

## Supporting-emotional needs of Iranian parents with premature infants admitted to Neonatal Intensive Care Units

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### Abstract

**Background:** Having an infant in the neonatal intensive care unit (NICU) is a stressful and painful experience. Unlike to normal births, this birth is associated with admission and separation of infant from parents. The aim of this study was to compile the supporting-emotional needs of Iranian parents who have a premature infant admitted in (NICU).

**Methods:** This study was performed using qualitative research approach. Twelve participants including 9 parents whose infant had been hospitalized in NICU; two nurses and one physician were also selected for sampling purposes. Data were gathered using semi-structured interview. Data were analyzed by inductive content analysis approach.

**Results:** Four subcategories emerged from data analysis expressed supporting-emotional needs of parents of premature infants admitted in NICU. These subcategories were: Need for interaction with infant, Need to medical team's empathy, need to exchange support with spouse, and Need to get help from others.

**Conclusion:** In order to develop mutual bonding with infant and attain parental roles, parents need to be close their neonate, also receive empathy and support to find a way to meet their needs. Participants in this study announced that resolving these needs can help parents to feel more confidence in infant's care and reduce their negative feelings.

**Keywords:** Emotions, Parents, Premature infant, Content, Neonatal intensive care unit.

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### Introduction

The birth of a neonate usually makes the family happy. However, the early birth of a neonate can lead to different vague emotions in parents (1). When a preterm neonate is born, parents do not feel enough psychological, emotional and physical readiness and would undergo too much

stress (2). In this situation, parents are confused and concern about survival of their neonate and their long term complications (3). Premature neonates are very fragile and need to receive special care in a Neonatal Intensive Care Unit (NICU) (4). Length of hospitalization depends on medical condition and may vary from a few days to sev-

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eral weeks or even months 5). Early separation from the neonate increases parents' NICU-related stress. Furthermore, prolonged separation between mother and her neonate causes maternal stress, anxiety, depression and psychological reactions and feelings such as frustration, guilt, hostility, irritability, fear, grief, and feeling of failure (6-7). These parents lose their self-confidence and feel incompetency in playing their parental roles. They also alienate from their neonate which may lead to problems in parent-baby attachment (6-7). In general, it can be said that in this situation, the natural parental process may be disrupted. Difficulties in communicating with neonate may cause developmental delay in infant (6). On the other hand, ignoring the parental emotions and their psychological stress will lead to trouble in bonding with infant, especially at the time of discharge or transition to home which causes increased vulnerability (6). According to family-centered interventions, health system should pay attention to the important parental roles. In family-centered approach, parents participate in decision making about their neonate and have the opportunity of choosing a therapeutic method which is proper for their conditions (8-9).

Occupational therapy is one of the members of rehabilitation team which has an important role in providing services for pre-term neonates and their parents. Although occupational therapists have their own frameworks and principles in their specialty, they strictly recommended to present family-centered services, so should consider parents' needs and priorities to deliver more effective and helpful therapeutic interventions (8-10). Also, family-centered intervention is widely suggested to other professions who work with children. As understanding of the parents' experience of having an infant admitted to the NICU increases, professionals will be better prepared to meet parental needs and alleviate parental suffering (11). Therefore, there is an increasing need to improve knowledge about parents' needs, feelings, and stresses.

Considering the limited literature which exclusively can describe the needs of Iranian parents of preterm infants admitted in NICU, and this fact that existing researches are not completely generalizable to Iran's context, running further researches to obtain better perspective in this field is strongly needed. Such information can be attained mainly by qualitative researches. The aim of this qualitative content analysis study was to compile the supporting-emotional needs of Iranian parents with premature infants, admitted in NICU.

### Methods

A qualitative design and a thematic content analysis were chosen to achieve the aim of the study. Analyzing the content of narrative data helps identifying prominent themes and patterns among the themes and is a method that is useful for studying phenomena about which little is known (12).

#### *Sample and data collection method*

In this study, parents, nurses, and a physician at the hospitals affiliated to Iran University of Medical Sciences (IUMS) in Tehran, Iran contributed.

