Critical Care Nursing

Iran J Crit Care Nurs 2013,5(4):172-181

Journal home page: www.inhc.ir

Mothers' experience of having a preterm infant in the Neonatal Intensive Care Unit, a Phenomenological Study

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ARTICLE INFO

Article type:
Original article

Article history:
Received: 5 Nov 2011
Revised: 9 Apr 2012
Accepted: 23 Apr 2012

Key words:
Mothers' experiences
Preterm infant
NICU
Phenomenological Study

ABSTRACT

Aims: Understanding the experiences of mothers could be as a strategy for the physicians, nurses who are working in NICU and administrators in the care centers in order to provide supports for parents, particularly mothers and an effective step to improve the quality of nursing care of premature infants and their parents.

Methods: In this study, one of the qualitative research methods as descriptive phenomenology was used with Colaizzi approach. Data were collected through semi-structured interviews with 20 mothers with experience of a preterm infant in intensive care unit of treatment- educational centers of children and Alzahra(s) of Tabriz to share these experiences in 2010.

Results: Among all the results of this study 4 themes were emerged which indicated structure of mothers' experiences of hospitalization of a preterm infant in NICU. Themes and subthemes of this study were as: Sense of Alienation, Lack of control, Caring and Depravation.

Conclusion: According to the findings mothers were encountered with some positive and negative experiences. In this regard nurse's practice was so effective to mothers' ability and their partnership in taking care of the infant in order to form positive experiences and reduce the negative ones. Thus promoting some methods to support mothers' feelings and to share caring of their babies seems to be necessary.

Please cite this paper as:
Malakouti J, Jabraeeli M , Valizadeh S, Babapour J. Mothers' experience of having a preterm infant in the Neonatal Intensive Care Unit, a Phenomenological Study. Iran J Crit Care Nurs. 2013,5(4):172–181.

1. Introduction

An infant's birthday is an exciting happening for every parent. Unexpected birthday of a sick or preterm infant can be an end to the emotions and replace anxiety and stress. New technologies of reproduction, high age of mother and improvement in cares during pregnancy and after that result in increase of level of preterm infant birthday and infants with severe anomalies in industrial countries [1]. Birthday of a healthy infant is the best gift for mother in delivery time while encountering with a preterm infant causes a severe mental problem for parents especially for mother [2].

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Parents are rarely prepared for the shock, tension and anxiety caused by birthday of a preterm and critically ill infant who is hospitalized in NICU. Birthday of a sick and preterm infant endangers process of passing to parental period necessarily [1].This lack of preparation results in parents' grief and incidence of mental disorders in form of hating the baby slightly to intensively and evidence and hidden negative reactions towards the infant [3]. Generally preterm infant needs to be hospitalized in NICU immediately after the birth [4]. Hospitalization of the infant in NICU is a stressful event for mothers that encounter them with several challenges [5].

Studies of 90th decade have shown that parents' stress sources of having a preterm infant includes size and infant's appearance that is surrounded by the device, experience of several aggressive treatments, change in parental role, long-term separation and compatibility with the hospital and environment of NICU. This environment can be stressful, noisy, strange and frightening for the parents since there is death and life at every moment [6]. Because most of the parents do not know about complex problems due to preterm infant and they do not know about its future health so lack of clear perception of future condition of the infant and unreliability of improvement are counted as the most important sources of stress and because of stress and tension, mothers' health who has delivered newly is in danger and she is at the risk of postpartum depression [7].

When connection between mother and the infant has been cut because of hospitalization in ICU, cutting of this attachment affects infant's emotional evolution negatively. Studies show that lack of interaction between mother and infant causes sense of alienation in mother and this sense and experience has negative effect on maternal feelings and emotions [5].

Mother's communication with the infant hospitalized in NICU is not onlyas important as mother's communication with a healthy child but also it is moreimportant [4]. So medical and nursing staff should prevent cutting communication process of mother with the infant and with giving enough information to mothers in taking care of the preterm infant should provide their full participation in taking care of the infant [8].

