

# Lived Experiences of the Caregivers of Infants about Family-Centered Care in the Neonatal Intensive Care Unit: A Phenomenological Study

Zahra Hadian Shirazi<sup>1</sup>, Farkhondeh Sharif<sup>1\*</sup>, Mahnaz Rakhshan<sup>1</sup>, Narjes Pishva<sup>2</sup>, Faezeh Jahanpour<sup>3</sup>

1. Community-Based Psychiatric Care Research Center, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Iran

2. Neonatology Research Center, School of Medicine, Shiraz University of Medical Sciences, Shiraz, Iran

3. School of Nursing and Midwifery, Bushehr University of Medical Sciences, Bushehr, Iran

## ABSTRACT

**Background:** Family-centered care (FCC) has recently been recognized as the most effective approach in pediatric and family care. Despite the emphasis of healthcare systems on commitment to the philosophy and application of FCC, the nature of this method remains unknown in the related studies. The present study aimed to describe and interpret the experiences of professional and familial caregivers about FCC in the neonatal intensive care unit (NICU) to reveal its structure and essence.

**Methods:** The study was conducted using Van Manen's phenomenological approach on 18 participants, including 10 professional and eight familial caregivers, who were interviewed. In addition, the interactions between the caregivers during the FCC practice were observed closely. Data were collected from the interviews, and the field notes were transcribed. Data analysis was performed using Van Manen's thematic analysis.

**Results:** Four main themes and 12 subthemes emerged in the study. Experiences of the caregivers about FCC were manifested through the themes of 'restoring stability' (subthemes: 'reconstituted family', 'comprehensive advocacy', and 'meta-family interaction'), 'oriented coalition' (subthemes: 'family as a care partner', 'professional group action', 'unity of action in caregivers', and 'collaborative space governance'), 'dynamics of care' (subthemes: 'family as an agent for the advancement of professional caregivers', 'perceived status of problem-solving', and 'confrontation of caregivers'), and 'empowering the family caregivers' (subthemes: 'accompanying to learn' and 'functional evolution').

**Conclusion:** According to the results, FCC is a dynamic care intervention, which is established through purposeful interactions between heterogeneous group members (professional and familial caregivers) in order to achieve care goals and create balance in all caregivers. Moreover, the approach enables familial caregivers to play their role efficiently. Application of this comprehensive care requires the attention of healthcare policymakers and managers to provide the proper context for optimal care provision in the NICU.

**Keywords:** Family-centered nursing, Neonatal intensive care unit, Qualitative research

## Introduction

Recent scientific and technological advancements in the fields of obstetrics and neonatology have resulted in the reduced rate of neonatal mortality and morbidity. Another advantageous outcome has been the improvement of viability to a minimum of 24 weeks of gestation, as well as the increased survival rate of very-low-birth-weight neonates

from 34-46% to 57-67% (1-3). In Iran, statistics suggest that the mortality rate in infants decreased from 19.1/1,000 per year in 1992 to 15.6/1,000 in 2004 (4). Nevertheless, admission in the neonatal intensive care units (NICUs) is still associated with significant burdens, difficult emotions, crises, and high stress for the families of the neonates (5, 6).

\* Corresponding author: Farkhondeh Sharif, Community-Based Psychiatric Care Research Center, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Iran. Tel: 0713647425051; Fax: 07136474252; Email: farkhondeh\_sharif@yahoo.com

Please cite this paper as:

Hadian Shirazi Z, Sharif F, Rakhshan M, Pishva N, Jahanpour F. Lived Experiences of the Caregivers of Infants about Family-Centered Care in the Neonatal Intensive Care Unit: A Phenomenological Study. Iranian Journal of Neonatology. 2018 Mar; 9(1). DOI: [10.22038/ijn.2017.23595.1294](https://doi.org/10.22038/ijn.2017.23595.1294)

Family is the constant in the neonate's life, and diseases or injuries in newborns largely affect all the family members. The experiences and challenges in the NICU may have a long-term impact on the health and function of families. Admission of neonates in the NICU may even influence the relationship of the parents, leading to their detachment. Considering the holistic care approach in the nursing profession, nurses are not only expected to focus on the care of the infants admitted in the NICU, but they must also consider the needs of the family members and provide them with proper care services through interaction (6-10). It is also notable that the emotional, social, and developmental needs of these neonates should be delivered by their families (11, 12). Therefore, in the NICU, family is considered to be the receiver and provider of care simultaneously, which should be taken into account in developing healthcare models and approaches.

Family-centered care (FCC) has recently been recognized as the most effective strategy in the care of hospitalized neonates and their families (10, 12). The American Academy of Pediatrics (AAP) has defined FCC as a healthcare approach that determines the policies, programs, facility design, and daily interactions between patients, their families, physicians, nurses, and the other healthcare team members (13). FCC encompasses several concepts, making it difficult to propose a definition (14).

