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Spiritual Challenges Experienced by Nurses in Neonatal End of Life: A Qualitative Study

Fereshteh Ghaljaei [1], Hamideh Goli [2], Nasrin Rezaie [3], *Narges Sadeghi [4]

[1]Community Nursing Research Center, Zahedan University of Medical Sciences, Zahedan, IR Iran.
[2]Child Nursing Department, Faculty of Nursing and Midwifery, Sabzevar University of Medical Sciences, Sabzevar, Iran.
[3]Nursing, Nursing and Midwifery Faculty Zahedan, Zahedan University of Medical Sciences, Zahedan, Iran.
[4]Community Health Research Center, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran.

Abstract

Background
The literature reviews show that taking care of dying newborns for a nurse is associated with stress and anxiety, and nurses will be faced with many challenges, the present study aimed to explain the spiritual challenges experienced by nurses in neonatal end of life in the NICU.

Materials and Methods
The present study was conducted with a qualitative method and "purposive" sampling. The study environment was NICU in the hospitals of Zahedan, Iran. Semi-structured interviews used for interview and data collection. A number of 24 participants with inclusion criteria were interviewed. Qualitative content analysis method was used with the conventional approach and inductive method with Graneheim and Lundman approach.

Results
Data analysis explored were categorized in three main themes: spiritual challenge of neonatal care with two-categories (palliative care, and care with love and affection); psychological / spiritual support challenges of family with two categories (spiritual support of family, psychological support of family), and nurses' spiritual distress with one category (nurse's trauma in neonatal care).

Conclusion
In this study three themes were obtained: 1- Spiritual challenge of neonatal care with two-categories (palliative care, and care with love and affection); 2- Psychological / spiritual support challenges of family with two categories (spiritual support of family, psychological support of family), and 3- The nurses' spiritual distress with one category (nurse's trauma in neonatal care).

Key Words: Death, Neonate, NICU, Nurse, Qualitative Research.

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***Corresponding Author:**

Narges Sadeghi, Community Health Research Center, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran.

Email: n45sadeghi@yahoo.com

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1- INTRODUCTION

End of life is a critical position to deliver health care. In America since mid-1970, much attention was focused on the quality of death and, therefore specific hospitals were established in 1974. In 1990, concerns about the right to die attracted a lot of attention. In the recent decade, efforts to improve the death quality and reduce the cost of care have been made for patients at the end of life, and palliative care is one of those cases (1). Palliative care is a holistic and comprehensive care (2), and is defined for newborn as providing comfort for the newborn and families from diagnosis to death and mourning. Care givers should consider physical, emotional, social and spiritual needs of patient and family (3).

Spirituality has been discussed since 1940 in nursing practice. During the 1970s and 1980s, some confirmed the need for holistic health care (3). Spirituality consider as a complex concept and based on religious and cultural issue is defined in different ways (4). With the advent of the concept of holistic care, a reawakening took place on the importance of spirituality and spiritual needs of the patient (5). Spiritual care is in line with the holistic care (6). The root of term holistic is taken from the Greek work "Holos", which means the whole. The term holism implies that it is important to pay attention to all aspects of life for being well, and the whole is greater than the sum of the parts. Therefore, in holistic care the whole person should be given attention. In this view, the holistic medicine deals with human being as a whole (7, 8). Holistic medicine isn't a different medicine or a different treatment method, but it has a different philosophy and considers every person as a whole rather than as a sum of body, mind and soul. The foundation of nursing care is based on holistic care. Florence Nightingale emphasized considering on light, sound, environment and touch on the holistic care (8). Four dimensions of holism include biological, psychological, social and spiritual dimensions. Holism and holistic terms are frequently used by nurses. With this approach it is necessary to treat the whole-person, or a situation should be provided in which all physical, social, psychological and spiritual aspects of the person are included. In holism people are considered as a whole (6). In this view, all systems, namely, biological, psychological, social and spiritual systems are not considered separately, because they all make a whole person together. So in holistic care, there exist concerns in relation to the whole person (7). Nurses must provide holistic care and the spiritual dimension cannot be separated from the physical, social and psychological dimensions (5). If care providers want to provide comprehensive and family-centered care, it is important to be sensitive about the dimensions of spirituality, religion, family values and culture systems (9).

Understanding the spiritual dimension of human experience is important for nursing, because nursing is an approach that deals with human concerns (10). There is much debate about the concept of spirituality. In a recent concept analysis, three components are specified: Transcendence, meaning of life and relationship with self / others and greater power for spirituality (11). Physicians have an ethical obligation to examine both physical problems and spiritual, psychological and existential distresses. The root of holistic approach to the patient is derived from health, in the definition of World Health Organization. This organization defines health as a complete dynamic of physical, psychological, spiritual and well-being and not merely the absence of disease. According to the definition of spirituality and spiritual care, the treatment teams are required to treat the patient as a whole and provide care for him with respect and

compassion. So the foundation of spiritual care is based on considering the person as a whole or holistic care. This means that all members of the care team should be able to examine the patient in the physical, emotional, social and spiritual fields and identify patients' distress in the above areas (12). Jean Watson is one of the experts in nursing that focuses on holistic care. This theory is based on the values of kindness, interest, loving oneself and others, and respecting for the religion of individuals. Watson sees human beings as a whole and an interactive entity (13).