Nowadays challenge of nurses in children's Unit is not only providing the best care programs for preterm infants but it is also helping mothers for accepting preterm infant and growing maternal sense[9]. So when infant's condition is favorable, at the first time nurses should help the infant with neurodevelopment and behavioral evolution by starting breast milk feeding and by skin contact between mothers and infant and stabilize lost chance of mother for taking care of the infant [2]. When mother is participated in taking care of the infant there is a continuous relationship between mother and the infant and mother is out of sense of alienation and sense of partnership is overcoming mother and this sense leads mother' feeling to positive direction[5]. According to Aliabadi et.al involvements of parents on taking care of the infant improves ability of parents in order to facilitate their infant's evolution during hospitalization and after discharge and reduce hospitalization time of the preterm infant in NICU that economic cost reduction and risk of hospital acquired infection reduction are among its benefits. This study also shows that active involvement of mothers in care, increases mother's confidence in taking care of the infant before discharge [10].

Lasbia et.alstudy (1994) and Aggard and Hall's study (2008) about a mother's experience of working in ICU during hospitalization of a preterm infant showed that loving the baby , valuable time of being with the baby and losing sense of uncertainty were among positive experiences said by the mother [11,12].

Wiger's study (2008) showed that meeting the infant in ICU and hearing bad news about the infant are among bad experiences and no mother is ready to experience them [13]. Mothers are angry with watching pain, suffering and deprivation of their infants. But

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most of them are afraid of talking about their anger to the medical staff, so experienced medical staff with knowing this issue should encourage the parents to talk about their internal feelings [14].

From what is said in the above it can be understood that mothers whose children were born preterm and they are hospitalized in ICU experience several tensions that can at the end endangermothers' health. It is clear that nurses as the member of treatment team with good communication and with making mothers participate in taking care of their infant can prevent cutting of communication between mother and infant that at the end the infant will benefit its results. Researchers' experience indicate that in the present system taking care of hospitalized preterm infant was infant – oriented and taking care of the parents of these infants especially mothers who are encountered with several tensions are less taken into consideration and sometimes it is ignored. So for finding present weaknesses, researchers decided to explain experiences of mothers whose preterm infants are hospitalized in ICU. In this regard researchers designed this qualitative study for answering the following questions: How are experiences of preterm infants' mothers in communication with the staff in ICU? To what extent did mothers have control on taking care of the infant? How was their perception of ICU's environment? How was relationship of mother with the infant in ICU? And at the end what was mothers' positive and negative experiences of their infants' presence in ICU? And the aim of this study was explaining mothers' experiences of infants' hospitalization in ICU.

2. Method

This study is a qualitative study of phenomenological description that sampling has been according to the aim; in this study 20 of mothers were chosen according to special knowledge and information with the aim of sharing the information. Samples were mothers that had experience of preterm infant hospitalization in NICU of children's treatment- educational centers and Alzahra(s) in at least the last three months and during infant hospitalization they had referred to the Unit at least three times a week to visit their infants and to follow its condition and during the study their infantswere hospitalized in the Unit. Mothers participated in the study after satisfaction. In the case of a mother's quit in the study she was excluded from the study. Information of this study was from semi-structured interview, it means it was collected in the form of designing some open questions. After giving information about study aims and their satisfaction, time and place of individual interviews has been determined. Interview time was 30-45 minutes. During the interview with permission of the research units their voice has been recorded and in the case of interviewee's disagreement their interviews has been written. After the interview vague things has been written and in the next session it has been reviewed again. Datacollection has been continued until data saturation, it means until the time that there was no information and new code of the interviews that can be extractive.

