



Investigating the Strategic Elements of Family-Centered Care in the Neonatal Intensive Care Unit: A Qualitative Study

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Abstract

Introduction: The family is an integral part of the health care team. Focusing on family-centered care in neonatal intensive care units (NICUs) involves using strategies to support families by supporting parental involvement in NICUs. Accordingly, the present study aimed to examine the strategic elements of family-centered care in NICUs.

Methods: The present study was conducted using conventional qualitative content analysis based on Graneheim and Lundman's approach and purposive sampling. This study was conducted in NICUs of Isfahan hospitals in 2018. The data were collected through unstructured face-to-face interviews with 15 participants including parents and NICU staff. The collected data were encoded and analyzed through Microsoft Word Office and OneNote 2010.

Results: The analysis of the data revealed 3 main themes and 7 subthemes related to the strategic elements of family-centered care. The extracted themes (and subthemes) were: (1) Family and care (family involvement in the care process, the interaction between the medical staff and the family), (2) Parental characteristics in care (the mother as the core element of care, the father's role in care), (3) Family needs (the need of the family for information, the importance of family preparation, the family's need for spiritual support).

Conclusion: The present study revealed the key elements of the structure of family-centered care from the perspective of families and medical staff. The findings of this study also highlighted the role of the family in caring for patients and meeting their needs. Accordingly, measures should be taken to improve the quality of family-centered care by taking into account the strengths of this strategy.

Keywords: Family-centered care, Neonatal intensive care unit, Parents, Qualitative study

Introduction

A family is a group of people bound together via marriage and birth and is an integral part of the health care team (1). Therefore, during patient care, the family needs a sound understanding of the disease and nurses are required to help promote family members' health and well-being by creating hope and trust in them. In fact, most families

tend to be involved in caring for their inpatient child and they find this participation beneficial for themselves and their children. Thus, one of the ways to empower parents is to implement family-centered care (2). Family-centered care is defined as the provision of services for family participation in the development and

implementation of interventions, reflecting the professional involvement of the family (1). Family-centered care is also a caring philosophy based on the vital role of the family, which is an essential component of child and infant nursing and promotes the health of the family and the infant (2). The focus on family-centered care in the neonatal intensive care unit requires using strategies to support families by supporting parental involvement and their unlimited attendance (3). Family involvement leads to positive effects on the physical, cognitive, and psychosocial development of infants (4). Furthermore, caring for infants and their families in the neonatal intensive care unit creates a complex network of health care providers (5). An infant needs to communicate with his/her parents to promote physical and psychological-emotional development. Moreover, parents need meaningful relationships with the infant to mark their identity as a mother or father (6). Thus, providing psychological and social care to parents whose infants are admitted to intensive care units can improve their functioning as well as their relationships with their infants (7). Besides, nurses can monitor the health of the infant and the infant's family by providing family-centered care (8).

A review of the literature shows that several studies have highlighted the importance of family-centered care in neonatal intensive care units in Iran. These studies have mostly used a quantitative method. For example, a cross-sectional study by Aran et al. showed that mothers and nurses had positive perceptions of family-centered care (9). In contrast, the results of a descriptive cross-sectional study by Mirlashari et al. suggested nurses and physicians did not agree on a large number of executive barriers to family-centered care in NICUs. Therefore, to facilitate family-centered care, it is necessary to pay attention to the attitudes of both groups (10). A review of the previous studies showed the absence of no in-depth data on the phenomenon of family-centered care and its elements in the neonatal intensive care units of Iranian hospitals. Therefore, it seems that conducting qualitative studies can fill this gap. Additionally, considering the importance of the role of parents and family-centered care, it is necessary to identify the key elements of its body. It is also necessary to recognize its strengths and weaknesses so that required measures can be taken to improve the quality of neonatal care and better implementation of family-centered care, which is very important in care policies. Accordingly, the

present study seeks to explain the factors affecting family-centered care strategy in neonatal intensive care units.