From 2000 to 2010, with the enhancement of technology in neonatal care, newborn mortality rate has dropped 20 percent. Though still out of 300 newborns, a neonate dies in the first four weeks of life (14). In 2013, 23,446 infants died that and the majority of their deaths was in the neonatal period or in the first 28 days of life, and 86 percent of deaths of newborns happens in infants or neonatal intensive care unit (15). Babaei et al. in a study showed that the most infant death occurred on birth day of 2-7 (16). The mortality rate of newborns and infants in intensive care units is more than other wards, and most deaths happen in the above sections (17). Infants unit must consider the entire family, for hospitalization of infants is a critical situation and should consider the spiritual needs of the whole family (5).

Neonatal Intensive Care nurses are responsible to consider the needs of infants and families and besides considering the physical and psychosocial needs, they must consider the spiritual needs as well (18). Family-centered care is a care that is provided based on uniqueness of patient along with respect for patients and families. Patient and family form the care unit, care plan is determined based on the goals and preferences of the patient and family with the support of the treatment team (19). Nurse should consider Family-centered care as a priority (20) Family-centered care goals are designing and implementing care, not only for infants, but also for the family as a whole and even all family members in case of need for care. Lifestyle is altered in the West. In the past, most attention was on the traditional nuclear family model and the diversity in family composition was neglected. Although the family structure is different, family members are dependent on each other. So everything that affects a member of the family will affect the entire family as a whole (21). Providing care for families is an important part of the task of health workers. Researches have shown that a link between staff and parents can have a significant effect on satisfaction, sadness and reaction of parents with infants at the end of life. For nurses, it is important to know how to prepare parents for the death of their child and what to say them and how to support them in reacting to sadness (17).

Nurses' experience of end of life care can be effective on their care. Also the fact that life in some newborns ends despite providing care, can affect psychological state of nurses and finally their neonatal care (22). Increasing advances in health care and technology has changed the ethical aspects of health issues, so that public concern about the moral and ethical challenges in this area is increasing. According to studies, approximately 11 percent of the nurses every day and 36% every few days face with the ethical challenges and problems (23). NICU nurses believe that the main sources of stress in taking care of babies includes the need for full awareness in working with infants, sensitivity and the risk of error in taking care of premature babies, coping with parents' anxiety, emotional attachment to the baby, having several tasks at the same time, fear of failure, lack of equipment and human resource, getting along with new technology and ambiguous changes and personal life, and emotional

loads of family life (24). Advances in technology have prolonged the life of infants which led to the creation of ethical challenges. Therefore, it is necessary to provide the infants and their families with compassion and respect in the neonatal intensive care unit (15). The literature review shows that caring dying newborns for nurses is associated with stress, anxiety and uncomfortable feelings. Therefore, because of the stress and problems that comes with caring for a newborn at the end of life, it is necessary to provide the nurses with the required supports (14).

Nurses who in neonatal intensive care units and infants are constantly around infants at the end life face with great challenges, which can be an important factor in creating anxiety, sadness and a sense of frustration. When a child or newborn dies nurses suffer with grief reaction and mourning experience for them can for long be sustainable, painful and associated with stress. If the roles and responsibilities of nurses is not clear at the end of life, it will aggravate these problems and nurses feel that their job is not done well (17), if the nurse feels that the plan for taking care of the baby is inappropriate or that it conflicts with the demands of the family, such stresses can lead to spiritual distress (3). So, as it was mentioned earlier, neonatal intensive care nurses are faced with many challenges in the workplace and infants at the end of life and death can be associated with stress and anxiety for the family and nurse and if it not taken into consideration, then it can be followed by spiritual and ethical distress. The present study aimed to explain the spiritual challenges experienced by nurses in the care of infants at the end of life and death.

2- MATERIALS AND METHODS

2-1. Method

Qualitative research is used; in cases where there is little knowledge about a phenomenon or when it's not clearly defined. Content analysis is a research approach, and scientific instrument with the aim of creating new knowledge, promoting researcher's understanding of phenomena and defining operational strategies (25). In this study qualitative content analysis was used with a conventional approach and inductive methods of Graneheim and Lundman (28).

2-2. Participants

In this study, "purposive" sampling was used. In qualitative research, participants are considered as research sample (26). The study environment was NICU wards in the hospitals of Zahedan city, South East of Iran, and the research population was all the nurses in neonatal intensive care units in Educational hospitals of Zahedan University of Medical Sciences, Zahedan (Iran). The inclusion criterion was having at least one experience of infant care and family at the end of life.