Recently, researchers have emphasized on the complexities associated with the concept of FCC, as well as its partial development and the importance of its recognition in the context of care provision through conducting fundamental studies (15, 16). For instance, MacKean et al. (2005) focused on the conceptualization of FCC, denoting the lack of cooperative approaches and clarified roles of care providers in this regard. In addition, the mentioned study assessed the methods used to improve FCC in practice by conducting participatory investigations with the family members of hospitalized patients, healthcare staff, managers, and policymakers (17).

Despite the challenges associated with the definition and conceptualization of FCC, the approach remains a standard, optimal care procedure in neonatal wards. Furthermore, FCC has been reported to have numerous benefits for neonates, their families, and healthcare providers (18, 19). According to a clinical trial in this regard, applying FCC decreased the length of hospital stay in neonates, as well as the

risk of moderate-to-severe bronchopulmonary dysplasia. The results also indicated that parents played the role of primary caregivers instantly (3). Similarly, Bastani et al. (2015) reported that the application of FCC increased parental satisfaction and decreased the readmission rate and length of hospital stay in neonates (20).

To date, few studies have focused on FCC, and there is inadequate evidence regarding its practice in various cultures and communities (18, 21). There are some misconceptions about the nature of FCC, especially in non-western countries, which have affected the quality of performance. For instance, some healthcare managers have been reported to use parents to solve the problem of nursing staff shortage (16, 21), which shows that the meaning and nature of FCC remain ambiguous and should be clarified through phenomenological qualitative studies.

No studies have focused on the nature of FCC in the NICUs in Iran. On the other hand, studies in other countries have considered the viewpoints of specific caregivers, whereas both familial and professional caregivers have been shown to be involved in the application of FCC. This further affirms the necessity to assess the common experiences of family and professional caregivers in this regard.

The present study aimed to describe and interpret the experiences of familial and professional caregivers in the NICU about FCC to comprehend the phenomenon.

## Methods

Phenomenological research generally aims to discover the meaning and nature of a specific phenomenon (22), and the nature of FCC in the NICU was the main focus of the current study. We used Van Manen's (2001) methodology (23). The members of the Utrecht School are in favor of the phenomenology as a reflective, practical approach rather than a professional philosophy (24, 25). The methodology (2001) combines Husserl's descriptive phenomenology, focusing on the study of a pre-reflective world and universal essences (24).

Van Manen's practical approach consists of six methodological themes. He emphasizes that despite the presence of a specific order, it is not obligatory to be followed. In other words, in the practical process of an investigation, a researcher may move in different directions simultaneously or intermittently (23). In the present study, we attempted to facilitate following the research processes for the readers by expressing the

activities of the researcher step by step. The activities were as follows:

**1) Turning to the nature of the lived experience:** The first step in the study of a phenomenon is to consider the nature of a lived experience, which consists of the three subsequent steps of tendency toward a phenomenon, providing questions leading to the recognition of the phenomenon, and clarifying the presumptions and former perceptions about the phenomenon (23). In the present study, the FCC phenomenon in the NICU was the main focus of the researcher, who contemplated it deeply since she believed the nature of the phenomenon to be questionable. After deciding on phenomenology, the researcher noted down her presumptions and previous perceptions in order to start the research with an open mind.

**2) Investigating the experience as we live it rather than as we conceptualize it:** In this stage, the researcher seeks a lived experience in various life situations, beginning with personal experiences as the most available source of information. Moreover, the researcher expresses their personal experiences through experimental words, focusing on a specific event and avoiding the causative explanations or interpretive generalizations. Afterwards, the researcher interviews other individuals to collect their experiences and directly connect with their lived experiences in order to obtain the necessary data through close observation (23, 26).

The present study was conducted in two NICUs affiliated to Shiraz University of Medical Sciences in Shiraz, Iran. After obtaining the permit from the Ethics Committee of the university and hospital authorities and informed consent of the participants, semi-structured interviews were conducted with the individuals with lived experiences. After ensuring that the lived experiences were sufficiently qualified, data collection was discontinued by the researcher.

Participants were 18 familial and professional caregivers, including six mothers, one father, one grandmother, three neonatologists, six nurses, and one social worker. The minimum, maximum, and mean duration of the interviews was 31, 75, and 48 minutes, respectively. Interpersonal interactions of the caregivers during the implementation of FCC were observed by the researcher during five morning and afternoon shifts.

Inclusion criteria for the family caregivers were having a neonate admitted in the NICU for a minimum of one week, stable physical status in

the neonate and stable physical and mental condition in the caregiver, and ability and willingness to participate in the research. Inclusion criteria for the professional caregivers were a minimum of one year work of NICU care experience and the ability and willingness to participate in the research.