Methods

This qualitative study was conducted in neonatal intensive care units in Isfahan over 10 months to identify the strategic elements of family-centered care. To this end, conventional qualitative content analysis was employed based on Graneheim and Lundman's approach. A content analysis study is not only a qualitative study but also a simple and effective technique for analyzing qualitative data (11). The participants were 8 nurses and 2 physicians working in NICUs, and 2 fathers and 3 mothers who were selected using purposive sampling. In this study, an attempt was made to select participants with maximum diversity. The inclusion criteria for nurses and physicians were having at least 1 year of clinical experience at NICU and giving voluntary and informed consent. The inclusion criteria for parents were having an infant admitted to the NICU for at least the last 1 year and giving voluntary and informed consent. After obtaining permission from the relevant authorities, the researcher selected the participants from among the persons who met the inclusion criteria. Some parents were also selected from among the persons introduced by colleagues. After obtaining the written and oral consent of the participants, the data were collected through unstructured face-to-face interviews conducted in places such as a quiet room in the NICU and sometimes at parents' homes. The interviews were audio-recorded. Each interview lasted 20 to 70 minutes. The interviews continued until the data were saturated (A number was assigned to each participant). Before conducting the interviews, the objectives of the study were explained to the participants. Besides, they were told that their data would be kept confidential. The interviewer tried to establish a sincere and honest relationship with the participants and gain their trust and confidence. The participants were then asked to describe the importance of family-centered care and what they considered to be the key factors in family-centered care and discuss the strengths and weaknesses of family-centered care in the neonatal intensive care unit. The participants' statements in the interviews were recorded. The interviews were continued until no new information was observed in the data. Then, each recorded interview was transcribed verbatim using Microsoft Word Office. The collected data were analyzed using conventional qualitative content analysis based on Graneheim

and Lundman's approach as follows: In the first step, each interview was considered as a unit of analysis, and the meaning units were determined. In the second step, the codes were extracted from the transcripts, and the words, sentences, or paragraphs were considered as codes. In the third step, the codes were summarized to reduce the size of the text while preserving the original meaning. Accordingly, the initial codes emerged. In the fourth step, the initial codes with a similar meaning were placed in a subcategory. Finally, in the fifth step, the primary subcategories were constantly compared with each other, and those with similar themes were placed in the same category (12). The data were managed using Microsoft Word Office and One Note 2010. Moreover, the robustness of the data was checked through the criteria of credibility, dependability, transferability, and confirmability. The credibility of the data was established through the researcher's in-depth engagement with participants and review of the extracted codes by 2 participants and 2 professors of Khorasgan University. Furthermore, the dependability of the data was ensured through in-depth and unstructured interviews and the description and recording of all details of the research procedure. The confirmability of the data was checked by ensuring that there was no bias in collecting and analyzing the data, and having the extracted codes confirmed via member checking and peer checking. Finally, the transferability of the findings was enhanced by collecting the data from participants with maximum diversity.

Results

The participants in this study were 15 persons including physicians, nurses, and parents of infants admitted to the neonatal intensive care unit. The average age of the physicians and nurses was 35 years and their education varied from a bachelor's to a Ph.D. degree. Besides, the parents' average age was 33 years and their education ranged from elementary school to master's. The analysis of the data showed that the strategic elements of family-centered care were categorized into 3 main themes and 7 subthemes. The extracted themes (and subthemes) were: (1) Family and care (family involvement in the care process, the interaction between the medical staff and the family), (2) Parental characteristics in care (the mother as the core element of care, the father's role in care), (3) Family needs (the need of the family for information, the importance of family preparation, the family's need for spiritual support) as shown in Table 1.

1. Family and care

The participants emphasized that the family members' presence in the NICU and their empowerment affect the process of care and the infant's condition. This theme was divided into two subthemes including family involvement in the care process and the interaction between the medical staff and the family.

1.1 Family involvement in the care process

The findings of the study indicated that the family is an integral part of the infant's life and part of the care process. Thus, the family members should be empowered through training during the infants' admission to the NICU. One participant stated, *"Families should definitely be involved in care, and our job is to empower them"* (Nurse 7). Furthermore, the presence of parents in the NICU is effective in learning care, the recovery process, and speeding up the infant's discharge. In contrast, their lower involvement adversely affects this process. One of the nurses said, *"The staff tells mothers that their infants need them to be there as the mother's presence is very effective in the infant's weight gain and brain development"* (Nurse 5). A physician also said, *"A mother who has not had much contact with her baby will return the baby very as soon as the baby is discharged because she does not know what to do. Moreover, parents need to see their baby as soon as possible, and we need to get parents into the NICU right away"* (Physician 1). Furthermore, to gain independence, the family should gradually get involved in care such as changing diapers, feeding, feeding the baby with the gastric catheter, etc. One of the physicians said, *"During the infant's hospitalization, we should gradually prepare the mother until she becomes independent in caring for the infant"* (Physician 2). However, it was found that parents sometimes cause problems with their presence in the NICU, such as disclosing issues within the NICU, inducing stress in other mothers and staff, and interfering with staff and caring for other babies. One of the nurses stated, *"They hear what we say about other infants and interfere with the care process for other children"* (Nurse 8). The participants also highlighted the importance of family involvement, parental decisions, and their agreement with care processes and actions. One of the nurses said, *"The law says, for example, you do not have the right to do a lumbar puncture (LP) for neonates without their parents' permission"* (Nurse 7).