Each participant was interviewed using a semi-structured format with open-ended questions. Interviews audio taped. The interviewer was a female occupational therapist, expert in neonatology and with a 16 year experience in the field of pediatric family-centered occupational therapy and 10 years of experience in early intervention. She has not been involved directly in the care of these infants. Interviews were conducted at a time and place of convenience to the participants. One participant was interviewed in his own home and others were interviewed in a quiet private room within the hospital. Prior to the beginning of each interview, researcher informed the participant the purpose of study and permission was sought to tape record. The participants were also guaranteed confidentiality and anonymity in the presentation of the results.

The interview began with questions about

their infant's current condition and the parents' social and demographic information. Then, parents were asked: "Please tell me what you do in NICU? The interview was supported by questions about their feelings and needs in this situation. They were encouraged to express themselves freely in narrative form. Each interview lasted approximately 20 to 60 minutes. The interviews took the form of a conversation, and the interviewer used active listening skills in this process.

Inclusion criteria considered for parents were: being Persian-speaker; having a singleton, low birth weight premature infant with gestational age of 28 to 37 weeks in NICU for at least 7 days; having no genetic disorder, no grade 3 and 4 intra ventricular hemorrhage, no Apgar score under 7, no cardiopulmonary arrest in their infants; and no history of having another infant in NICU. The mean length of hospitalization in NICU was 34.5 days. Exclusion criterion was the participant's dissuasion in any step of the study.

### Data analysis

The interviews were tape recorded, transcribed and then, the transcriptions were reviewed for accuracy by some other writers of this article which were expert in fields of occupational therapy and/or qualitative researches. Each transcription was

coded by hand, using the qualitative content analysis method (13). Using this method, each interview was coded line by line by interviewer (first author) who was qualified in qualitative research methods and a research assistant (fifth author) who was trained in this field. These primary codes were meaningful statements, which lengths from a word to one or more complete sentence(s), in participant's own words. In the next step, these primary codes were reworded into shorter phrases. After that, similar phrases were collected and subcategories developed. Finally, the main category was emerged through more abstraction of subcategories. This process is shown in Box 1.

Credibility of data was provided through member checking, peer checking, prolonged engagement with participants and data and, maximum variation of sampling. Member checks confirmed whether or not interpretations of participants' statements were accurate. Ten of twelve participants had the opportunity to review their full transcript of their coded interview at the next visit, while two of them (both were parents) did not check their statements due to discharge from hospital and their reluctance with being followed. The use of peer checking process helped decreasing possible biases. For this purpose, 2 investigators (sixth and seventh authors) independently

#### Box 1. Data analysis process

##### -First phase. Line by line coding

*"I just want him to be around me, I want to hold him, I stand beside him and I start playing with him when His smile makes me calm and love to be around him and hug him."*

"It would be good if parents could see their child whenever they want. For example, when my husband comes to see our child, our baby is slept. Or my husband loves to come back from work at night to see our baby, which is impossible. He loves to see our baby opens his eyes and smiles or start laughing. We want to speak with him and hear his voice. It makes us calm."

##### -Second phase. Phrasing shorter codes

Want to have baby around herself to have an opportunity to see, hold, play with, and hug him whenever they want love to speak with baby and hear his voice

##### -Third phase. Developing final codes

Need to embrace and hug the neonate

Need to speak with neonate and hear her/his voice

##### -Fourth phase. Making and naming

Need to interact with the neonate

reviewed each interview to code them and reached an acceptable agreement on them with main research team. Prolonged engagement with participants and data helped researcher to achieve a better communication with participants and have a deep understanding of context.

### *Ethical considerations*

Verbal and written informed consent was acquired from each participant according to a protocol approved by the research ethics committee of Iran University of Medical Sciences. Participants were informed that participation in this study is voluntarily and they could refuse to enter or withdraw from the study at any time. Interviews were conducted with the presence of only the interviewer and the interviewee and participants were identified by an identification code to protect their privacy and confidentiality.

