IJN
Iranian Journal of Neonatology
http://ijn.mums.ac.ir

Open Access

Original Article

An Exploration of the Viewpoints of Parents and Nurses on Care Provision in Neonatal Intensive Care Units

Haydeh Heidari[1], Marzieh Hasanpour[2*], Marjan Fooladi[3]

1-Assistant Professor, Faculty of Nursing and Midwifery, Shahrekord University of Medical Sciences, Shahrekord, Iran
2-Pediatric and Neonatal Intensive Care Nursing Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran
3- Fulbright Scholar and Professor at Florida State University, College of Nursing

ABSTRACT

***Background*:** Infants are regarded as a vulnerable group in need of nursing care, particularly during NICU admission. Parents of these infants often experience emotional, psychological and physical upheavals. Therefore, nurses can be of great help to the parents and facilitate a healthy transition from this period. Improper communication with parents, who seek information on their infant's condition, intensifies their stress, fear and misunderstanding. In fact, inadequate communication with healthcare providers and lack of family support are major issues for the parents of NICU-admitted infants.

***Methods*:** In this qualitative study, via content analysis, we objectively selected and collected data from parents, physicians and nurses, residing in Isfahan, Iran in 2012. Data saturation was reached after conducting 25 in-depth, semi-structured interviews.

***Results*:** Based on the findings, five major categories were extracted: 1) care provision in NICUs; 2) diagnostic difficulties; 3) NICU admission process; 4) challenges of hospitalization; and 5) maintenance of infant viability.

Conclusion: Nurses' proper response to parents' questions about the infant's condition reduced stress among parents. Based on the findings, training is essential to healthy family dynamics and infant's well-being, particularly for younger parents who support their infants at home. Also, regular updates on infant's condition could help reduce parents' stress and discomfort.

Keywords: NICU, Parents, Qualitative content analysis

Introduction

The neonatal period is defined as the first 28 days of infant's life after birth (1). An infant has specific physiological needs for adaptation to the extra uterine environment and is highly vulnerable to medical complications. The highest neonatal mortality rates have been reported in poor extra uterine adaptation phase (2), when infants may suffer from hypothermia and maladjustment due to asphyxia, premature birth or congenital anomalies. These conditions can be life-threatening and cause adverse effects stemming from untimely and traumatic birth (3). Overall, neonatal mortality and morbidity rates are the highest shortly after birth (4). Statistically, over 9-12% of infants in the United States and 5-7% of infants in European countries are born prematurely (5).

Parents of premature infants are eager to participate in the process of care provision for their infants in neonatal intensive care units (NICUs). Parents of NICU-admitted infants often rely on healthcare professionals to gather information on their infant's condition. However, many of their questions remain partially or completely unanswered, thus hampering parents' involvement in infant care.

Effective communication is an essential component of neonatal care, resulting in stress reduction among parents and NICU staff (6). After all, the primary goal of every NICU team is to guarantee the survival of newborns; consequently, parents' psychological needs are less noticed. Interpersonal communication is the initial step for information exchange between parents and healthcare providers in NICUs. In fact, parents need open and honest discussions about the condition of their infants.

In general, nurses have a unique status as they are more approachable than other members of healthcare teams and parents feel comfortable to inquire about their infant's condition. Accordingly, nurses need to be sensitive and understanding

* *Corresponding author*: Marzieh Hasanpour, Pediatric and Neonatal Intensive Care Nursing Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran Tel:+98(31)37922909-37922921 Email : hasanpour@nm.mui.ac.ir

and establish an effective communication with the parents of NICU-admitted infants (6).

Premature and low-birth-weight infants account for the majority of NICU admissions (7). Parents experience high levels of emotional stress in addition to physical discomfort due to the ambient noise, excessive light and constant interactions with infants in NICUs. In case nurses are impatient, hasty or unresponsive to parents' questions, the NICU atmosphere might become unfriendly for the parents.

Vague and short interactions with the parents only intensify their stress, anxiety and misunderstanding of the process. Nurses' sensitivity to mothers' needs is dependent on the perceptions and priorities held by the parents and NICU nurses. Over the years, unexplored perceptions of parents and nurses have exposed parents to unpleasant experiences and influenced the quality of care for NICU infants (8).