Table 1. The themes and subthemes identified in the study

Main themes	Subthemes
Family and care	Family involvement in the care process, The interaction between the medical staff and the family
Parental characteristics in care	The mother as the core element of care, The father's role in care
Family needs	The need of the family for information, The importance of family preparation, The family's need for spiritual support

1.2 The interaction between the medical staff and the family

The participants emphasized the need for effective communication between the family and treatment staff. They believed that continuous communication leads to better understanding and cooperation between them. One father said, *"If I worked at NICU, I would emphasize the connection between nurses and people accompanying the patient"* (Father 2). However, if there is no effective communication between the medical staff and parents, it will reduce the quality of care. One of the nurses stated, *"Unfortunately, we do not learn the art of communication well from the beginning, so we cannot support the family well"* (Nurse 4). Besides, the way the treatment staff treats parents can lead to satisfaction and empathy, or dissatisfaction and unhappiness of the parents. One of the mothers said, *"One of the nurses did her best and used all her skills so that I could do breast pumping, and every word she uttered encouraged me"* (Mother 1). On the other hand, one of the fathers said: *"The hospital staff did something that made me very upset. My sister-in-law came to help my wife breastfeed the baby. She did not know how to do it and asked a nurse for help. The nurse angrily ordered her to leave the room if she couldn't do it"* (Father 1). The participants also stated that when talking to parents, it is necessary to use simple words that are understandable and fit their level of education. One of the nurses stated, *"We provide explanations to parents by considering their level of education and the family condition"* (Nurse 5). Furthermore, the words used when addressing parents are important especially when talking to a grieving family. One of the physicians stated, *"It's okay to say sad things like 'I understand you' because it makes families not be defensive against accepting the situation"* (Physician 1).

2. Parental characteristics in care

The participants pointed to the importance of the role and influence of both parents in care. However, the analysis of the data indicated that less

attention was paid to the role of the father in care. Parental characteristics covered two subcategories: The mother as the core element of care and the father's role in care.

2.1 The mother as the core element of care

The results of the present study indicated that mothers play a very important role in the care process to the extent that their interest in caring for the baby can make them partners in the treatment team, and thus, empowering them is very important. One of the mothers said, *"I would go to the NICU and say, 'Well, let me do something, and I will help you as much as I can' ..."* (Mother 1). One of the nurses stated, *"The mother is a member of our treatment team"* (Nurse 1). Participants also highlighted the importance of maternal comfort and rooting out their problems in the care process. One of the participants stated, *"I cannot deprive a mother of seeing her critically ill baby or I cannot remain aloof to. If we did so, we would not have done our care duty because the mother's peace is important"* (Nurse 3).

2.2 The father's role in care

The participants stated that the father has abilities that can be used for better care of the infant. In fact, the father is a good psychological supporter for the mother during the care process and can do a lot of care. One physician said, *"A father can do almost everything a mother does, and he is very effective in kangaroo care"* (Physician 2). However, many findings indicate that the father's role in care, education, and involvement in the NICU are less considered due to the structure of the NICU and religious restrictions, and fathers are ignored in most cases. One of the fathers said, *"I feel that they do not engage many fathers in training, because the father may not give a sign of how important it is to him"* (Father 2). One of the nurses stated, *"The truth is that fathers are often overlooked and fathers are more thought of a financial sponsor"* (Nurse 5).

3. Family needs

The results of the study showed that the families

with an infant admitted to the NICU have needs that must be met during the care process. These needs were divided into subcategories including the need of the family for information, the importance of family preparation, and the family's need for spiritual support.