Interviews began with the main research question, followed by exploratory questions. The participants were enquired about the meaning of FCC in the NICU, their mental associations of the phenomenon, their emotions and assumptions about FCC, their perceived role in FCC, and the roles of other individuals in FCC. Additionally, exploratory questions (e.g., "Could you explain more?", "What did you mean when you said...?", "Can you recount a memory?") were asked to achieve comprehensive data. Data collection and analysis were performed simultaneously. To do so, the researcher listened to the interviews repeatedly, and verbatim transcription was carried out. Finally, the interview transcripts were analyzed using MaxQ-7 software.

**3) Reflecting on the essential themes that characterize the phenomenon:** In this stage, the researcher attempts to grasp the essential meaning of the phenomenon by reflecting on the lived experience using thematic analysis. Thematic analysis consists of holistic, selective, and detailed approaches. According to the holistic approach, the researcher evaluates the text in general, determines the reflective phrase that might denote the main meaning of the text, and writes the phrase down. In the selective approach, the researcher reads the text several times and distinguishes the sentences and phrases that seem suitable for describing the main experience. In the detailed approach, the researcher scrutinizes each sentence, phrase, or group of sentences in the text to find out about the phenomenon (23). In the present study, thematic analysis was performed for all the descriptions of lived experiences. Afterwards, collaborative analysis was carried out in accordance with Van Manen's methodology in two formal seminars and some informal sessions in the presence of scholars. In the next step, the essential themes were distinguished from the themes using the free imaginative variation technique. Finally, the results were presented in four main themes and 12 subthemes.

**4) Describing the phenomenon through the art of writing and rewriting:** Writing and rewriting clarify the structure and meaning of lived experiences (23). In the current study, the

researcher registered her personal presumptions regarding the phenomenon and wrote down the events during the study period. Moreover, the researcher monitored the written texts continuously, rewriting them based on the opinions of the scholars, the results of which are presented in the Results section of the paper.

**5) Maintaining a strong and oriented relation to the phenomenon:** In all the stages of the methodology, a strong and oriented connection should be maintained with the phenomenon, so that an oriented, strong, comprehensive text would be obtained (23). In the present study, the researchers were constantly involved with the FCC phenomenon, attempting to obtain a text with the aforementioned criteria.

**6) Balancing the research context by considering parts and whole:** Since sub-structures are important in the general structure, the researcher should monitor the general study design continuously in order to decide the final stage of the research (23). Van Manen has introduced a number of approaches to organize a phenomenological text (23). In the present study, the researchers monitored the parts and general base of the phenomenology continuously through up-and-down observation procedure to ensure reaching the final stage of the research. In addition, the text organization was performed thematically.

### **Ethical Considerations**

The study protocol was approved by the Ethics Committee of Shiraz University of Medical Sciences, and the study processes were explained to the participants verbally and in the written form. Furthermore, the participants were informed of their personal rights and asked to submit their written, voluntary consent to enroll in the investigation. The participants were allowed to withdraw from the study at any given time with no consequences, and confidentiality

terms were observed regarding the anonymity of their records.

### **Trustworthiness**

This study is trustworthy based on Van Manen's criteria (2014) and positive answers to four validation questions. Initially, the study was conducted in accordance with a credible phenomenological question regarding the nature of the lived experiences. Following that, the experimental reports were analyzed disregarding the beliefs, opinions, and attitudes of the participants. In the next step, only primary resources were used proportionately. Finally, the project avoided validation by non-phenomenological validation criteria (26).

### **Results**

The current investigation aimed to describe and interpret the FCC phenomenon in the NICU. The phenomenology of FCC in the NICU yielded four main themes, including 'restoring stability', 'oriented coalition', 'dynamics of care', and 'empowering the family caregivers' (Table 1).

**A) Restoring Stability:** According to the participants, FCC was of a balance-making nature, which brought the former stability to the family. Professional caregivers were supported by the families and intra/interdisciplinary colleagues, resulting in professional stability. The main theme of 'restoring stability' consisted of three subthemes, including 'reconstituted family', 'comprehensive advocacy', and 'meta-family interaction'. According to the comments of the participants, emotions of the parents and family foundations were affected by the illness of the neonates and their admission in the NICU. However, FCC could reconstruct these emotions and foundations effectively. One of the mothers participating in the study described her assumptions regarding the disturbance of her newborn, finding nurses as the only healthcare

**Table 1.** Themes and Subthemes of Family-Centered Care in Neonatal Intensive Care Unit (NICU)

Themes		Subthemes
A	Restoring Stability	Reconstituted Family Comprehensive Advocacy Meta-family Interaction
B	Oriented Coalition	Family as a Care Partner Professional Group Action Unity of Action in Caregivers Collaborative Space Governance
C	Dynamics of Care	Family as an Agent for the Advancement of Professional Caregivers Perceived Status of Problem-solving Confrontation of Caregivers
D	Empowering Family Caregivers	Accompanying to Learn Functional Evolution

providers to support her under such circumstance. She remarked:

*"Every mother calls her baby with words like chubby or nice, and everyone believes their baby is the cutest one; but I could not experience this feeling not at all (with emphasis). Her nurse was the only one to help me."*

The subtheme of 'comprehensive advocacy' was composed of 'inspiration by the presence of advocacy', 'received advocacy', and 'perceived advocacy'. One of the nurses described the inspiration by the presence of advocacy, as follows:

*"I mean, if you feel that her body has become cold, let me know again. If you feel tired or if you feel you cannot take care of your baby, let me know. I am here any time."*

Based on the responses of the participants, their different needs were recognized, and advocating measures were taken accordingly. One of the nurses explained about providing the fathers of the admitted infants with their health information in order to make them familiar with the medical procedures, commenting:

*"I allow the father to visit the baby and see how he/she is doing. I also tell him that some devices are attached to the baby. For example, if it is a respirator, I tell him that this machine brings oxygen to your baby."*

The subtheme of 'perceived advocacy' was based on the stage after receiving support by healthcare providers. In this regard, one of the mothers described her emotions about having an advocacy during the care process of her neonate, stating:

*"Tell me, don't you want us to help you? I say I will get it myself, but I see them looking at me from a distance to look out for me. So, I have nothing to worry about when I need help. Her nurse is there to help me."*

The professional caregivers experienced comprehensive advocacy in the FCC as well. They mentioned the supporting role of the intra/interdisciplinary members or even the family caregivers. One of the physicians remarked on providing nurses with information, as follows:

*"Like today that we have a class, every week on Thursdays, we try to hold a class and give new information to the nurses, so that they would know what the conditions of the patients are."*

The interactions that are established during FCC could make the caregivers emotionally dependent on each other, which might persist after discharge in order to meet the needs of the

neonates and their families. In this regard, one of the nurses described her close relationship with the mother of an infant, as follows:

*"This is not only when the baby is at the hospital. This connection is so close that when the baby is discharged, they have my cell phone number and can call me if they have any problems."*

**B) Oriented Coalition:** The experiences of the participants indicated that all the professional and family caregivers attempt to reach a common goal in a collaborative environment, which involves the health of the infants, stability of their families, and complete satisfaction. This theme consisted of four subthemes, including 'family as a care partner', 'professional group action', 'unity of action in the caregivers', and 'collaborative space governance'. FCC introduces family as a partner with equal opportunity in the process of care provision. Therefore, families are entitled to making decisions for their neonates. In this regard, one of the physicians explained about the role of mothers in the care and treatment of neonates, as follows:

*"There was a mother whose baby was admitted here. During the two months of hospitalization, she did not leave the hospital for a minute. She could perform KMC and cooperated with us very well. The baby was also detached from the machine successfully."*

In the NICU, all the healthcare team members are involved in achieving the predetermined therapeutic goals. The participants denoted the provision of dependent and independent services by the professional caregivers, as well as their dependency on each other. For instance, one of the nurses stated:

*"It is team work. When one day, you know, if one of the members is absent, our work increases two- or three-fold. We are all dependent on each other."*

The participants also emphasized on the unity between the professional and familial caregivers. One of the physicians described the important role of mothers in the treatment of neonates, as follows:

*"If my patient needs more oxygen, I ask where the mother is because she talks to the baby every day and touches him/her. I mean, I have got positive results."*

As mentioned earlier, heterogeneous members of a group require a collaborative environment in order to improve their performance, which could be achieved through trust-oriented communication, commitment, responsibility, and confidentiality. In this regard,



a nurse described establishing trust-oriented communication, as follows:

*"By showing the care we take, by admitting them when they come over to visit, by listening to their problems, and by sympathizing with them, we try to gain their trust. When they trust us, many problems are solved for both parties."*

In addition, one of the mothers mentioned the role of the physician's commitment after the medical examinations, remarking:

*"The doctor kindly asked me to leave, so that he could do her job. She said he would come to me and we will talk. Finally, she came back and explained everything to me."*

**C) Dynamics of Care:** This theme emerged after listening to the explanations of the participants about the interactions of the caregivers and the outcomes. The theme consisted of three subthemes, including 'family as an agent for the advancement of the professional caregivers', 'perceived status of problem-solving', and 'confrontation of the caregivers'. A nurse described her willingness to study more in order to obtain information answer the questions of the parents, stating:

*"They are very watchful and pay attention to all the details of care. Therefore, they ask me some questions that make me study more to answer them."*

The professional caregivers attempted to make decisions based on the conditions. To do so, they even changed the rules and regulations of the ward if possible, so that the family caregivers would receive individual care and be treated differently. In this regard, one of the mothers commented:

*"I felt that they treated me rather differently, especially because they knew that I was emotionally vulnerable and in need of care."*

The lived experiences of the participants were indicative of the caregivers' attempt to prevent inter-group confrontations, which could be upon the family or professional caregivers depending on the conditions. In this regard, one of the mothers explained about preventing the confrontations between her and the staff about leaving the ward during a procedure, commenting:

*"Although I would like to stay and calm my baby, I have to leave the ward because they do not want to be disturbed while working."*

The subtheme of 'confrontation in the caregivers' highlighted the interactions among the caregivers, which could arise from differences in opinion or performances, as well as interference

in professional care procedures, which may lead to favorable or adverse outcomes. One of the mothers, who was not permitted by the physician to be at the bedside of her infant during the examinations, stated:

*"I did not talk at all although I might have been offended."*

In contrast, another mother claimed that she learnt from a nurse after a confrontation, remarking:

*"In these tiny wrangles or strictures, I learnt many things."*

**D) Empowering the Family Caregivers:** The essence of FCC in the NICU was partially denoted in the theme of 'empowering the family caregiver's, which consisted of the two subthemes of 'accompanying to learn' and 'functional evolution'. In the subtheme of 'accompanying to learn', the professional caregivers supported the family caregivers step by step by providing proper training in order to ensure their learning. This was possible through evaluating the performance of the family caregivers, and the frequently used approach was education and training through demonstration and back-demonstration. In this regard, one of the nurses stated:

*"We train them, and then, they perform it. We oversee if they have a problem in the learned process, such as pouring a drop and we explain their mistake to them. If they repeat the mistake, it means they are not able to do it, so we do not allow them to perform the procedure."*

During the empowering process, the family caregivers actively transform from a novice to an expert with willingness and effort. This improvement reinforces the professional caregivers in the training of the family caregivers, creating opportunities for them to practice the learned points. One of the nurses described the willingness of a mother to learn, as follows:

*"She came in calmly and asked whether she could do the procedures she was trained on the day before on her baby, and I allowed her to do it."*

At first, the family caregivers may experience fear, anxiety, and instability in the empowering process. Nonetheless, they gradually become adequately skilled to even criticize the performance of the professional caregivers. Finally, they become capable of providing care for their infant if they require special procedures at home. A grandmother participating in the study described her experience about the discharge of an infant, as well as her skills in the infant's home

care, as follows:

*"I mean, by changing the position of the infant, saturation increases gradually. You know, when we put him in this position (pointing by her hands), saturation increased. As we turned the baby, the oxygen increased to 99 or 98-100."*

## Discussion

The present study aimed to describe and interpret the nature of FCC in the NICU by assessing the experiences of professional and familial caregivers. Based on the descriptions of the lived experiences of the participants, the essence of FCC was reflected in four main themes, including 'restoring stability', 'oriented coalition', 'dynamics of care', and 'empowering the family caregivers'.

One of the meanings of the FCC phenomenon was 'restoring stability', which was derived from the subthemes of 'reconstituted family', 'comprehensive advocacy', and 'meta-family interactions'. In general, hospitalization of neonates is associated with the distance between the infant and parents. Therefore, parents are not capable of perform their roles properly, which in turn gives rise to excessive stress and anxiety. This has been shown to adversely affect the infant-parent attachment (27-29). Since the admission of neonates may last for several months in some cases, the relationship of the parents might be disrupted as well (9). Therefore, healthcare providers should attempt to reinforce parental roles in the NICU using the FCC approach. To do so, parents must have complete access to the neonate, so that they would be encouraged to be in touch with the neonate as far as possible. In addition, the family caregivers should enjoy the full support of the professional caregivers (30).

Another subtheme in this regard was 'comprehensive advocacy', which covered a broad spectrum of meanings based on the descriptions of the participants about the studied phenomenon. The professional caregivers assured the family caregivers about having access to advocacy. Being provided with complete advocacy in accordance with their needs, the family caregivers were reassured of the presence of advocacy in the NICU.

In a study conducted by Molina et al. (2009) in NICUs and pediatric intensive care units, parents and neonates both received proper care, which was not perceived only as a series of techniques and procedures since they involved their emotions and attitudes through care,

attention, and benevolence (31). On the same note, Follet (2006) introduced FCC in the NICU as advocacy for the neonate, family caregivers, and even the healthcare staff, which resulted in the establishment of collaborative trust-centered and respect-oriented communication (32). It should be noted that the study by Follett was only conducted on nurses, while FCC is a collaborative phenomenon encompassing the experiences of all the participants in the process of care provision.