Data analysis has been done simultaneously with its collection. For analyzing the data Colaizzi 7-steps process has been used [15]. After the interview in the first step the researcher wrote it down by listening to the tape several times and then with reading it several times they tried for immersion in the data and to have the same feeling with the participants. Writing the recorded information on the paper was for perception of participants' experiences and deeper understanding of their experiences. All the texts were read carefully and important phrases (containing rich themes about mother's experience of having preterm infant in NICU) have been excluded. In the second step, meaning of every phrase has been explained and the meaning has been written in code form. In the next step it has been tried to put the extracted codes in certain categories of subject.In this regard some subcategories had been made that from their mixturesub-themes

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(sub-themes or sub-categories) had been formed. And from mixture of some sub- themes main themes of the research had been made finally. In the next step results were mixed in the form of a complete description of preterm infant experience s of the participants of the study in NICU and the results were reviewed for achieving clear and unequivocal themes. Participants' emotions and ideas in every theme were in the form of analytical description and with details are with the name of this comprehensive description, which includes main themes or general, concepts and the researcher recognized the main structure for comprehensive explanation. In step 7for determining validity and to see that if the researcher did not remove any thing, main themes or the general themes were referred to the participants and reliability of the achieved results was confirmed by them in the last interview that it is called members control.

Ethical considerations of this study includes participants' consent for participating in the study and recording their interview, not writing the name of the interviewees on the tapes and written texts, respecting the principle of confidentiality and confidentiality of the information and maintaining the right to withdraw was in every step of the research.

3. Results

In this study the average age of the mothers was at least 19 and at most 37. The education level in most of the mothers was in secondary or elementary level. Mothers were housewives and the social-economic condition of most of the families was at the average level. Most of the mothers had normal delivery method.

In this study 96 codes were extracted from the interviews that in the reduction step of the data 12 sub-themes and at the end 4 themes or main themes were extracted that include: sense of alienation, lack of control, care and deprivation that they are in table 1.

3.1. Sense of alienation towards the infant

They also said that they could not accept the infant at first and they asked themselves why it is like this. Why did it happen? Some explained that may be it was our guilty that a preterm infant has been born. In the following there are some examples of mothers' talking about this issue: "The children seemed very strange , you don't know which one is your child, my baby was very small, it was only 850 grams. I wondered how this baby is going to be a usual child" (interview 9). "Because it was too thin its head didn't stand on its body. I was afraid to hug and take care of it; I always asked myself is this baby born from me?"(Interview 10).

3.2. Sense of alienation towards the Unit environment

In this study mothers thought connection of the infant to the incubator indicates worsening of the infant's condition and sometimes they cried because of watching this scene and they had left the unit. Because they did not know about function of this device and they had sense of alienation and they were always afraid that if these devices do not work well and the baby is suffocated under the device. "I liked to know what for are these things and how do they work to be sure that my baby's device is working well "(interview 9). Physical space of ICU caused feeling of sadness in mothers "TheUnit seemed to be dark because it didn't have any windows and a person had the feeling of choking and couldn't breathe" (interview 1).

3.3. Lack of control

When mothers did not participate in taking care of the infant or they had to leave it they felt that they do not have enough control on the infant's condition, this theme included description of unstable emotions like fear, feeling of being guilty , anxiety and feeling of insecurity "feeding on time" and " attending the infant ".

3.4. Fear

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Results of this study showed that sense of fear happened in mothers when they visited their babies in the Unit for the first time. They said that after seeing the baby they didn't want to go back to the house and leave their dear baby there and sometimes they treated this separation as a long-term separation and they asked themselves " Am I going to see my child again?!" or "When am I going to see my baby again?!" Fear of infant's death and fear of adding problems to the infant because of hospitalization was always among mother's words clearly. "I had a lot of stress, I was afraid that my baby dies" (interview9). "Because other babies were connected to these devices I was afraid that my baby takes infection" (interview 6).