2-3. Data collection

In this study data collection method was in-depth and semi- structure interview (13) Researcher after obtaining permission from the hospital authorities introduced herself to the head nurse of NICU and qualified nurses included in the study. All participants were visited in the NICU. After obtaining written and oral informed consent, the participants were interviewed in their desired location. All interviews were conducted in the hospital, in a quiet room with comfortable and quiet condition. In-person interviews were conducted with 24 participants with inclusion criteria. Interview time varied from 35 to 65 minutes. All interviews were recorded with Sony MP3 player, made in Japan. Unstructured interview begins with a general question in the wide study area and generates the most enriched data (27). Interview began with a general question "Please explain about your experience with the challenges in the care of infants and

their families the end of life"; and then, based on the given responses to this question, the next questions were asked - and directed on the spiritual challenges. In this study, sampling was continued until data saturation and saturation was obtained through 22 interviews. In order to ensure data saturation two further interviews were conducted, but no more data and category were obtained. Data from interviews was analyzed using content analysis with qualitative approach.

The process for extracting codes continued by repeated reading of the interview texts till naming the codes. To increase the accuracy and acceptance of the findings, through the integration of several interviews, the participants are rechecked and re-interviewed. The codes obtained by data analysis will be revised and modified until the final stages of writing the management plan. Data was collected by the investigators within 6 months of deep interviews. The first and last author conducted all the interviews. All interviews were recorded using an MP3 player and transcript word by word by two researchers (N.S. and F.GH) at the end of each day separately. Analysis was done manually without any software package. The researchers read and categorized all of the interviews several times for finding the meaning of words and phrases and find a general sense.

2-4. Data Analysis

Since the researcher in this study was seeking to discover and identify the intellectual challenges of participants and there were limited information and ideas, particularly in the cultural and social context of Iran in this regard, therefore qualitative content analysis was used with a conventional approach and inductive methods of Graneheim and Lundman (28) with the following steps to obtain a deep understanding and description of this phenomenon:

In the first stage, the analytical content and unit of analysis were determined. At this point it is necessary to transcript the data before beginning the analysis. In general, the data in content analysis are written. The entire interview can be considered as the unit of analysis. In this study the unit of analysis is considered the whole interview. In the second stage, the meaning unit or coding unit was identified. Meaning unit is the part of the original text and can be words, sentences or paragraphs. Meaning unit refers to a text that is to be set during the analysis. In the present study proportionate to the text messages, phrases and sentences were selected as meaning unit. At the third stage, condensation, abstraction, and the formation of codes were done. Condensation means reducing the size of the text while maintaining the original concept.

With the process of reduction and condensation, condensed meaning units were formed. In the fourth stage, the codes were categorized in subcategories. After the formation of codes with the inductive method, the same codes were merged according to the features, characteristics and criteria related to the meaning of the codes, and finally the codes that have similar concept are grouped in a category and the subcategories are determined. At the fifth stage, Categories were formed out of subcategories. In this stage, subcategories are compared with each other, and concepts with the same concept were put in a category. Thus the categories were formed through grouping the subcategories based on similarities and differences. In the sixth stage, themes emerged from categories and themes were discovered (28).

2-5. Ethics

This study was approved in Ethics Committee of Zahedan University of Medical Sciences with No (IR.ZAUMS.REC.1395.172). Before the interview oral and written informed

consent was obtained from all participants. The information in the consent form such as optional participation in the study, the right to withdraw from the study at any point of the study and without providing any reason, and the confidentiality of the information obtained and participation - were fully justified and informed.

3- RESULTS

The results of 24 interviews with nurses working in neonatal intensive care units indicates that the average age of nurses was equal to 33.5 $\pm$ 0.384 year, which shows that the sample were relatively young. Of the nurses studied, 21 subjects had a bachelor's degree (nursing), and 3 subjects had a master's degree (Master of Nursing). Of the 24 nurses, participating, 14 were single and 10 were married. The average work experience of nurses in the NICU was 5.3 years, which is shown at the **Table.1**. In this study three themes, five categories and eleven subcategories the following were obtained: **1**- Spiritual challenge of neonatal care with two-categories (palliative care, and care with love and affection); **2**- Psychological / spiritual support challenges of family with two categories (spiritual support of family, psychological support of family), and **3**- The nurses' spiritual distress with one category (nurse's trauma in neonatal care) which are shown in **Table.2**.

1. SPIRITUAL CHALLENGE OF NEONATAL CARE

The first theme of the study is "spiritual challenges of the neonatal care" with categories "palliative care" and "care with love and affection".

1-1. Palliative Care

This category is made of two sub-categories "treatment needs of infants" and "psychological needs of infants".

1-1-1. Treatment needs of infants

One of the most important issues was attention to the treatment needs of dying newborns. Most participants in this regard believed that the therapeutic interventions for newborns should be done up to the final stage, on the other hand, by doing invasive actions for the dying infant felt guilty. One of the nurses expressed her experience in this field:

"*When it comes to the point that all the efforts of medical and nursing care for treating and saving the life of a newborn are useless, thereafter, we should try to have the baby at the end of life under high quality care. That is, they should be at least in proper physical condition, changed regularly, if there are no prohibition on drinking milk, it certainly be fed with milk and reduce pain, nausea and vomiting and"* [PN13].

Another nurse in this regard said:

"*... Such babies are more sensitive... because they can tell nothing and are completely dependent and need special and more care. The feeling it's just me the patient and God! Leads to more attention to these patients*" [PN17].