3.1 The need of the family for information

According to the findings of this study, parents' need for information is part of the family's rights, and providing accurate information will lead to more peace and easier acceptance of the situation by the parents. One of the mothers said, *"I think the parents are the first persons who should know the condition of the child"* (Mother 2). Another mother stated, *"I told the doctor I would like to know about any problem with my child. I am a mother; I have the right to know it"* (Mother 3). However, parents' lack of information may lead to consequences such as pessimism about the treatment system, mistrust, anxiety, and aggression. One of the nurses stated, *"What is the reason for the parents' aggressive behavior? I am aggressive when you are to blame because I do not know what you did for my patient"* (Nurse 7). Therefore, participants stated that the information should be provided to the parents step by step. One of the nurses added, *"Information is given to the mother piece by piece"* (Nurse 4).

3.2 The importance of family preparation

The analysis of the participants' statements indicated that the parents needed to be prepared for any possible events during care as they can accept events more easily. One of the participants stated, *"If the family needs to know about the patient, we can't do anything else, why not tell them? Experience has shown that if the mother is ready, she will accept the death of her baby more easily"* (Physician 2). Another participant said, *"We must prepare the parents. As soon as the parents see the child's condition, they will get along to it quickly"* (Nurse 3). Besides, preparing the parents before the time of discharge is of special importance because it empowers the parents and reduces their stress. Therefore, preparing parents through training and increasing monitoring of their performance is effective. One of the nurses said, *"The closer we get to the moment of discharge, the more training is provided, so the parents are not afraid of the problems that may happen for their child at home"* (Nurse 6).

3.3 The family's need for spiritual support

The findings of the present study indicated the stressful conditions governing the neonatal intensive care unit and the uncertain future of the critically ill baby expose parents to a lot of emotional and psychological stress. Therefore, the parents always seek to avoid tension and sear for peace and support. One participant said, *"As soon as I got out of the hospital, the fresh air, the trees, and the sky gave me energy"* (Mother 1). Some parents also stated that they needed support from medical staffs, and believed that the medical staffs were very good supporters for the parents. One of the participants stated, *"I think nurses are very helpful and can show more sympathy and understanding for a family"* (Mother 2). One of the nurses also stated, *"My duty as a nurse is to be aware that parents also need care and peace of mind"* (Nurse 2). Furthermore, many participants pointed out that support from professionals such as counselors, psychiatrists, and psychologists can be very helpful, and in some cases even more effective than the support provided by medical staff. However, they also believed that such professionals are not used as they should be. One mother said, *"I think there should be a very competent counselor in the hospital to provide advice and counseling to the mother who is very concerned about her infant's condition and explain everything step by step"* (Mother 2). One of the nurses also stated, *"A professional counselor can be sympathetic to parents and provide very helpful advice. I do not know how to do this. Unfortunately, such professionals are not available and used in the hospital"* (Nurse 5).

Discussion

The findings of the study concerning the first theme (Family and care) indicated that the presence of parents in the NICU increases their ability and independence to provide care in the NICU and home. They also can bear stress more easily, and the improvement of their mood speeds up the infant's recovery and increases their interaction with the treatment staff. However, the parents' low involvement leads to problems such as poor care of the baby, more stress during discharge, and less interaction with staff. Consistent with this finding, Coats et al. acknowledged that the constant presence of parents at the NICU provides a greater opportunity for care, building relationships, and familiarizing staff with their needs, and nurses are more confident to leave the infant to the parents if

they are trustworthy (13). The present study also showed that to empower the parents and reduce their stress during discharge, they should be provided with step-by-step training to do things such as changing diapers, feeding the baby with a gastric catheter, bathing the baby, and getting to know warning signs. Previous studies have also shown that parental involvement and preparation should take place in the neonatal intensive care unit from the first moment of admission until discharge because it increases parents' confidence, empowers them, and facilitates the discharge process (14,15). The present study also suggested that parents' meeting with their baby is very important from the very first moments of admission, and mothers are usually allowed to visit their infants freely. However, in some NICUs, the baby could be visited only at the time of the appointment or for breastfeeding. These restrictions were stricter for the father. However, Li et al. stated that parents want to have more access to their baby and more involvement in care in the NICU, as this is likely to improve the baby's condition (16). Therefore, it is necessary to identify the barriers to the presence of parents and remove these barriers, so that parents can be actively involved in NICU care and easily meet their baby.