3.5. Sense of being guilty

Some mothers that had history of infertility and they were pregnant after years of practice were

Table 1: Examples of the initial codes, main themes and sub- themes

Main themes	Sub-themes	Examples of the initial codes
Sense of alienation	Sense of alienation toward the infant itself	Separation from the infant Not accepting the infant Strange appearance of the infant
	Sense of alienation toward stressful environment of the Unit	Mothers' feeling of sadness of the Unit's physical space to not be familiar with devices function fear of lack of work of devices Linking to the incubator means deteriorating of the infant
Lack of control	Fear	Fear of being separated from the infant Fear of the infant's death Fear of adding problems to the infant
	Sense of being guilty	To know herself responsible for a preterm infant To blame herself for insisting on having a baby To know herself responsible for the infant's suffering
	stress	Mother's stress with deteriorating the infant To be regretful for having a child
	Sense of insecurity	Sense of insecurity about attending the infant To be worried for the child of being hungry To be worried for not giving oxygen
Care	Trust	Mothers trust on the nurses in taking care of the infant Sense of trust because of giving enough information and good relationship Sense of being relaxed in the case of seeing attending to the infant.
	Love	Having a good feeling with patting and hugging the infant Enjoying partnership in taking care of the infant.
	Compatibility with motherhood role	Nurses' support for overcoming fear of providing care Teaching and partnership of the mothers in taking care of the infant Sense of being a mother
Deprivation	achieving information and discovering the truth	Desire to achieve a complete report of the infant's condition Mothers' desire to get an honest answer to her questions Not giving vain hope Saying the truth
	Private place	To be sad to look at the infant behind the glass Mother's wish for having a private and individual place Desire to take care of the infant with the presence of her husband Fear of finishing time and leaving the Unit Belonging of the infant to the hospital

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regretful of their insisting on having a child and they knew themselves responsible for their baby's suffering. Some others thought that lack of enough care of themselves is the reason of preterm infant and they blamed themselves for this negligence. "I wanted him/her by force and I delivered him/her with medicine and treatment may be it is because of this" (interview 3). "I blamed myself why I did this to my child. Because I worked hard, my amniotic sac was broken and it caused preterm delivery that now I'm regretful for that" (interview 17).

3.6. Anxiety

Mothers experience anxiety when the infant was worsening or there was a new problem and the infant was deteriorating in. "When he/she was feeding with NG tube his/her oxygen pressure was low and he/she was completely black and he/she was dying. I don't know how these bad moments passed on me but when he was given oxygen he was better little by little but I was dead before him/her "(interview 3).

3.7. sense of insecurity

Mothers' sense of insecurity was mostly about "feeding on time" and "attending the infant". I was really afraid that may be they do not attend well and my baby had been left hungry but they said that we feed him/her on time but I was always worried " (interview 5). " When the baby was born I was always thinking of him/her that is he given oxygen? May be my baby's chocking? I liked to see what happened or where he is?"

3.8. Care

Parents because of lack of caring role, pressure due to technologic environment, feelingof doubt and lack of confidence for taking care of the infant areanxious. Care theme included subthemes like: "trust", "love" and compatibility with motherhood role (support and partnership)".

3.9.Trust

When mothers saw that nurses take care of the infants well or they give them enough information, experienced sense of trust:" Nurses in NICU are very exact and they work hard because I was sure that they attend well I wasn't worried about my child" (Interview 2). "I was always crying and nurses gave me spirit and said that trust in God. Every question that I asked they answered. They had a very good deal. They were good-tempered and friendly and they didn't make me sad" (interview 14).

3.10. Love

These feelings were when mother was by the infant. "I had a good feeling that I changed his/her diaper, I pat him/her or I massaged him/her , I prayed for him/her and when he/she was in the incubator I asked him/her what clothe do you like to have on? Are you better my sweetie?" (Interview 9).

3.11. compatibility with motherhood role

Some mothers believed that although nurses took care of their infant well but they never could fill the place of mother for the infant, but most of the mothers at first experienced fear of providing care for their preterm infant. Nurses' "support" and mothers' "partnership" was very helpful for overcoming their fear and at the end they helped their compatibility with their role. Some mothers' explanations about this issue were like this: "Atfirst they gave milk via tube and we looked but then they taught us how to milk our milk and bring it with ourselves. They taught us to keep our breast clean in order to prevent infant's infection … little by little I had the feeling of being a mother" (Interview 9). "At first they changed the infant's diaper themselves but after that they taught me to change its diaper while I was very afraid. They said to me that I picked up the infant and I take care of the infant fearlessly" (interview 6).