1-1-2. psychological needs of infants

Most nurses participating in this study stated that a dying baby needs peace more than anything else and it is very important to meet the psychological needs of the infant such as the need to touch, the presence of parents beside him, and caress. One of the nurses in this field, said:

"*... When a baby is in the last stages and there's nothing we can do, we try to love it as much as possible, to take its hand and talk with it. I think the only thing they need is to love them"* [PN8].

Another participant stated his own experiences as such:

"*... Sometimes the babies are strongly stress*ed *and get wound*s *all around the body. Although we know that they don't*

survive, but we bother them with unnecessary treatments. I think newborns with no hope of survival. The only thing they need is caress and peace and shouldn't spend their last moments with pain and suffering..." [PN17].

1-2. Care with love and affection

This category is comprised of two sub-category "passionate care" and "considering the infant as a human".

1-2-1. Passionate Care

Statements of participants in this study showed that nurses in taking neonatal care work with a good feeling and in some cases feel attached to the baby. In the following, there are examples of quotes from participants' experiences. One of the participants stated:

"*Some say that work*ing with *the baby is difficult, but for me it's not, I love them so much, and work with enthusiasm, despite the fact that sometimes the pressure is too high, so that we don't have the opportunity to sit for a moment. In principle, working in intensive care unit is difficult, but I love it, for instance, if I am off for several days, then I miss it"* [PN7].

1-2-2. Considering infants as a human being

One of the ethics that participants in this research considered important when facing dying babies was considering them as a human being. One of the nurses said about it this way:

"*The most important thing we should know is that infants are like us human beings, they have soul and understand everything. If we believe in this, then we can take better care of them, we will be more responsible to them, and could better understand them, but it is difficult for many to understand. When we see some nurses treat indifferently with the infants, I get so upset"* [PN17].

Most of the participants in the study stated that even the baby's corpse should be respected as a great man as well. Another nurse in the field, said:

"... *It is very important for parents to know that at least their infant has reached peace and their body is treated with respect. Perhaps for some these things have become conventional and trivial, but, that dead baby has been all life of its parents and more importantly, a human being. So we should treat him with respect, and lay it towards Mecca"* [PN18].

As participants' statements showed, nurses in taking care of babies at the end of life are faced with cases such as infant's need to receive palliative care, and receiving care with love and affection. On the other hand, due to lack of a specific clinical guide, they weren't able to provide proper care which faced them withspiritual challenges.

2- CHALLENGE OF SUPPORTING PSYCHOLOGICAL / SPIRITUAL CARE OF THE FAMILY

The second theme of this study was challenge of supporting the psychological / spiritual care of the family with categories "spiritual support of family" and "psychological support of family".

2-1. Spiritual support of family

This category is formed of two sub-categories of "understanding and empathy" and "spiritual / religious beliefs".

2-1-1. Understanding and empathy

Most of the nurses participating in this study believed that supporting the family and proper treatment with them is their duties and families with an infant at the end of life will need to be understood and empathized. One of the nurses expressed his experience in this field as follows:

"... *We should exercise caution in dealing with such families, because they are in difficult conditions, and we can both*

support them or bother them with our behavior and actions. Even when we are tired and there is a lot of pressure, we should try to treat the family with sincere and compassion..." [PN18].

Another nurse stated her experience:

"*... The only thing that could help the families in difficult conditions of dying infant, is the intimate and compassionate behavior of the nurse, they should know they're not alone and we understand them, which spiritually strengthens them. Even sometimes our acts have a strong effect, where parents appreciate the efforts of nurses despite the death of their child"* [PN20].

2-1-2. Spiritual / Religious beliefs

Most of the participants stated that spiritual / religious beliefs of families are an important factor to calm the family, however, a number of nurses believed that if the families are allowed for such actions, then the treatment procedure of newborns would be disrupted.

One of the participants said:

"*... A mother who lost its child after two weeks of hospitalization was consoling herself by saying these words: Perhaps it's the providence and will of God... God didn't want my child to bother anymore and.... it was a sad and shocking scene that a mother consoles herself by remembering"* [PN20].

One of the participants also expressed their experiences:

"*... A lot of mothers put a Quran under the head of their newborns and some asked us to play Quran at the end of the life of their babies, so that they listen and get calm. Even mothers put a piece of cloth which is blessed with the shrine of a Son of Imam or holy place and put it into the bed of their infant"* [PN15].

2-2. Psychological support of family

This category is formed of two sub-categories of "non-acceptance of illness and death of newborns" and "psychological / spiritual problems of the family".

2-2-1. Non-acceptance of illness and death of newborns

In this research one of the main concerns of the participants was facing with parents that did not accept the baby's death or illness. One of the nurses expressed her experience in this field as:

"*... Some parents do not accept their child's death, and shout and break windows and doors and other things. In this case, the nurses must be patient"* [PN22].

Another Nurse says:

"*I try to stay away from ill patient, I am very sad when I see critically ill patients and think their families, in some cases that CPR is done, I'll try not to be in touch with the family and avoid direct contact*" [PN10].