However, the participants highlighted some disadvantages of the family's constant presence in the NICU such as disclosing secrets in the NICU, creating stress for other families and staff, interfering with the affairs of the medical staff, and care for other newborns. In a similar vein, Coats et al. argued that the constant presence of parents in the NICU leads to issues such as fatigue and confusion of nurses, spending too much time responding to families while caring for a critically ill baby, lack of complete concentration on care, the feeling of pressure due to parents' attention and feeling uneasy when providing information to colleagues in the presence of parents (13). Accordingly, such problems must be addressed more carefully and further studies are needed to eliminate them. The present study also suggested that it is very important to pay attention to parents' decisions at all stages and all issues must be clarified for them so that they can make the right decision. Consistent with this result, other studies have shown that families should be involved in the decision-making process, be allowed to choose the appropriate treatment, and receive the required instructions (1,17).

The findings of the present study also indicated

that medical staff's poor communication skills are one of the most important issues because effective family support depends on learning the art of communication, which will result in more parental involvement and reduce parental stress and fear. Studies have shown that interaction with parents was a difficult aspect of staff work, and evidence suggests that parents in the neonatal intensive care unit are under emotional stress due to poor communication with staff (15,18). The present study also suggested that parents considered the good treatment and rapport of the treatment team as a pleasant experience, and ineffective and unprofessional treatment made them resentful. Accordingly, Wigert et al. argued that poor communication skills of NICU staff lead to feelings of loneliness and abandonment of parents and the staff's communication skills must be improved through good staff training (19). In addition, the findings of the present study highlighted the importance of verbal communication and the use of simple and understandable language fitting to the level of understanding and education of parents and the use of compassionate expressions to sympathize with them in adverse events. Accordingly, Craig et al. pointed out that the relationship of medical staff with parents must be comprehensible (4). Furthermore, Macdonell et al. stated that most NICU staff, regardless of their role and experience, needed more training to tell the bad news (20). Therefore, it seems that there is a greater need for organizing communication skills training courses for medical staff, and more studies need to be conducted on challenges facing ahead.

The results of this study concerning the second theme, i.e. parental characteristics in care, suggested that both parents can have a share in care according to their capabilities because one of the most effective ways to prevent premature infant injury during hospitalization is the involvement of both parents in care (21). The present study also showed that mothers are considered as members of the treatment team, and their interest in participating in care is effective in accelerating the recovery of the infant and reducing the workload of the staff. Mothers can also encourage the father to participate in care. Accordingly, more attention should be paid to the mother as she can play a vital role in caring for the baby because maternal care leads to better outcomes such as: reducing the length of stay and readmission, increasing weight gain, reducing the need for feeding through the nasopharyngeal tube, and increasing maternal self-confidence (22,23). Furthermore, the present study

highlighted the need for testing mothers in terms of readiness and mental health. A study by McGowan et al. found that one-third of mothers of neonates admitted to the neonatal intensive care unit had mental health disorders and were much less prepared for discharge (24). Therefore, given that mothers have a significant share in providing neonatal care, it is possible to help advance the care process by meeting their needs and using their abilities. However, the present study showed that less attention is paid to training, support, and the role of fathers in care and fathers appear more in the role of sponsors. Nevertheless, fathers are not likely to express their feelings and thoughts as there are more introverted than mothers. Accordingly, Prouhet's study suggested that changing parental role, infant appearance, the NICU setting, and relationship with medical staff are stressors for fathers (25). Ionio et al. also found that fathers are not expected to be as involved in caring for their infants as mothers, while their involvement reduces stress and develops a paternal role in them (26). Moreover, the data in the present study showed that fathers can play a very effective role in caring for their baby such as kangaroo care, establishing an emotional connection with the baby, and providing emotional and spiritual support to the mother. A study by Kim et al. also suggested that the father's tactile stimulation of the infant improves the infant's physiological responses and increases the father's attachment (27). Therefore, it is necessary to pay more attention to the importance of the father's role in caring. Besides, related problems such as the physical condition of the NICU, religious restrictions on supporting fathers, and the lack of a well-designed program to educate them should be taken into account.