One of the items derived from the lived experiences of the nurses in the present study was respecting their culture and religion by interdisciplinary colleagues. For instance, kangaroo care was performed by the father with the help of a male physician. This finding opens a new horizon regarding the nature of FCC in the NICU, which requires further investigation.

'Meta-family interactions' represented a series of statements in the current research, which denoted the deep emotional bonds among the healthcare staff, neonates, and mothers, leading to the willingness to have mutual, stable relationships after discharge. However, this relationship would be disregarded when the needs of the family caregivers are met without transforming into a social bond after the discharge of the infant from the hospital. In a study in this regard, Fegran et al. (2008) explored the experiences of nurses and parents about their relationships, concluding that the long-term presence of neonates and their families in the NICU may create friendly bonds between the parents and nurses. However, nurses were aware of the emotional load of this communication on themselves and the parents and attempted not to go beyond the professional relationship. The main benefit of this professional approach was the independence of the parents, so that they could remain responsible for the care of the infant until discharge (33, 34).

'Oriented coalition' was the second theme about the FCC phenomenon in the NICU, which represented the significance of teamwork in implementing FCC. Accordingly, professional and familial caregivers must perform cooperatively in order to achieve the predetermined therapeutic goals. Attaining these goals requires a collaborative environment. In a research, Raiskila et al. (2014) denoted that the provision of the constrictive training through close collaboration with parents in the NICU resulted in the weight gain of premature neonates during 1986-2008. The intervention was performed by

taking gradual measures to facilitate parental participation in the process of infant care. Furthermore, the frequency of the invasive procedures was reported to decline as a result of the intervention (35).

In the current research, the essence of FCC was partly included in the professional group action. In fact, healthcare providers mentioned asking for the help of intra/interdisciplinary members when they were faced with complicated conditions and could not achieve appropriate results in order to obtain optimal health outcomes. In a survey in this regard, the role of interdisciplinary collaboration in the discharge process was investigated in the NICU, and the findings showed that most professional staff supported this phenomenon. However, such collaboration was found to reduce at the time of urgent discharge. Other challenges against the participation of the interdisciplinary team members include inadequate communication, ambiguity in the roles, and necessity of mutual respect (36). Since interdisciplinary collaboration in the NICU is of paramount importance in resolving complicated issues in neonates and their families, the FCC philosophy encourages such collaborations.

The subtheme of 'unity of action in the caregivers' was based on the unified actions of the family and professional caregivers in order to achieve a common goal. In this regard, Barbosa (2013) considered the theory of system to be compatible with such relations, in which a series of commissions are made among professional caregivers, neonates, and families in the NICU, so that each individual would be in touch with the others, and all the members would be interdependent. This in turn leads to the achievement of optimal health outcomes (37). Collaboration among professional and family caregivers is accomplished through trust-oriented communications, commitment, responsibility, and confidentiality. Referring to the experiences of nurses in FCC, Follet (2006) has emphasized on establishing respectful, trust-oriented communications to create a supportive environment for all the individuals involved in the provision of care, so that parents could receive the essential information to making crucial decisions (32).

With respect to the concept analysis of FCC in the NICU, Malusky (2005) proposed that this type of care provision is a philosophy requiring commitment and respect from all the individuals involved in the care of neonates and their families

(15). The statements of the participants in the present study highlighted the necessity of considering the cultural, professional, and legal aspects in the implementation of FCC in order to complement the structure of the phenomenon. Moreover, the obtained results decoded a few dimensions affecting the establishment of a collaborative environment for FCC. It is suggested that further investigation be conducted in this regard for the comprehensive analysis of this issue.

Another theme regarding FCC in the NICU was the 'dynamics of care' in the current research, which denoted the interactions among the professional and familial caregivers about FCC. The subtheme of 'family as an agent for the advancement of professional caregivers' focused on the role of inspirational motivation by the family members in enhancing the performance of professional caregivers, as well as the healthcare services. Although some studies have assessed this issue, further comprehensive investigations are required. For instance, Martins et al. (2012) claimed that nurses came to the conclusion that the presence of the parents in the NICU increased their understanding of the reactions and habits of the neonates (6).

The subtheme of 'perceived status of problem-solving' referred to a dimension representing variability based on the current conditions. According to the statements of the participants, the rules and regulations of the hospital lacked sufficient stability and sternness, and therefore, they could change depending on the situation. Consistently, Griffin (2006) believes that real commitment to FCC requires a flexible system, which responds to different conditions. For instance, the policies of visiting patients should be directed so as to facilitate the implementation of FCC (11).

According to the statements of the participants in the present study, variations in the families and parents should be considered in the provision of special care. In other words, healthcare staff must consider each family as an individual unit with unique requirements. Furthermore, the NICU should be managed based on the uniqueness of each family and their specific needs (38, 39). However, conflicts may occur in the groups with heterogeneous members. According to the statements of our participants, they struggled to prevent such conflicts by perceiving the situation. In this regard, Barbosa stated that conflicts are unavoidable in the teams that attempt to reach common goals, and a successful team should have



committed members who are able to manage conflicts (37).