3.12. Deprivation

Sub-themes of these themes were "achieving information" and "discovering the truth", "Unique sense of motherhood" and "privateenvironment".

3.13. Achieving information and discovering the truth

Some mothers because of being from towns had to get the information via telephone and the only answer that they heard was that "He/ she was as what you saw or there was no difference

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with him/her". While they liked to achieve a complete report of the infant's condition especially about its improvement and nourishment" It was good that despite lots of work of the staff they put a time for us, the parents. I liked them to say to me what works I can do for his/her improvement or how much time is neededfor his/he complete improvement" (interview 4). Mothers liked to get an honest answer to their questions and they liked that the information that is about their infant to be completely true: "Neither I like to tell me lie and give me vain hope nor to make me worried without any reason I just want them to tell me the truth about my baby's condition" (Interview 2).

3.14.Unique sense of motherhood

Mothers were sad because they had to watch their children behind the glass and they liked to hug him/her. They liked to take care of their infants alone and they were dissatisfied because they had to get nurses' permission for taking care of their own infants: "I just could to do hug care. I liked to pat him/her, to change his/her diaper, to clean his/her face and hands, to hug him/ herand to talk to him/her. It was very important for me to do these works but they didn't let me" (Interview 2). "I think when a person hugs her baby and milk him/her then she thinks that she is really a mother" (interview 20).

3.15. Private environment

Mothers wished for an individual place and they wanted to be alone with their infants: " I really wished to have a room in the hospital with all those equipment for that me and my husband attend our baby without any stress , without any anxiety and fear for finishing the time or nurses' insist for leaving the Unit" (Interview 9).

4. Discussion

From all the findings of this study, four main themes were extracted thatthey were about structure of mothers' experiences of having a preterm infant in NICU that included: sense of alienation, lack of control, care and deprivation.

In the present study mothers experienced sense of alienation towards the infant that this sense was because of separation from the infant and not accepting the infant because of its strange appearance. There was a study in Tabriz which showed that from mothers' point of view the most important source of stressrelated to the infant was its separation [16]. When an infant was hospitalized in NICU sense of being away and lack of interaction between mother and the infant cause sense of alienation in mother and this sense has negative effect on mothers'emotions [17]. Nystrom and Axelsson's study (2006) about mothers' experiences of having a preterm infant in ICU showed that mothers experience sense of alienation because of their separation from the infant [18].

Another factor that caused sense of alienation in mothers was ICU's environment. In Valizadeh's study (2008) presence of monitors and special equipment of the Unit,presence of other children under mechanical ventilation in the Unit and continuous noise of the monitors were the most important environmental stressors [19]. Study of Shields et.al (2003) showed that ICU's environment is one stressor for parents [20]. In the study of Miles et.al (1992) mothers experienced ICU's environment more stressful than fathers [21].

Another main theme that was extracted from the participants of the present study was lack of control, that infant's hospitalization in ICU caused that mothers could not have close interaction with the infant and mother's stress about infants' health encountered attachment process with problem. Mothers' anxiety in the present study was when there was a serious problem with their infants. If mothers could control the situation they never experienced anxiety and fear like this. In study of Kohan et.al (2011) mothers feltthat they do not have any role in their infants' destiny and their infants' life conditions is out of their hands [22]. Nystrom and Axelsson (2009) achieved to theme of lack of control in their study [18]. Study of Jackson et.al (2003) showed that

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mothers in ICU need to participate in taking care of their infants and to control it [23].