The third theme that was revealed in this study addressed "family needs". Accordingly, the present study showed that the need for information is one of the most important factors affecting family care. Parents of infants admitted to the neonatal intensive care unit need accurate information about the infant's condition (28). Besides, parents' perceptions of their child's situation can vary depending on the information received (1). The present study suggested that the parents are always looking for answers to their questions through books, the internet, or medical staff. Moreover, having information is a parental right because most parents felt more relaxed and eager to continue caring if they had access to scientific information. Lack of adequate and accurate information, on the other hand, created anxiety, distrust in the

treatment team, and parental stress. Therefore, it is necessary to inform the parents from the very beginning of the care process about the condition of their baby, sometimes even in detail. As a result, providing honest, understandable, and timely information reduces parental stress and depression and improves their bond with the baby (29). Modé et al. also found that providing reliable information to fathers from the beginning of hospitalization leads to an increase in their sense of security and control over the situation (30). In addition, the results of the present study considered the readiness and preparation of the parents for discharge or any other event in the NICU as another important need of the family. It was also noted that due to parents' anxiety and worry, it is necessary for them to be sufficiently prepared before discharge, and receive necessary instructions and get familiar warning signs before going home. Besides, parents must be prepared throughout the care and in the event of any incident occurring. Similarly, previous studies have shown that adequate parental preparation is essential for infant care (31), while parents of infants admitted to the NICU are often not sufficiently prepared for infant discharge, which increases their anxiety. (32). Therefore, medical staff is required to prepare parents for any possible event and to pay special attention to this important issue and the need of parents.

The data in this study showed that another need of parents was the need for emotional support and comfort. It was also shown that the medical staffs are important people who can provide this support because they spend a lot of time with their parents. In the same vein, Aliabadi et al. found that participants acknowledged parental concern is reduced with the support from medical staff (17). Abdeyazdan et al. also found that the emotional support of parents of premature infants reduces their stress (33). Furthermore, Milford et al. suggested that nurses have a key position to support parents because they are aware of the psychological, emotional, and financial impact of the neonatal intensive care unit (34). Aliabadi et al. also pointed to the supportive role of spouse and family as the main sources of adjustment (17). The present study showed that some mothers tended to leave the NICU and spend time at home and be with their families to relax. This can reduce the effective involvement of the mother in caring for the baby. Hence, more studies are needed to explore factors that can improve the situation for mothers and use the supportive role of the family to

help parents. On the other hand, although the medical staffs are very good supporters, most of the time, due to time constraints, they neglect interaction with parents. Therefore, some participants in this study pointed out the involvement of counselors, psychologists, or psychiatrists in all stages of care is required because sometimes they can help parents better than the medical staff. Therefore, interdisciplinary collaborations, including the participation of counselors, are needed to support parents and infants (4). Penny et al. also found that mothers of infants admitted to the neonatal intensive care unit are in dire need of psychiatric services due to psychological problems (35). However, the present study showed that the fact that such professionals are not members of the treatment team is a big gap and there are many problems with the employment of counselors and psychologists in medical teams. Therefore, it is suggested that these people are added to medical care teams to improve the quality of care.

Conclusion

The present study indicated that parents are important members of the care system in the neonatal intensive care unit that can produce many rewarding outcomes. For instance, the attendance of parents in the clinical setting and meeting the baby is very important for empowering them, engaging them in care, and gaining independence. However, attention must be paid to the barriers to the presence of parents and trying to remove them. Besides, the behavioral and verbal communication of the medical staff with parents is a very important issue that should be studied, and the necessary training should be provided to the staff. What's more, the caring role of both parents is important. The mother can play a vital role as a partner in the treatment team. The father also plays an undeniable role. However, the results of the study showed that the father's role does not receive much attention,

but it can be used as an opportunity to improve care. Furthermore, parents have needs that must be addressed. One of these needs is to obtain information that is part of their rights. Lack of parental awareness and information about the infant's condition can lead to consequences such as confusion, mistrust, and aggression towards the treatment team. Another need is to prepare the parents for the events that may happen for the infant and this can help them adapt to and accept the situation. Furthermore, given the special circumstances of the parents, they need to receive full support from the medical staff and specialists, and this need is sometimes ignored. All these factors together make the key elements of family-centered care in the neonatal intensive care unit. Accordingly, effective measures can be taken to improve the family-centered care process by taking into account these factors. Additionally, more studies are needed to address the limitations, weaknesses, barriers, and strategies to improve family-centered care.

Limitations

One of the limitations of the present study was that it was conducted in Isfahan. Therefore, more studies can be conducted in other cities to enrich the findings of this study.

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Conflict of Interest

The authors reported no conflict of interest.