The most challenging and stressful experience for the parents of NICU-admitted infants is to watch their newborns undergo painful medical procedures. In fact, mothers' memory of such events remains vivid long after NICU discharge. Stressed and anxious parents normally suffer from fatigue, loss of control, fear and anxiety (9). Parents' grief is manifested as fear, insomnia, anger and utter exhaustion. These parents express their need for sympathy, care and respect by healthcare teams. In fact, dismissing or belittling parents' concerns or emotions intensifies the family's anguish (10).

Loss of control as a caregiver or parent brings a sense of defeat and hopelessness to the parents of NICU-admitted infants as they experience extreme stress in this stage (11). In many countries, support programs, based on Individualized Developmental Care and Assessment Program (NIDCAP), have been implemented to assist parents and newborns. NIDCAP was designed as a novel and evolutionary approach to identify behavioral changes in premature infants, promote their health, reduce their vulnerability and alleviate parents' anxiety (12).

Valizade et al. (2004) studied the sources of stress among parents of NICU-admitted infants and realized that inability to participate in neonatal care was a major source of anxiety (13). Additionally, Berim Nejad and colleagues (2011) suggested immediate training on coping skills for mothers after a premature birth in order to reduce their level of stress and anxiety (14).

Qualitative research aims to provide a thorough understanding of a phenomenon via evaluating firsthand experience, based on quotations from actual conversations. This type of research aims to shed light on how individuals derive meaning from their surroundings and how these meanings can influence their behaviors. Such studies can highlight the need for designing support systems for parents by healthcare providers, especially nurses, given their close contact with the parents. In this study, we aimed to explore the perspectives of parents and nurses on NICU functions.

Method

Qualitative content analysis was applied in the present research to describe how parents and healthcare providers perceive their NICU experiences (15). In total, 21 participants including six fathers, seven mothers, five nurses and three physicians were enrolled in this study in 2011. Nurses and physicians were employed at governmental and private hospitals of Isfahan, Iran.

The inclusion criteria for the parents were as follows: 1) willingness to participate in the study, and 2) having no prior NICU experience within the last 24 hours. On the other hand, the exclusion criterion was a prior history of anxiety, depression, obsession or psychosis. Moreover, the inclusion criteria for healthcare providers were willingness to participate in the study and having at least six months of work experience in NICUs.

The study objectives were explained to each participant. The time and place of interviews were mutually agreed upon by both parties verbally and in writing. Researchers also obtained a written informed consent from each participant for voluntary engagement in a tape-recorded interview session. The participants were assured of their anonymity and confidentiality of the data.

The hospitals were selected from different regions of the city for a broad representation of the population. Individual interviews with nurses and physicians were conducted at the hospitals. The parents were interviewed either at their workplace, home, hospital or an arranged private location.

Purposeful sampling of the parents was followed by initial, semi-structured interviews, which were conducted by asking the following open-ended questions:

- "Please describe your NICU experience."

- "Please talk about your concerns on having your infant admitted to the NICU."

Upon recording parents' responses to the questions, further detailed questions were asked. Each interview lasted 30-60 minutes and continued until data saturation was reached. Although we included 21 participants in our study, 25 interviews were carried out in total.

Content analysis of raw data involved open coding for categorizing and abstracting the data, using a seven-stage process as follows: 1) information on the research question; 2) sampling for analysis; 3) describing the relevant categories; 4) determining the coding process and training the coder; 5) implementing the coding process; 6) determining the trustworthiness of the research process; and 7) analyzing the results of the coded data (16).

The researchers listened to the recorded interviews and read the transcribed data several times to form a general perspective on the contents. The transcribed interviews included verbatim expressions, which helped identify the major contents of interviews and allowed for code extraction. At this point, perceptions and codes were classified based on their similarities and dissimilarities in order to derive a series of categories.