Care is among main themes extracted from mothers' experiences who participated in this study. When mothers watched good care and good relationship of the nurses, their satisfaction and trust on the nurseswere attracted. But sometimes this relationship was not appropriate and caused mothers' uncertainty. Study of Ayeenet.al (2007) showed that lack of time and lots of work due to imbalance of human source with needs and also inadequate skill of nurses in communication and communication nature of the physician-nurse caused to put interaction of parents and infants in downgrading.Nurses despite knowing about priority of relationship with the patients in nursing, because of lots of work had to give priority to technical cares in compare with communication with the infant and parents [24]. Fenwick et.al (2000) in their study found that nurse's talking to the parents isvery strong clinical equipment that can help in mothers' self-confidence in taking care of the infant and in communication of parents and the infant [25]. In this study mothers liked to participate in taking care of the infant and when this chance was given to them their motherhood sense was getting stronger and they took care of their infant tirelessly. Levin's study (1994) showed that mothers partnership in taking care of the infant caused mothers' confidence evolution in taking care of the infant and makes attachment with the infant stronger [26]. Also results of study of Aliabadi et.al (2011) showed that mothers' partnership in taking care of preterm infant is effective in mother's anxiety reduction. Mother's partnership in taking care of the infant is not only useful for mother but it is also useful for her infant. In this study hospitalization time of the infants whose mothers participated in taking care of their infants was less than those whose mothers were not present in the clinic for taking care of their infants [10].

Mothers' experience of deprivation sense was related to not achieving enough information about the infant's condition. They liked to get exact information about their infants and they liked to get clean information about the medicine, reason of doing the tests, time of the infant's improvement and side effects of the sickness. In study of Kohan et.al (2011) participants believed that one of the supportive sources that can have an effective role in solving mothers' problems are nurses and physicians that participate in taking care and treatment of the infant that accompany of these people with mother in being an active listener and teaching and guiding them can be effective in accepting the infant's condition [22].

Lindberg's study (2007) about experiences of preterm infants' fathers who were hospitalized in the Unit showed that they liked to achieve information about every work that is done on the infant and they also liked to participate in decisions related to their infants [27]. Also in Mock and Leung' study (2006) mothers liked to achieve continuous information [28].

Also when mothers could not take care of their infants along with their husbands in a private place without any stress about finishing of the time felt deprivation. In Jebriyeli's study (2009) lack of time for being alone with the infant was the third source of stress from mother's point of view [16]. Heermannet.al(2005) and Jackson et.al (2003)wrote: mothers need a private and individual place and in ICU moments of a family members of being with each other in a private place without any intruderare lost [23,29].

Hall's study (2009) showed that not having a private place with the infant caused sense of belonging of the infant to the hospital in mothers [30]. Wigert(2006) wrote : Nurses should decrease sense of deprivation in mothers and increase sense of motherhood partnership during the time that the infant is in ICU[17].

5. Conclusion

All the findings of this study show that mothers of the infants who are hospitalized in ICU are encountered with several problems. Relationship between parents-infant and also

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their relationship with the hospital's staff are extremely affected by infant's hospitalization and problems due to that. Results of this study to the high extent indicates realities that mothers of the hospitalized infant are encountered with themthat most of these problems are hidden from treatment team and health zone's eye. A deep look at what mothers explain indicates that they extremely need treatment team's support that this support can be in the form of making a good relationship, giving information to mother about infant's condition or teaching to the mother and her partnership in taking care of the preterm infant . In this study mothers encountered with positive and negative experiences. Among this, nurses' function in partnership and empowerment of mothers for taking care of the infant is really effective in forming sweet experiences and reducing negative ones. So developing methods that support mother's emotions and provide their partnership in taking care of the infant seems important and necessary.

Findings of this study are useful for nurses and midwives in taking care of mother and her infant. Nurses and other caregivers should ask mothers to explain their experiences during delivery and infant' hospitalization. Mothers must be involved in decisions and cares and thy must be supported for reducing anxieties and stresses. Also midwives during pregnancy period should inform mothers who are at risk about common problems of preterm infant and give them some information about ICU.

6. Acknowledgment

At the end researchers know it necessary to themselves to thank and appreciate all the mothers who helped us in this study and also respected authorities of centers of treatment-educational of Alzahra(s) and children of Tabriz, and respected head nurses of Infants' Unit that provided chance of doing this study. Researchers also thank and appreciate sponsorships of respected deputy of research of this university.

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