References

1. Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol* 2015; 35(S1):S19-23. doi: 10.1038/jp.2015.145.
2. Nouhi E, Karbalaizadeh M, Abazari F. The effect of mothers' participation and the family-centered care on mother's anxiety with children suffering from gastrointestinal infections: a randomized clinical trial. *Journal of Clinical Nursing and Midwifery* 2015; 3(4):47-55. [In Persian].
3. Brelsford GM, Ramirez J, Veneman K, Doheny KK. Religious and secular coping and family relationships in the neonatal intensive care unit. *Adv Neonatal Care* 2016; 16(4):315-22. doi: 10.1097/ANC.000000000000263.
4. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol* 2015; 35(S1): S5-8. doi: 10.1038/jp.2015.142.
5. Henderson L, Reis MD, Nicholas DB. Health care

- providers' perspectives of providing culturally competent care in the NICU. *J Obstet Gynecol Neonatal Nurs* 2015; 44(1):17-27. doi: 10.1111/1552-6909.12524.
6. Roque AT, Lasiuk GC, Radünz V, Hegadoren K. Scoping review of the mental health of parents of infants in the NICU. *J Obstet Gynecol Neonatal Nurs* 2017; 46(4):576-87. doi: 10.1016/j.jogn.2017.02.005.
 7. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol* 2015; 35(S1):S9-13. doi: 10.1038/jp.2015.143.
 8. Verklan MT, Walden M. *Core Curriculum for Neonatal Intensive Care Nursing*. 6th ed. USA: Elsevier; 2020.
 9. Aran A, Abazari F, Farokhzadian J, Azizzadeh Forouzi M. Comparing the perception of family-centered care from the perspectives of nursing staff and mothers of hospitalized children in children's wards. *Hayat* 2018; 24(1):48-58. [In Persian].
 10. Mirlashari J, Sadeghi T, Sagheb S, Khanmohammadzadeh T. Nurses' and physicians' perspectives about barriers to implement family centered care in Neonatal Intensive Care Units. *Iran Journal of Nursing* 2015; 28(93):140-50. doi: 10.29252/ijn.28.93.94.140. [In Persian].
 11. Abedi H, Abbaszadeh A, Motaghi M. Factors influencing school health in elementary schools in Isfahan, Iran: a qualitative study. *Int J Community Based Nurs Midwifery* 2016; 4(4):352-62.
 12. Ghaljaei F, Goli H, Rezaee N, Sadeghi N. Spiritual challenges experienced by nurses in neonatal end of life: a qualitative study. *International Journal of Pediatrics* 2018; 6(9):8161-75. doi: 10.22038/ijp.2018.28630.2511.
 13. Coats H, Bourget E, Starks H, Lindhorst T, Saiki-Craighill S, Curtis JR, et al. Nurses' reflections on benefits and challenges of implementing family-centered care in pediatric intensive care units. *Am J Crit Care* 2018; 27(1):52-8. doi: 10.4037/ajcc2018353.
 14. Aloysius A, Kharusi M, Winter R, Platonos K, Banerjee J, Deierl A. Support for families beyond discharge from the NICU. *Journal of Neonatal Nursing* 2018; 24(1):55-60. doi: 10.1016/j.jnn.2017.11.013.
 15. Purdy IB, Craig JW, Zeanah P. NICU discharge planning and beyond: recommendations for parent psychosocial support. *J Perinatol* 2015; 35(S1):S24-8. doi: 10.1038/jp.2015.146.
 16. Li XY, Lee S, Yu HF, Ye XY, Warre R, Liu XH, et al. Breaking down barriers: enabling care-by-parent in neonatal intensive care units in China. *World J Pediatr* 2017; 13(2):144-51. doi: 10.1007/s12519-016-0072-4.
 17. Aliabadi F, Kamali M, Borimnejad L, Rassafiani M, Rasti M, Shafaroodi N, et al. Supporting-emotional needs of Iranian parents with premature infants admitted to Neonatal Intensive Care Units. *Med J Islam Repub Iran* 2014; 28:53.
 18. Fleury C, Parpinelli MA, Makuch MY. Perceptions and actions of healthcare professionals regarding the mother-child relationship with premature babies in an intermediate neonatal intensive care unit: a qualitative study. *BMC Pregnancy Childbirth* 2014; 14:313. doi: 10.1186/1471-2393-14-313.
 19. Wigert H, Blom MD, Bry K. Parents' experiences of communication with neonatal intensive-care unit staff: an interview study. *BMC Pediatr* 2014; 14:304. doi: 10.1186/s12887-014-0304-5.
 20. Macdonell K, Omrin D, Pytlik K, Pezzullo S, Bracht M, Diambomba Y. An effective communication initiative: using parents' experiences to improve the delivery of difficult news in the NICU. *Journal of Neonatal Nursing* 2015; 21(4):142-9. doi: 10.1016/j.jnn.2015.01.002.
 21. Kalhor M, Samiee Rad F, Garshasbi M, Mohit Abadi Z, Sefollah S. Evaluating the effect of mother-baby skin-to-skin care on neonatal outcomes in preterm infants. *Journal of Shahid Sadoughi University of Medical sciences* 2016; 24(5):375-86. [In Persian].
 22. Arzani A, Valizadeh L, Zamanzadeh V, Mohammadi E. Mothers' experiences of caring for prematurely born infants: growth sparks in the face of caregiver burden. *Journal of Qualitative Research in Health Sciences* 2014; 3(3):217-29. [In Persian].
 23. Warre R, O'Brien K, Lee SK. Parents as the primary caregivers for their infant in the NICU: benefits and challenges. *NeoReviews* 2014; 15(11):e472-7. doi: 10.1542/neo.15-11-e472.
 24. McGowan EC, Du N, Hawes K, Tucker R, O'Donnell M, Vohr B. Maternal mental health and neonatal intensive care unit discharge readiness in mothers of preterm infants. *J Pediatr* 2017; 184:68-74. doi: 10.1016/j.jpeds.2017.01.052.
 25. Prouhet PM, Gregory MR, Russell CL, Yaeger LH. Fathers' stress in the neonatal intensive care unit: A systematic review. *Adv Neonatal Care* 2018; 18(2):105-20. doi: 10.1097/ANC.0000000000000472.
 26. Ionio C, Colombo C, Brazzoduro V, Mascheroni E, Confalonieri E, Castoldi F, et al. Mothers and fathers in NICU: the impact of preterm birth on parental distress. *Eur J Psychol* 2016; 12(4):604-21. doi: 10.5964/ejop.v12i4.1093.
 27. Kim MA, Kim SJ, Cho H. Effects of tactile stimulation by fathers on physiological responses and paternal attachment in infants in the NICU: a pilot study. *J Child Health Care* 2017; 21(1):36-45. doi: 10.1177/1367493516666729.