The trustworthiness of the present study was supported by four criteria: credibility, dependability, conformability and transferability. To achieve credibility, opinions of the research group were considered in the interviews and data analysis. Interview texts, extracted meaning units and major categories were discussed by some participants and two PhD graduates in nursing.

To determine data dependability, opinions of an external viewer, who was an experienced researcher in qualitative research (not a member of the research team), were noted; a consensus was reached on the results. To attain conformability, all procedures were recorded, and a report was prepared on the research progress. To ensure data transferability, the information obtained from two patients outside the study, who were under similar circumstances as the study participants, was discussed and confirmed.

Results

Based on the evaluation of demographic characteristics, the mean age of the mothers of NICU-admitted infants was 27 years. In total, three nulliparous and four multiparous mothers were evaluated in this study. Three mothers had basic education, while four had high school diploma or higher; one of the mothers had pursued academic education and received a BS degree.

The mean age of the fathers of NICU-admitted infants was 37 years. Two fathers had primary education, three had less than high school diploma and one had earned a BS degree. The mean age of the nurses was 35 years, with an average NICU experience of six years. Moreover, the mean age of physicians was 39 years, with an average NICU experience of five years.

Based on the content analysis, five major categories were extracted in our study: 1) care provision in NICUs; 2) diagnostic difficulties; 3) NICU admission process; 4) challenges of hospitalization; and 5) maintenance of infant viability.

1. Care provision in NICUs

This category focused on mothers' concerns about the possible damages to their newborns. Mothers perceived intravenous therapy as traumatic and complained of inadequate care, unpreparedness of nurses and lack of discharge planning. They were also concerned about home care of premature infants with medical complications. It was difficult for the parents to watch their newborn undergo medical procedures:

"They move the needle in the vein in order to draw 5 cc blood samples. Sometimes, they take blood from the infant's heel by hitting and holding it tight; so, the infant starts to cry…This is an unbearable experience." [m2, age: 30 years]

NICU-admitted infants are often hospitalized for a long period of time and their veins are damaged due to repeated venous access by physicians or inexperienced healthcare providers:

"Before finding the proper site for venous access, they puncture many parts of the infant's body. The detected vein soon becomes irritated and injured and the procedure needs to be repeated all over again. I think the infant loses more blood and experiences too much pain…" [m6, age: 28 years]

In this regard, a nurse with 13 years of experience stated:

"Parents are disturbed as they see us perform different medical tests and draw blood samples from their infants…" [n4, age: 42 years]

"The NICU is always crammed full and medical teams cannot constantly attend the infants. This makes the parents upset and dissatisfied…" [n4, age: 42 years]

"The staff is not skilled enough. They do not take any measures unless the infant's condition

deteriorates to its worst state…This is too late…" [m7, age: 33 years]

Mothers of NICU-admitted infants become anxious as their infants start to cry; some even doubt the skillfulness of nurses:

"I asked them to contact me if my baby started to cry, but no one cared enough to contact me for a day. When I paid a visit to the hospital, I found my baby crying. I asked the nurses why they had neglected to call me, but I received no response, not even a kind gesture…There must be something wrong with them." [m4, age: 20 years]

As the parents stated, their NICU experience was unpleasant and they eagerly looked forward to the discharge of their infants. The stress level of the parents intensified as they spent more time in the NICUs, since more procedures were required for the infants. In this regard, a nurse with one year of NICU experience said:

"It is uncomfortable for the parents to be a witness of the procedures, since they do not have a prior experience in this area; but, we do these routine procedures on a daily basis. Parents refuse to face this fact as this is their first experience…" [n3, age: 26 years]

2. **Diagnostic difficulties**

This category was comprised of four sub-categories: 1) misdiagnosis; 2) delayed diagnosis; 3) contradictory diagnosis; and 4) lack of diagnosis. Delayed diagnosis was the most stressful situation for the parents. At university hospitals, parents reported more frequent contradictory diagnoses:

"We were informed that our baby needed electrocardiography, while at hospital "X", we were assured about the normal status of our newborn's heart. We have waited for almost 12 days and now after getting the results, we all feel terrible." [f2, age: 28 years]

A mother whose infant required specific medical tests for diagnostic purposes said:

"At the hospital, I reminded the doctor of the required tests, but he ignored me. If they had put my baby in the apparatus, the situation would not have deteriorated." [m3, age: 24 years]

"The doctor had mentioned the risk of seizure, but they refused to tell me if my baby had experienced a seizure before or after delivery. I asked more questions, but they told me to leave. Am I not supposed to know what is wrong with my baby? No one gave me a proper answer." [m4, age: 20 years]

Moreover, misdiagnosis by physicians induces stress in all parents:

"Why do they make a decision or confirm a diagnosis when they are uncertain?" [m7, age: 43 years]

3. NICU admission process

This category included two major sub-categories: 1) uncertainty about the length of hospital stay; and 2) family visiting hours. Once the infant's condition has been diagnosed, the parents ask for further information on the nature of the disease and the required length of hospital stay. Unanswered questions on these issues make the parents doubt the providers' credibility:

"I talked to doctor X and he said he didn't know what's wrong with my baby. I wonder how he can prescribe medications for a patient if he is not fully informed." [f1, age: 41 years]

As time passes by, parents lose their hope in the process of healthcare provision:

"No one seems concerned…They don't tell me why my baby is naked or explain why or what they are doing to my baby…I think it's all a waste of time." [m4, age: 20 years]

Some parents travel long distances from the suburbs to city hospitals to visit their newborns. This process is costly, stressful and troublesome for families with more than one child:

"We traveled 40-50 km to the closest medical center for my wife's prenatal care. Now, we have to travel this distance three to four times a week without getting any results. This is upsetting for all of us." [f5, age: 30 years]

Exploration of parents' experiences revealed problems such as long-distance travelling, irregular infant feeding and parents' work-related concerns:

"The problem is my job. I must take my wife to the hospital to breastfeed the baby; sometimes, we bring a bottle of breast milk with us. But, the travelling time is not fixed…We all feel stressed with these conditions." [f4, age: 34 years]

4. Challenges of hospitalization

This category addressed parent-infant attachment issues and maternal rejection of unstable newborns, suffering from physical abnormalities. Parents had difficulties with infants' unexpected NICU admission after birth and the slow progress of their status. They felt as if they had lost control of their lives by being present in the NICU and their infant was exposed to multiple procedures due to respiratory distress or other conditions. In this regard, a nurse with nine years of NICU experience said:

"Another frightening aspect of NICU admission for the parents is to watch their newborn being

placed on a ventilator, which seems like a giant machine." [n1, age: 33 years]

Most infants were assigned to specific feeding programs, which worried most parents. It was difficult for them to see a vulnerable newborn under intravenous therapy:

"I never imagined a day like this. I thought I would take him home with me, but they said he was too small and required hospitalization." [m5, age: 26 years]

Parents saw unfamiliar equipments and devices in the NICUs and felt intimidated, ineffective and uncomfortable:

"He was born in the seventh month…He was weak and didn't stop crying. So many things were attached to him." [m3, age: 21 years]

Feeding tubes are used for infants with feeding difficulties. These tubes may be connected to the chest wall and appear menacing or frightening to the parents:

"With all these devices and tubes attached to the baby, it is hard to get close to him…They do not wipe away the blood on his body." [f2, age: 28 years]

Infants with respiratory problems are connected to a ventilator, which resembles a huge apparatus in parents' eyes:

"After two days, I came to visit my baby and found him to be weak and fragile…He was placed on a large apparatus with many tubes attached to it." [m6, age: 28 years]

All the equipments seem complex and unfamiliar in an isolated atmosphere where people wear gowns, masks and shoe covers to avoid infections. Infants' oxygen level may drop and they may lose the ability to breathe. As the parents watch their weak, fragile newborns in the incubator, their stress and discomfort become intensified:

"When they open the incubator cover, the alarm for "low oxygen" goes off…This makes me mad." [m2, age: 30 years]

5. Maintenance of infant viability

This category included issues such as infertility and high-risk pregnancies. Parents are under extreme stress throughout infertility treatment, preconception, pregnancy and postpartum period. These parents hopefully anticipate a successful fertility intervention and find the NICU experience beyond their tolerance:

"We tried and tried and after four IVF attempts, we finally succeeded. I gave birth four weeks early and had to take maternity leave. Everyone took good care of me and we all anticipated a healthy birth." [m1, age: 43 years]

"Couples who become parents after struggling with infertility call their newborn the 'Golden Baby'." [n5, age: 37 years]

We found that the parents of so-called "golden babies" had the maximum level of stress during NICU admission.

