned:

"Those mothers who stay in the unit around the clock are able to look after their children and have successful breastfeeding. This results in gaining weight of infants."

## **Effectiveness of training**

Training the staff is one of the educational goals in the NICU to facilitate infants' transition. Achieving the goal requires activities and commitments of NICU personnel. There have

been some efforts which improved the staff's competency and enhanced procedural trainings. Professionals perceived that some of the efforts were not effective enough for achieving the goals and educational programs were deteriorated shortly.

## Attempts to train skilled personnel

Although NICUs are equipped with high-tech devices and with the increased survival rates of infants, the authorities have to take responsibility to train competent professionals. To do this, they established a neonate intensive course for nurses and employed more neonatologists. Associated with infant and pediatric department, the administration of university hospitals held a continuing education course and different workshops to train more competent personnel. A physician mentioned promoting Kangaroo Mother Care:

"Mother-infant bonding issue is important. We intend to form that from the first day of delivery. We focus on that and we are responsible to hold educational programs throughout the country [Iran]."

Increasingly, improvement in competency and confidence of staff were considerable. A nurse stated:

"Now, we have more fellowship in the NICU. Also, we have skilled nurses like respiratory nurse because they have passed some courses."

## Perceiving ineffective trainings

The goal of education is to train skilled health providers for curing patients and taking care of them. They have to be able to physiologically stabilize infant and enable the mother to take care of her child. This goal is not completely fulfilled yet. The personnel understood that they are theoretically taught about medical and nursing interventions but the most concern is the practice. A head nurse complained:

"All nurses have attended resuscitation classes and also there is a frame on the wall indicating resuscitation guidelines easily seen by everyone but they do not know what kind and how much medication must be administrated practically. So the infant would be damaged."

A physician stated:

"Most residents who have passed resuscitation workshop make a mistake during inserting intubation. They could not manage a patient without injury."

Uncoordinated teaching and lack of protocols cause mothers to lose their trust in medical staff. A nurse said:

"A nurse had instructed a mother to do the gavage feeding in one way and another nurse had done it in a different way. By shift rotation, the medication was also changed when another physician had visited the patient."

# Deterioration of education

All staff realized the theory–practice gap in professional duties between the clinical setting and academic instructions. Nurses have to follow the routines of the unit and physician's orders which consequently could deteriorate academic education of graduates. A nurse said:

"We are still working traditionally. Sometimes a patient is injured during diagnostic procedure. They just follow routine orders without thinking. They deteriorate educational programs and evidence-based studies."

## **Organizational context**

Context and structure of organization are the factors that affect the management of infant's transition from NICU to home and professionals usually would faceit. The main portions of these factors involve equipments, manpower, and management.

## Inadequate equipments

Curing and taking care of infant are highly dependent on today's technology. Insufficient or defective equipments could endanger infants' well-being. A physician said:

"Is it reasonable to have the baby under phototherapy for 2-3 days with no decrease in bilirubin?! It can be judged that there is some defects in the equipment. There are few advanced phototherapy devices in the unit."

He continued, mentioning the importance of milk feeding and maintaining the milk.

"Most of our fridges are not standard for keeping and freezing milk. We have no milk bank for storing."

# Shortage of staff

Nurses and physicians are two key members who are responsible for infant's care and treatment. The shortage of such workforce can affect infant's health. A nurse claimed:

"There should be a residence physician for every under ventilation patient. If the tracheal tube should be removed or the patient needs an emergency action, a physician must be available in any shift."

## A nurse expressed:

"Each nurse must take care of 5-7 patients. It is obvious that they cannot follow standard practice procedures. Younger and inexperienced personnel are appointed to work on weekends and holidays. They are not expert enough to perform vein puncture and consequently, the baby will be prone to injury."

# Uncoordinated program

The safe transition of infant necessitates having an efficient management from the beginning of the hospitalization till after the discharge. Participants expressed that uncoordinated plans are the most concern in the safe transition. Nobody is responsible for coordinating a safe transition. One neonatologist stated that:

"The university hospitals are overcrowded. The work load is high. The physicians have to perform the task of other staff, including social worker duties too. It is the social worker who is responsible for infant transportation and family protection. There are no defined regulations. We perform based on profession commitments."

Other physician expressed:

"Our discharge plan is weak and different from standard practice procedure. The NICUs are highly overcrowded. All we can do is to encourage mothers to refer to clinics for follow-up. There are no home visit plans available now, and the parents themselves are responsible for following the growth and development of their baby."

# DISCUSSION

The result of the study showed that cognition of infant's needs, effectiveness of trainings, and organizational context are factors affecting infants' transition from NICU to home as follows:

# The cognition of infant's needs

The cognition and meeting of infants'needs can expedite smooth transition from NICU. Cognition is a scientific term for mental processes including: Knowing, attention, understanding, reasoning, solving problem, making decision, applying knowledge, and changing preferences.<sup>[17]</sup> The result of the study showed that professionals have known only few elements of the cognition. According to the normal infant's needs, the developmental needs are left unmet due to lack of other elements. Similar with other countries, there are some barriers to infant's developmental care which is a care model to meet infant's needs in the NICU settings.<sup>[18-21]</sup> The atmosphere of the NICU is typically characterized by constant noise, excessive light, painful procedures, disturbance of sleep-wake cycles, and multiple care giving.<sup>[3]</sup> Infants are bombarded by invasive procedures which produce pain for infants and the nurses know about the interventions. A study reported 86 times invasive

procedures per day such as inserting tracheal tube, suctions, and vein puncture during 6 successive days of infants hospitalization without pain management in the NICU.<sup>[22]</sup> Painful procedures can adversely affect oxygenation and gaining weight about which the staff is well aware. Pain management is, however, not implemented correctly in the most NICUs. It has been indicated in a study that less than half of the nurses felt that infants are well managed.<sup>[23]</sup>