2-2-2. Psychological / spiritual Problems of family

Newborn death is one of the most difficult life experiences of parents, relatives and medical staff at the hospital. Some nurses said that families face with psychological / spiritual problems after the death of their child. One of these psychological problems of families is the feeling of guilt on behalf of parents and attributes the cause of this event to them. One of the nurses said in this regard:

"*... In such cases, the family suffers from bad psychological conditions. Many of them complain that why my baby? Why it should happen to me? What was wrong about me? What was my problem?"* [PN20].

Another participant expressed his own experience in this field:

"... *I'm a mother.... A mother... nothing about what you say and do can justify me. I always think that God wanted to punish me; because I am married, my husband without the consent of my family. God did it to me, because I broke the heart of my father. Because my husband separated me from my family and mother, God also wants to get my baby"* [PN18].

Another nurse in this regard says: My spiritual mood in dealing with ill infant depends on the hospitalization time, and conditions of family. If families follow-up the treatment and are very strict and I try to help, but if the family is poor in terms of income, and don't follow up the treatment of their infant, I'd like the infant to be expired as soon as possible, so that the cost of family is reduced and the baby is relieved.

In addition, most of the participants in this study pointed out that:

"... *Parents would like to know that they are blamed and the baby's death wasn't due to their failure, for example, it it's congenital defects then it's not their fault and may occur to other parents as well"* [PN3].

So as participants' statements indicate, families need to be understood and empathized at the time of illness and death of infants and using their spiritual / religious beliefs we can move towards spiritual support of family. On the other hand, most families face with psychological problems in accepting the illness and death of their infants, and their statements shows that they are experiencing spiritual distress. Nurses need to be aware of these challenges and provide them with the required psychological / spiritual support.

3- SPIRITUAL DISTRESS OF NURSE

The third theme of this study was nurses' spiritual distress with category "nurses' trauma in caring newborns".

3-1. Nurses' trauma in caring newborns

This category is formed of tree sub-categories of "ill infant", "the causes of neonatal death" and "announcement of bad news to the family".

3-1-1. Ill infant (un-well infant)

Nurses believe that taking care of the baby at the end of life is very difficult and stated that taking care of the babies has been effective in their spirit and left psychological / spiritual problems for them. They believe that these psychological problems are due to the critical conditions of the baby, which has led to the psychological torture in some of the participants.

One of the participants in this field has stated:

"... *given that most babies who are admitted in our ward, would unlikely return to life and probably their spending their last hours or minutes of their lives, therefore, caring for them will impose bigger damage to us in spiritual terms, and such situations will never become normal to us"* [PN13].

Also one of the nurses described his experience in this field:

"... seeing such small and innocent creatures in these circumstances and taking care of them hurts so much and seems like a torture to me, and it feels to me that why should I see and handle these things" [PN23].

Nurses reported that they had repeatedly witnessed the death of babies, and this is one of the psychological damages that nurses encounter with. One of the nurses participating in this study state their experience in this field:

"... *Nursing of newborns that are in the last stage of life is so hard and painful and witnessing their death is a difficult experience that can deteriorate the spirit of the nurses"* [PN21].

Another participant stated this spiritual – psychological damage:

"*... After a few years of working in this sector, still when I see that such a small child dies, I can't stop thinking about it for a few days and even sometimes for several months.Wherever I go and whatever I do I can't forget the death of the infant. I suffer a really hard psychological pressure when I see a baby dies before experiencing her mother's arms and so many other things in the world"* [PN16].

3-1-2. The causes of neonatal death

Nurses at the time of death of infants are faced with mental conflicts about the causes of the problem and the causes of neonatal deaths because accepting the neonatal death was very difficult for nurses. One of participants in this regard stated:

"*Sometimes I say thank you God, I don't meddle into your works, but really this baby was innocent and not guilty*" [PN7].

The other participant states:

"*I sometimes become nerves, and say that these [infants] are not guilty, why this happens to them? Why should they have much pain and this makes me nervous and preoccupies my mind*" [PN12].

3-1-3. Announcing bad news to family

Participants stated that the announcement of bad news about the bad condition of the baby is very difficult. They also believed that so far they haven't been trained on how to convey bad news to the family. One of the participants in this regard stated:

"*I have a coworker with 20 years of experience, Oh, for God's sake* don't ask me to give the news of the *infant's death to its family, it's a difficult work. We are not trained in this regard,* during all these*15 years nobody told me how to treat, of course, we have passed a course about the dying infants, but we aren't trained about how should we deal thereafter, for example, how should I treat the family, what should be our first reaction, no courses are held and there has been no training in this regard*" [PN7].

When the nurses cared an ill baby at the end of life and had to give bad news to the family, they had a lot of spiritual stress. Therefore, from subcategories of ill infant, the causes of neonatal death and announcement of bad news to the family emerged spiritual distress of nurse.

Table-1: Frequency distribution of demographic characteristics of participated nurses.