Discussion

The content analysis of the obtained data, which were classified into five categories, revealed limited parental awareness about NICU environments and the provided services. The parents were concerned about inadequate nurse-patient relationship, information exchange and the support system, which facilitates home care of the infants.

Schlittenhart (2011) found that in the United States, discharge planning was an invaluable component of NICU function in preparing parents for infant care at home. Nurses were trained on discharge planning, and parents of NICU-admitted infants were required to have a certification in neonatal cardiopulmonary resuscitation before discharge. In fact, parents' lack of participation in discharge planning sessions delayed neonatal discharge, with legal ramifications for the parents (17).

Based on the mentioned study, further efforts are required to secure infants' well-being and eliminate the possible risks. Extended educational programs were provided in form of video clips to be used at home. Moreover, community nurses paid regular home visits to protect infants against further complications while being at home (17).

Our findings revealed a lack of attachment between NICU parents and their infants. Cleveland (2008) highlighted the importance of parent-infant attachment and explored maternal tendency to hug the infant or at least sit close and touch him/her in order to fill the emotional void. The parent-nurse relationship is a priority in this realm. Nurses must provide an atmosphere of compassionate care for the parents in order to empower them for assuming their role in NICUs. Parents should feel comfortable to ask questions and seek information. Every effort in the NICU should focus on infant care and a successful discharge planning should start upon admission.

Despite all medical advances in care provision in NICUs, no technology has replaced human care and contact (18). Melinko et al. (2006) expressed that parents who participated in "parent enhancement training" were more optimistic

about their infant's health in NICUs. They experienced less fatigue and tension during the infant's NICU stay (19). Jafari et al. (2011) found that mothers' early involvement and acquisition of written information from the hospital staff had positive impacts on their emotional state (20).

Based on our findings, parents faced difficulties in establishing a bond with their infants during hospitalization. Infants with malformations and physical disabilities were rejected by the parents. Moreover, unexpected hospitalization of infants after delivery affected parents' self-perception as they questioned their ability in care provision for their infants; other studies have reported similar findings. Lee et al. (2005) in Korea asserted that mothers' concern was mostly related to the small size of the infants and their poor health status; in their study, negative perceptions caused adverse consequences (21).

Vasu and Modi (2007) in England reported that NICU staff should promote infant nutrition, while other studies (22) focused on reducing the duration of parent-infant separation after birth. Moreover, Boykova and Kenne (2008) in Russia found that mothers were concerned about their infants' sleep patterns, nutrition, bowel movements and breathing; however, they were satisfied with the information they received from the NICU staff. In most studies, mothers were worried about long-term care of their infants. Moreover, family members and relatives were the main source of support for the mothers by providing relevant information (23).

Balakrishnan (2010) in the United States stated that long periods of treatment by ventilators could affect many aspects of infant care. In general, the oxygen cannula agitates the infant's skin and intensifies parents' stress. Infants with low birth weight and necrotizing enterocolitis are hard to feed and require prolonged hospitalization (24). Our findings indicated that parents with a prior history of infertility experienced severe stress at NICUs. However, our findings on infertile parents in NICUs were limited and we found no published articles for making further comparisons.

Conclusion

The main strengths of this study were the positive impact of oral stimulation and NNS on weight of healthy preterm infants. Based on our results, in clinically stable preterm neonates, oral stimulation and NNS should be implemented to increase their weight; however, further studies are required to address this issue

Acknowledgements

We would like to thank all the participants for their contribution to this study. We also extend our gratitude to the administrative board of Isfahan University of Medical Sciences for their support. This study was approved by the Ethics Committee of Isfahan University of Medical Sciences (grant No.: 389294).