28. Sadeghi N, Hasanpour M, Heidarzadeh M. Information and communication needs of parents in infant end-of-life: a qualitative study. *Iran Red Crescent Med J* 2016; 18(6) e25665. doi: 10.5812/ircmj.25665.
29. Wang L, He JL, Fei SL. Perceived needs of parents of premature infants in NICU. *Western Journal of Nursing Research* 2018; 40(5):688-700. doi: 10.1177/0193945916683679.
30. Modé RI, Mard E, Nyqvist KH, Blomqvist YT. Fathers' perception of information received during their infants' stay at a neonatal intensive care unit. *Sex Reprod Healthc* 2014; 5(3):131-6. doi: 10.1016/j.srhc. 2014. 05.001.
31. Lake ET, Hallowell SG, Kutney-Lee A, Hatfield LA, Del Guidice M, Boxer B, et al. Higher quality of care and patient safety associated with better NICU work environments. *J Nurs Care Qual* 2016; 31(1):24-32. doi: 10.1097/NCQ.000000000000146.
32. Larsson C, Wågström U, Normann E, Thernström Blomqvist Y. Parents experiences of discharge readiness from a Swedish neonatal intensive care unit. *Nurs Open* 2017; 4(2):90-5. doi: 10.1002/nop2.71.
33. Abdeyazdan Z, Shahkolahi Z, Mehrabi T, Hajiheidari M. A family support intervention to reduce stress among parents of preterm infants in the neonatal intensive care unit. *Iran J Nurs Midwifery Res* 2014; 19(4):349-53.
34. Milford CA. Care of the family of an infant with a congenital heart defect during the NICU hospitalization. *J Perinat Neonatal Nurs* 2016; 30(1):64-7. doi: 10.1097/JPN.000000000000155.
35. Penny KA, Friedman SH, Halstead GM. Psychiatric support for mothers in the neonatal intensive care unit. *J Perinatol* 2015; 35(6):451-7. doi: 10.1038/jp.2014.221.