'Empowering the family caregivers' was the final theme to emerge from the lived experiences of the caregivers about FCC in the NICU. This theme had two subthemes, including 'accompanying to learn' and 'functional evolution. 'Accompanying to learn' means that the professional caregivers accompany parents in informing them of the procedures they need to be aware of in the care of their infants until they become independent in playing their parental role. In addition, the subtheme of 'functional evolution' was interpreted as when the familial caregiver willingly enters the empowering process and advances step by step until becoming skilled in neonatal care.

In the study by Martins et al. (2012), provision of care for the family of the infants was considered as part of the process, with the aim of preparing the parents for the care of the infants after discharge (6). At first, parents should observe the nurses in the care process of the neonates, and they could improve their parental roles as independent caregivers to be ready for the discharge of the infant under the supervision of the nurses (40). Until discharge, parents should have the opportunity to practice the care processes, especially those that may continue after discharge. The FCC approach enables parents to make decisions and commit to the recovery activities for the neonate and family members (41).

## Conclusion

According to the results, the experiences of the professional and family caregivers about FCC in the NICU were interpreted with the themes of 'restoring stability', 'oriented coalition', 'dynamics of care', and 'empowering the family caregivers', which represented a team effort to restore stability to the family unit in order to achieve the predetermined therapeutic goals. In this context, some groups with heterogeneous members and common goals attempt to play their roles sympathetically. The success of such groups depends on the reciprocal understanding of the members regarding their interactions and management of inevitable difficulties. Such beneficial interactions lead to the improvement of primary caregivers (i.e., family caregivers) and continuation of their independent performance in the provision of care for neonates.

The findings of this study could eliminate the gap between theoretical and practical knowledge

in the current literature (10). Furthermore, they could be effective in optimizing the performance of professional caregivers. These goals could be achieved through improving the knowledge regarding the implementation of FCC in the NICU. Findings of the current research could also provide useful educational materials on FCC for medical students and NICU staff. As the first study conducted in Iran in this regard, our research could be the basis for further investigation.

Although it is considered an inherent element of qualitative research, one of the limitations of the present study was the small sample size, which affects the generalizability of the findings.

## Acknowledgments

The present article was extracted from Zahra Hadian Shirazi's PhD dissertation (proposal No. 92-6901). Hereby, the researchers would like to thank the Research Vice-chancellor of Shiraz University of Medical Sciences for their financial support. They would also like to thank the family and professional caregivers in Hazrat Zeinab (PBUH) and Namazi hospitals who generously gave their experiences to the researchers. Thanks also go to professor Van Manen and Dr. Van Manen for humbly answering the questions. Last but not least, Ms. A. Keivanshekouh at the Research Improvement Center of Shiraz University of Medical Sciences is appreciated for improving the use of English in the manuscript.

## Conflicts of interest

None declared

## References

1. Van Riper M. Family-provider relationships and well-being in families with preterm infants in the NICU. *Heart Lung*. 2001; 30(1):74-84.
2. Cone S. The impact of communication and the neonatal intensive care unit environment on parent involvement. *Newborn Infant Nurs Rev*. 2007; 7(1):33-8.
3. Örténstrand A, Westrup B, Broström EB, Sarman I, Åkerström S, Brune T, et al. The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity. *Pediatrics*. 2010; 125(2): e278-85.
4. Heidari H, Hasanpour M, Fooladi M. The Iranian parents of premature infants in NICU experience stigma of shame. *Med Arh*. 2012; 66(1):35-40.
5. Saunders RP, Abraham MR, Crosby MJ, Thomas K, Edwards WH. Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units. *Pediatrics*. 2003; 111(4 Pt 2):e437-49.