No.	Participants	Age, year	Academic degree	Marital status	Working experience in NICU, year
1	PN1	29	Bachelors	Single	6
2	PN2	32	Bachelors	Single	7
3	PN3	32	Masters	Single	5
4	PN4	32	Bachelors	Single	5
5	PN5	38	Masters	Single	7
6	PN6	34	Bachelors	Single	4
7	PN7	37	Bachelors	Married	15
8	PN8	32	Bachelors	Single	1
9	PN9	45	Bachelors	Married	20
10	PN10	34	Bachelors	Married	1
11	PN11	29	Bachelors	Married	1
12	PN12	28	Bachelors	Married	2
13	PN13	25	Bachelors	Single	15

14	PN14	32	Bachelors	Single	9
15	PN15	38	Bachelors	Married	7
16	PN16	24	Bachelors	Single	5
17	PN17	44	Bachelors	Married	4
18	PN18	32	Bachelors	Married	3
19	PN19	28	Bachelors	Single	3
20	PN20	30	Bachelors	Single	3
21	PN21	33	Bachelors	Single	2
22	PN22	46	Bachelors	Married	2
23	PN23	35	Bachelors	Married	1
24	PN24	35	Masters	Single	4

Table-2: Themes, categories and sub-categories obtained of this study

Themes	Category	Subcategory
Spiritual challenge of neonatal care	Palliative Care	Therapeutic needs of newborns.
		Psychological needs of newborns.
	Care with love and affection	Passionate care.
		Considering infants as human.
Challenge of psychological / spiritual support of family	Spiritual support of family	Understanding and empathy.
		Spiritual / religious beliefs.
	Psychological support of family	Rejection of illness and death of newborns.
		Psychological / spiritual problems of the family.
Spiritual distress of nurse	Nurses' Trauma in neonatal care	Ill infant.
		The causes of neonatal death.
		Announcement of bad news to family.

4- DISCUSSION

In this study, the spiritual challenges experienced by nurses at the end of life and death in the NICU includes three themes of spiritual challenge of neonatal care, challenge of psychological / spiritual support of family and spiritual distress of the nurse. The first theme resulting from this study is the spiritual challenge of neonatal care with the categories of palliative care and care with love and affection. Nurses believe that the lack of palliative care guide is a big problem, and they often have this problem of being unaware of what to do for infants at the end of life and families. The results of two studies about the importance of palliative care in dying babies has shown that care at the end of life, control and relief, as well as providing emotional and psychological comfort of dying patients is an essential issue; because when there's no effective treatment for a disease, it is possible to control and relieve excruciating pains of patients, and award a superficial peace to the patients (14, 17, 29, 30). Another newborn's need at the end of life is the need to care with love and affection. Nurses believed that infants should be considered as a human and receive care with love and affection. In the research of Henley, appreciative were those whose child was recognized as a respected human being (31). In the research of Meert et al. the parents needed to have their child recognized and respected as a human (32). In the study of Bloomer et al. nurses in the study believed that newborns have a personal integrity and must have a name

and addressed by a name (17). In the present study, nurses knew the neonatal and the family needs, but because of overcrowding and lack of awareness towards spiritual care, they didn't know how to respond to these needs. The second theme of the research was challenges of psychological / spiritual support of the families. Nurses believed that families need to be understood and empathized and their religious and spiritual beliefs must also be respected. Of course, a number of nurses, face with challenges in the field of understanding the families as well as respecting their religious beliefs because they felt these beliefs could interfere with providing neonatal care. In the research of Bloomer, nurses believed that we should understand the families, but sometimes it may be neglected (17). When a mother loses her fetus, she may experience bad feelings for years (33).

In the study of Moghaddam Tabrizi et al. mothers said about the role of nurses in helping them to improve their confidence in maternal role when they have premature infant (34). In the study of Sadeghi et al. families at the end of life stage, needed empathy on behalf of the treatment team, also resorting to religious and spiritual beliefs is considered as an important factor in gaining peace at the time of neonatal death. In situations of despair, prayer may be experienced as a source of strength, patience, persistence and hope (35). In a study, 82 percent of Americans believed in healing of a person through prayer (36).
In the research of Meert et al., parents prayed to seek help from God, so that their infant is healed through prayers, they even felt the need for the prayers of others such as family, friends and the medical team (32). In the present study, the nurses believed that most of the families couldn't accept the illness and death of their baby and suffered from psychological problems and needed to get psychological support from the nurses. While nurses faced challenges in providing this care due to lack of time (37, 38). In the research of Bloomer et al. nurses believed that they can help families to accept the illness and death of their baby, and take them time to ask questions, because families might not be able to ask some questions from the doctor (17). Many families suffer with psychological problems after the death of their child; they often wonder about the cause of death of their child; and whether the cause of death was due to negligence on their part in taking care of their child (39). In the study of Rosenbaum et al. also most families in facing with the experience of losing infants began asking questions like why this problem happened to them; or what was wrong about them? Or why God has allowed this problem to happen for them (9). All the above items indicate the psychological and spiritual problems of families and the need to receive psychological / spiritual support, which should be considered by the nurses and the medical team.