The findings of thisstudy revealed that health professionals had perceived contextual factors of neonatal needs. Indeed, a basic understanding about maternal conditions and process of labor and delivery is crucial to those who are infant's care givers. Approximately,75% of perinatal risk factors for an adverse pregnancy outcome can be identified before labor. Maternal conditions such as mother's hypertension, infection, and diabetes can affect the newborn. Because of this, a consistent and well-documented prenatal care is essential to ensure fetal well-being.<sup>[24]</sup>

Reasoning is another aspect of the cognition. All professionals were adequately trained to well identify the reasons of infants' weight gain for instance. For example, round the clock presence of mother and her involvement in care giving were considered by the staff as important factors on gaining weight and smooth transition. Many studies have proved that not being involved in care giving or just being an observer, the mother can adversely affect successful patient's transition to home; and that she must be involved in care giving process as a partner or a primary caregiver to ensure infant's growth and development.<sup>[25]</sup> In fact, infant growth patterns are valuable indicators of well-being.<sup>[3]</sup>

Exact assessment of cognition elements crystallized that the infant's needs are not appropriately met. We suggest a developmental care model can meet the needs of infants and facilitate their transition provided, the standards such as providing developmentally supportive environment and planning an individualized developmental care plan are applied.

## **Effectiveness of trainings**

Findings revealed that authorities have been trying to achieve the goals of the NICU which include the provision of skilled professional care. The effects of professional training are reflected in the infants'smooth transition. An effective neonatal intensive care team consists of trained professionals of many disciplines.<sup>[3]</sup> With regards to this team, policy makers have arranged a continuing education program, workshops, and seminars about the subject of discussion such as resuscitation, breastfeeding, Kangaroo care, and infection resources during this decade in Iran.<sup>[26-28]</sup> Some challenges and problems emerged with these programs. A study showed that holding workshops on infection in the high-risk infants leads to discuss and focus on the major gap between knowledge and practice and the issues in priority. The result of the workshop yielded some strategies to solve the existing problems and suggested some issues for the future research.<sup>[29]</sup> In addition, use of a training program enhances nurses' cognition abilities to take care of preterm infants.<sup>[30]</sup>

Despite all attempts which have been done by the stakeholders, participants believe that the morbidity and the mortality rates are high in the NICUs because of some reasons such as unskilled personnel and still more is needed. Although we do not have the exact statistic of medical errors in Iran, other NICUs around the world seem to experience the same problems.<sup>[31]</sup> For instance, iatrogenic, which may inadvertently happen in a condition or a therapy, was noticed in a study. The importance of an efficient training course on prevention of iatrogenic complication was emphasized on for the NICU personnel. Approximately, half of the iatrogenic complications are due to administration of nutrition solution, skin damage, and insertion of invasive catheters.<sup>[31,32]</sup>

It has been shown that high-risk infant follow-up programs are crucial for providing clinical care, trainee education, and facilitating outcomes research.<sup>[33]</sup> It must be considered to get feedback of the training program because most of the learned skills deteriorate after completion of the course, especially resuscitation program. Thus, implementing a plan to practice resuscitative measures or other skills on a regular basis is an effective strategy for physicians and nurses to practice the skills they have already learned in the class.<sup>[34]</sup>

## **Organizational context**

The result of thisstudy indicated that the organizational context, structure, and performance can together affect the transition of infants. Inadequate equipment, shortage of staff, and uncoordinated programs are identified as barriers to the safe transition. Similarly, Kuppla*etal*.<sup>[33]</sup> (2010) reported that the lack of personnel and funding were the most common causes for not having a follow-up program. Other studies confirmed that patient-to-nurse ratio had influenced the outcomes such as decreasing daily weight gain and oxygenation.<sup>[35,36]</sup> In recent studies, shortage of staff and high workload caused insufficient trainings for mothers about breastfeeding that led to inappropriate weight gain of infants. Thus, ample staff can help preparing mother and facilitates infant transition to the home.

Lack of clinical guidelines was also noted to have influence on taking care and curing. Authorities pointed out that they are planning some protocols for the NICUs and even though the guidelines may not directly reduce the infants' mortality rate, but surely they will impose positive effect on the reduction of morbidity and mortality rates.<sup>[3]</sup> On the contrary, these programs are being evaluated in some countries. In a study, it is confirmed that executing a follow-up program in cooperation with an academic center can ease care and research<sup>[33]</sup> and that the management of nutrition, breastfeeding, and neurodevelopment outcomes was the most common service provided. Getting feedback from the developed plan and making coordination are helpful to the infant and the family. Cooperetal.<sup>[37]</sup> (2007) evaluated a national program about family center care which had positive impact on infant and family during neonate hospitalization and transition to home in the USA.

Uniquely, this qualitative study made it possible to identify effective factors on safe infant's transition, based on which key participants had experienced. The cognition of infant's needs could be considered a positive factor among the staff; but the ineffective trainings and organizational context were barriers to the transition. Indeed, the later issues can affect some of the cognition aspects. It can be concluded that the staff cannot put their knowledge into practice to make a solid decision and solve the problems properly. Recalling the standards of developmental care can help meeting the needs of infant and family and yet develop better discharge plans.

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