6. Martins LA, da Silva DS, Aguiar AC, Morais AC. Insertion of the family in the neonatal intensive care unit: a systematic review. *Rev Enferm UFPE*. 2012; 6(4):861-8.
7. Frost M, Green A, Gance-Cleveland B, Kersten R, Irby C. Improving family-centered care through research. *J Pediatr Nurs*. 2010; 25(2):144-7.
8. McKiernan M, McCarthy G. Family members' lived experience in the intensive care unit: a phenomenological study. *Intensive Crit Care Nurs*. 2010; 26(5):254-61.
9. Manning AN. The NICU experience: how does it affect the parents' relationship? *J Perinat Neonatal Nurs*. 2012; 26(4):353-7.
10. Trajkovski S, Schmied V, Vickers M, Jackson D. Neonatal nurses' perspectives of family-centred care: a qualitative study. *J Clin Nurs*. 2012; 21(17-18):2477-87.
11. Griffin T, Abraham M. Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process. *J Perinat Neonatal Nurs*. 2006; 20(3):243-9.
12. Shields L. Family-centred care: effective care delivery or sacred cow? *Forum Public Policy*. 2011; 2011:1.
13. Wong DL. *Wong's nursing care of infants and children*. New York: Mosby/Elsevier; 2011.
14. King L. Family-centred care: a review of current literature. *Plymouth Stud J Health Soc Work*. 2009; 2:9-17.
15. Malusky SK. A concept analysis of family-centered care in the NICU. *Neonatal Netw*. 2005; 24(6):25-32.
16. Mikkelsen G, Frederiksen K. Family-centred care of children in hospital—a concept analysis. *J Adv Nurs*. 2011; 67(5):1152-62.
17. MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expect*. 2005; 8(1):74-85.
18. Staniszewska S, Brett J, Redshaw M, Hamilton K, Newburn M, Jones N, et al. The POPPY study: developing a model of family-centred care for neonatal units. *Worldviews Evid Based Nurs*. 2012; 9(4):243-55.
19. Ramezani T, Hadian Shirazi Z, Sabet Sarvestani R, Moattari M. Family-centered care in neonatal intensive care unit: a concept analysis. *Int J Community Based Nurs Midwifery*. 2014; 2(4): 268-78.
20. Bastani F, Abadi TA, Haghani H. Effect of family-centered care on improving parental satisfaction and reducing readmission among premature infants: a randomized controlled trial. *J Clin Diagn Res*. 2015; 9(1):SC04-8.
21. Shields L. Questioning family-centred care. *J Clin Nurs*. 2010; 19(17-18):2629-38.
22. Burns N, Grove SK. *Understanding nursing research: building an evidence-based practice*. 5<sup>th</sup> ed. New York: Elsevier Saunders; 2011.
23. Van Manen M. *Researching lived experience: human science for an action sensitive pedagogy*. New York: State University of New York Press; 2001.
24. Dowling M. From husserl to van manen. a review of different phenomenological approaches. *Int J Nurs Stud*. 2007; 44(1):131-42.
25. Ehrlich LC. *Revisiting phenomenology: its potential for management research*. British Academy of Management Conference, London; 2005.
26. Van Manen M. *Phenomenology of practice: meaning-giving methods in phenomenological research and writing*. California: Left Coast Press; 2014.
27. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ*. 2009; 18(3): 23-9.
28. 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.
29. Malakouti J, Jebraeili M, Valizadeh S, Babapour J. Mothers' experience of having a preterm infant in the Neonatal Intensive Care Unit, a Phenomenological Study. *J Crit Care Nurs*. 2013; 5(4):172-81.
30. Newnam KM, McGrath JM. Following the diagnosis of neonatal hypoxic ischemic encephalopathy: a family-centered approach. *Newborn Infant Nurs Rev*. 2011; 11(3):98-101.
31. Molina RC, Fonseca EL, Waidman MA, Marcon SS. The family's perception of its presence at the pediatric and neonatal intensive care unit. *Rev Esc Enferm USP*. 2009; 43(3):630-8.
32. Follett TL. *Nurses' perceptions of practicing family-centred care in the neonatal intensive care unit*. Michigan: ProQuest; 2006.
33. Fegran L, Fagermoen MS, Helseth S. Development of parent–nurse relationships in neonatal intensive care units—from closeness to detachment. *J Adv Nurs*. 2008; 64(4):363-71.
34. Hadian Shirazi Z, Sharif F, Rakhshan M, Pishva N, Jahanpour F. Lived experience of caregivers of family-centered care in the neonatal intensive care unit: "evocation of being at home". *Iran J Pediatr*. 2016; 26(5):e3960.
35. Raiskila S, Axelin A, Rapeli S, Vasko I, Lehtonen L. Trends in care practices reflecting parental involvement in neonatal care. *Early Hum Dev*. 2014; 90(12):863-7.
36. Manogaran M. *The role of interprofessional collaboration on the discharge planning process in the neonatal intensive care unit*. Ontario: University of Ontario Institute of Technology; 2011.
37. Barbosa VM. Teamwork in the neonatal intensive care unit. *Phys Occup Ther Pediatr*. 2013; 33(1): 5-26.
38. Mundy CA. Assessment of family needs in neonatal intensive care units. *Am J Crit Care*. 2010; 19(2):156-63.
39. Cleveland LM. Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs*. 2008; 37(6):666-91.
40. Kearvell H, Grant J. *Getting connected: how nurses*

can support mother/infant attachment in the neonatal intensive care unit. *Aust J Adv Nurs*. 2010; 27(3):75.

41. Gephart SM, McGrath JM. Family-centered care of the surgical neonate. *Newborn Infant Nurs Rev*. 2012; 12(1):5-7.