On the other hand, the rejection of neonatal death in Iranian society is much more significant, where family relationships and emotional ties are of greater intensity and strength. In the present study alike the previous research, the nurses knew that meeting these needs for the family is essential according to the necessity of family-centered care, but they faced with a challenge due to a lack of program tailored to the cultural conditions of the society. The third theme of the study was the spiritual distress of the nurses. The nurses involved in the care of the baby at the end of life and death suffered with trauma. Sometimes nurses by observing the malignant conditions of the baby become upset and even ask themselves why should the baby endure such suffering and dye. Speaking of nurses indicate spiritual distress. Spiritual distress is expressed sometimes as a sense of loss, which could mean losing self,

communication or meaning (40). In a study, it was stated that the nurses involved in the neonatal care experience high levels of emotional stress. Nurses when faced with the death of a baby can experience a great spiritual distress (3). Spiritual and ethical supports is essential by colleagues, administrators, neonatologists, Clergymen, and nursing supervisors of nurses and doctors who directly take care of dying babies (41). The results of Archibald showed that the experiences that the nurses often experience in intensive care unit for newborns include severe sadness, confusion, frustration, fear and anger (42). Therefore, due to the trauma suffered by nurses, creating support systems on behalf of the management system is recommended with regard to special solutions in announcing the condition of the baby to the family, holding training courses on how to convey bad news, supporting the family and how to visit end of life patients and also providing the necessary guides in the above-mentioned fields.

4-1. Limitations of the study

Given that religious and spiritual conditions of nurses are influenced by culture and can be linked to the experienced challenges, conducting the present research in a particular area is one of the limitations of this study.

5- CONCLUSION

In this study three themes and five categories were obtained. The first theme was Spiritual challenge of neonatal care with two-categories (palliative care, and care with love and affection); the second theme was Psychological / spiritual support challenges of family with two categories (spiritual support of family, psychological support of family), and the third theme was the nurses' spiritual distress with one category (nurse's trauma in neonatal care). Results of this study showed that nurses working in NICU face with a triangle of challenges in neonatal care at end of life and death. One point is related to neonatal care and the needs that newborns encounter at this stage of life and the absence of a clinical guide on palliative and spiritual care of nurses has faced them with difficulty. The other point of the triangle is the challenges of family care, for families who have lost their children need to receive psychological / spiritual support on the side of the treatment team, and nurses due to lack of clinical and teaching guide in this area are having challenges.

Neonatal care and family care are part of family-centered care approach; however, in this approach we should also consider another dimension that makes up the third angle of challenges, the problem that the nurse taking care of the baby at end of life and death is unaware of it, but has experienced it again and again. There were some cases in the speaking of nurses that expresses the experience of spiritual distress. Therefore, the dimension of nurses' trauma should be paid special attention and in family-centered care approach three dimensions of neonatal care, family care, and nurse care should be taken into consideration and necessary policies be developed in this regard.

6- CONFLICT OF INTEREST

7- ACKNOWLEDGMENT

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8- REFERENCES

1. Flory J, Emanuel E. Recent History of End-of-Life Care and Implications for the Future.Expanding Horizons in Bioethics: Springer; 2005. pp. 161-82.

2. Reid S, Bredemeyer S, van den Berg C, Cresp T, Martin T, Miara N. Palliative care

in the neonatal nursery: Guidelines for neonatal nurses in Australia. Neonatal, Paediatric and Child Health Nursing. 2011; 14(2):2.

3. Mendel TR. The use of neonatal pallative care: reducing moral distress in NICU nurses. Journal of neonatal Nursing. 2014; 20(6): 290-3.

4. Zeighamy F, Sadeghi N. Spiritual Religious needs of adolescents with cancer. Religions. 2016; 7(7): 91.

5. O'Brien ME. Spirituality in nursing: Jones & Bartlett Publishers; 2008.

6. Attard J, Baldacchino DR, Camilleri L. Nurses' and midwives' acquisition of competency in spiritual care: A focus on education. Nurse education today. 2014; 34(12):1460-6.

7. McSherryW. Making sense of spirituality in nursing and health care practice: An interactive approach: Jessica Kingsley Publishers; 2000.

8. Papathanasiou I, Sklavou M, Kourkouta L. Holistic nursing care: theories and perspectives. American Journal of Nursing Science. 2013; 2(1):1-5.

9. Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care.The Journal of perinatal & neonatal nursing. 2011; 25(1):61-9; quiz 70-1.

10. Tanyi RA. Spirituality and family nursing: spiritual assessment and interventions for families. Journal of Advanced Nursing. 2006; 53(3):287-94.

11. Ross L, Giske T, van Leeuwen R, Baldacchino D, McSherry W, Narayanasamy A, et al. Factors contributing to student nurses'/midwives' perceived competency in spiritual care. Nurse education today. 2016; 36:445-51.

12. Mitchell D. Spiritual and cultural issues at the end of life. Medicine. 2008; 36(2):109-10.

13. Watson J, Woodward T. Jean Watson’s theory of human caring. Nursing theories and nursing practice. 2010:351-69.

14. Nurse S, Price J. No second chance– junior neonatal nurses experiences of caring for an infant at the end-of-life and their family. Journal of Neonatal Nursing. 2017; 23(2): 50-7.