References

1. Verklan T, Walden M; AWHONN. Core Curriculum for Neonatal Intensive Care Nursing. 4th ed. Philadelphia: Saunders; 2010.
2. Kliegman RM, Behrman RE, Jenson HB, Stanton BF. Nelson Textbook of Pediatrics. 18th ed. Philadelphia: Saunders. 2007.
3. Merenstein GB, Gardner SL. Handbook of Neonatal Intensive Care. 6th ed. St. Louis: Mosby; 2006.
4. Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. Adv Neonatal Care. 2006; 6(1):37-53.
5. Khalajinia Z, Jandaghi Gh. Maternal risk factors associated with preterm delivery in Qom province of Iran in 2008. Sci Res Essays. 2012; 7(1):51-4.
6. Jones L, Woodhouse D, Rowe J. Effective nurse parent communication: a study of parents' perceptions in the NICU environment. Patient Educ Couns. 2007; 69(1-3):206-12.
7. Carter JD, Mulder RT, Darlow BA. Parental stress in the NICU: the influence of personality, psychological, pregnancy and family factors. Personal Ment Health. 2007; 1(1):40-50.
8. Punthmatharith B, Buddharat U, Kamlangdee T. Comparisons of needs, need responses, and need response satisfaction of mothers of infants in neonatal intensive care units. J Pediatr Nurs. 2007; 22(6):498-506.
9. Gale G, Franck LS, Kools S, Lynch M. Parents' perceptions of their infant's pain experience in the NICU. Int J Nurs Stud. 2004; 41(1):51-8.
10. Laing IA, Freer Y, editors. Reorientation of care in the NICU. Semin Fetal Neonatal Med. 2008; 13(5):305-9.
11. Turan T, Başbakkal Z, Özbek Ş. Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit. J Clin Nurs. 2008; 17(21):2856-66.
12. Als H. Newborn individualized developmental care and assessment program (NIDCAP): new frontier for neonatal and perinatal medicine. J Neonatal Perinatal Med. 2009; 2(3):135-47.
13. Borim Nejad L, Mehrnosh N, Seyyed Fatemi N, Haghghani H. Maternal stressor agents with premature infants in neonatal intensive care units. IJCCN. 2011; 4(1):39-44.

14. Valizadeh L. Akbarbegloo M, Asadollahy M. The effective stressors on mothers of preterm babies in the neonatal intensive care unit. Tabriz Univ Med Sci. 2009; 31(1):85-90. (Persian)
15. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005; 15(9):1277-88.
16. Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs. 2008; 62(1):107-15.
17. Schlittenhart JM, Smart D, Miller K, Severtson B. Preparing parents to care for NICU discharge: an evidence based discharge teaching tool. Nurs Womens Health. 2012; 15(6):848-94.
18. Cleveland LM. Parenting in the neonatal intensive care unit. J Obstet Gynecol Neonatal Nurs. 2008; 37(6):666-91.
19. Melnyk BM, Feinstein NF, Alpert-Gillis L, Fairbanks E, Crean HF, Sinkin RA, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the creating opportunities for parent empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. Pediatrics. 2006; 118(5):e1414-27.
20. Jafari Mianaei S, Alaee Karahroudy F, Rasuli M, Zayeri F. Effectiveness of" parent empowerment" program on anxiety and stress in mothers who have preterm infants hospitalized in NICUs. Payesh. 2012; 11(2):253-8.
21. Lee I, Norr KF, Oh K. Emotional adjustment and concerns of Korean mothers of premature infants. Int J Nurs Stud. 2005; 42(1):21-9
22. Vasu V, Modi N. Assessing the impact of preterm nutrition. Early Hum Dev. 2007; 83(12):813-8.
23. Boykova MV. Follow-up care of premature babies in Russia: evaluating parental experiences and associated services. Infant. 2008; 4(4):126-30.
24. Balakrishnan A, Stephens BE, Burke RT, Yatchmink Y, Alksninis BL, Tucker R, et al. Impact of very low birth weight infants on the family at 3months corrected age. Early Hum Dev. 2011; 87(1):31-5.