15. Currie ER, Christian BJ, Hinds PS, Perna SJ, Robinson C, Day S, et al. ParentPerspectives of Neonatal Intensive Care at the End-of-Life. J Pediatr Nurs. 2016; 31(5):478-89.

16. Babaei H, Dehghan M, Mohammadi Pirkashani L. Study of Causes of Neonatal Mortality and its Related Factors in the Neonatal Intensive Care Unit of Imam Reza Hospital in Kermanshah during (2014-2016). Int J Pediatr 2018; 6(5): 7641-49.

17. Bloomer MJ, O’Connor M, Copnell B, Endacott R. Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: nurses’ emotional talk and sourcesof discomfort. A mixed methods study. Australian Critical Care. 2015; 28(2):87-92.

18. Caldeira S, Hall J. Spiritual leadership and spiritual care in neonatology. Journal of Nursing Management. 2012; 20(8):1069-75.

19. American Academy of Hospice and Palliative Medicine; Center to Advance Palliative Care; Hospice and Palliative Nurses Association; Last Acts Partnership; National Hospice and Palliative Care Organization. National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. J Palliat Med. 2004; 7(5):611-27.

20. ArshadiBostanabad M, NamdarArshatnab H, Balila M, Asghari Jafarabadi M, Ravanbakhsh K. Effect of Family-centered Intervention in Neonatal Intensive Care Unit on Anxiety of Parents. International Journal of Pediatrics. 2017; 5(6):5101-11.

21. Corkin D, Clarke S, Liggett L. Care Planning in Children and Young People's Nursing: John Wiley and Sons; 2011.

22. Beckstrand RL, Kirchhoff KT. Providing end-of-life care to patients: critical care nurses’ perceived obstacles and supportive behaviors. American Journal of Critical Care. 2005; 14(5):395-403.

23. Kozier B. Fundamentals of nursing: concepts, process and practice :Pearson Education; 2008.

24. Das RR, Sankar MJ. Stressful Life in NICU: Time to Nurse the Neonatal Nurses. Indian Journal of Pediatrics. 2015; 82(11):983.

25. Krippendorff K. Content analysis: An introduction to its methodology: Sage; 2004.

26. Burns N, Grove SK. Understanding nursing research: Building an evidence-based practice: Elsevier Health Sciences; 2010.

27. Halloway I, Wheeler S. Qualitative research in nursing and healthcare. Oxford, United Kingdom: Wiley–Blackwell; 2010.

28. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse education today. 2004; 24(2):105-12.

29. Kelly L, Linkewich B, Cromarty H, St Pierre-Hansen N, Antone I, Gilles C. Palliative care ofFirst Nations people A qualitative study of bereaved family members. Canadian Family Physician. 2009; 55(4):394-5. e7.

30. Smith AK, Sudore RL, Pérez-Stable EJ. Palliative care for Latino patients and their families: whenever we prayed, she wept. Jama.2009; 301(10): 1047-57.

31. Henley A, Schott J. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. Seminars in fetal and neonatal medicine. 2008; 13(5):325-8.

32. Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study. Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies. 2005; 6(4):420-7.

33. Salehi K, Kohan S, Taleghani F. Factors and Interventions Associated with Parental Attachment during Pregnancy in Iran: A Systematic Review. International Journal of Pediatrics. 2018; 6(1):6823-42.

34. Moghaddam Tabrizi F, Alizadeh S, Radfar M. Barriers of Parenting in Mothers with a Very Low-Birth-Weight Preterm Infant, and their Coping Strategies: A Qualitative Study. International Journal of Pediatrics. 2017; 5(9):5597-608.

35. Sadeghi N, Hasanpour M, Heidarzadeh M, Alamolhoda A, Waldman E. Spiritual Needs of Families with Bereavement and Loss of an Infant in Neonatal Intensive Care Unit: A Qualitative Study. J Pain Symptom Manage. 2016;52(1):35-42.

33. Catlin EA, Guillemin JH, Thiel MM, Hammond S, Wang ML, O'Donnell J. Spiritual and religious components of patient care in the neonatal intensive care unit: sacred themes in asecular setting. Journal of perinatology: official journal of the California Perinatal Association. 2000; 21(7):426-30.

37. Silbermann M, Khleif A, Tuncer M, Pitsillides B, Shad A, Oberman A, et al. Can we overcome the effect of conflicts in rendering palliative care? An introduction to the Middle Eastern Cancer Consortium (MECC). Current oncology reports. 2011; 13(4):302-7.

38. Davies B, Sehring SA, Partridge JC, Cooper BA, Hughes A, Philp JC, et al. Barriers to palliative care for children: perceptions ofpediatric health care providers. Pediatrics. 2008; 121(2):282-8.

39. Robinson MR, Thiel MM, Backus MM, Meyer EC. Matters of spirituality at the end of life in the pediatric intensive care unit.Pediatrics. 2006; 118(3):e719-29.

40. EdwardsA, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliat Med. 2010; 24(8):753-70.

41. Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. Neonatal Network: The Journal of Neonatal Nursing. 2002; 21(4):37-49.

42. Archibald C. Job satisfaction among neonatal nurses. Pediatric Nursing. 2006; 32(2):176.