### **Results**

**Participant's characteristics:** A purposive sample of 12 participants (5 mothers, 4 fathers, 2 nurses, and 1 physician) participated in this study.

Nurses had master's degree in nursing and 5 to 7 years of experience working in NICU, and physician also was a subspecialty in neonatology with 18 years of experience. Parents' age ranged between 20 and 42 years. Six of parents were first-time parents, two were second-time parents, and only one of them was third-time parents. The neonates were born with a gestational age between 28 and 36 weeks. The mean length of hospitalization in NICU was 34.5

days (Table 1).

Analyzing the data and interviews of present study in order to compiling and identifying the supporting-emotional needs of parents with premature infants resulted in four subcategories.

The supporting-emotional needs category and its subcategories and codes are illustrated in Table 2.

### *Need to interact with neonate*

One of subcategories of the supporting-emotional needs which parents and other participants reported was "Need to interact with neonate". This subcategory contains two codes: "Need to speak with neonate and hear her/his voice" and "Need to embrace and hug the neonate". Hospitalizing a baby in NICU is a critical situation for many parents which may cause arousing negative feelings in them. Separation of parent and neonate has been recognized as a major source of stress for parents. Accordingly, being near the neonate and touching her/his up may reduce parents' stress and develop emotional support. The parents explained the need to have closeness and proximity and belonging to their infant. One of the participants expressed this need to:

*"I just want him to be around me, I want to hold him, I stand beside him and I start playing with him when he open his eyes and smiles or start laughing. His smile makes me calm and love to be around him and hug him."*

Parents also tended to spend more time

Table1. Participants / infant demographics

Gender	Role	Age	Education	Infant Gestational Age at Birth (wk)	Length of hospitalization (day)	Birth Order
Female	mother	42	diploma	32	29	Third
Female	mother	20	diploma	36	21	first
Male	father	30	Scholastic degree	31	24	first
Female	mother	20	Pre university	34	28	first
Male	father	28	diploma	28	36	second
Female	mother	25	diploma	31	29	first
Male	father	28	Bachelor	34	30	first
Female	mother	29	Associate Degree	34	49	second
Male	father	36	master	33	17	first
Female	nurse	-	master	-	-	-
Female	nurse	-	master	-	-	-
Female	physician	-	subspecialist	-	-	-

Table 2. Supporting-emotional needs of parents of premature infants, admitted in NICU

Category	Subcategory	Open codes
Supporting-emotional needs	Need to interact with the neonate	Need to speak with neonate and hear her/his voice
	Need to medical team's empathy	Need to embrace and hug the neonate
		Need to have a respectful and empathic relationship established by the medical staff
	Need to exchange support with spouse	Need to be ensured and satisfied of proper care providing for their neonate by staff
		Need to receive appropriate answers by staff
		Need to be understood by the spouse
		Need to interact with spouse
	Need to get help from others	Need to get help from family
Need to get help from significant others		

and to be near their infant whenever they want. For example:

*"It would be good if parents could see their child whenever they want. For example, when my husband comes to see our child, our baby is slept. Or my husband loves to come back from work at night to see our baby, which is impossible. He loves to see our baby opens his eyes and smiles or start laughing. We want to speak with him and hear his voice. It makes us calm."*

#### *Need to medical team's empathy*

Another subcategory of supporting-emotional needs is "Need to medical team's empathy" which includes three codes: "Need to have a respectful and empathic relationship established by the medical staff", "Need to be ensured and satisfied of proper care providing for their neonate by staff", and "Need to receive appropriate answers from staff". Parents need to have a respectful and empathic relationship with medical team and wish to be understood by them. They believe that healthcare professionals as a team can play a big role in reducing their stress. As one participant said:

*"Personnel should be changed with someone who shows their heart and great to us. Some of them have bad attitude toward you and they don't care about you when you need to talk to them."*

Participants stated that relying on the quality of care delivered by staff may reduce their stress and negative feelings, even when they are not present in the neonate's bedside. One participant said:

*"My baby needs me to be here all day*

*long, because personnel don't do their job right, they really don't take care of us thoroughly and I have to be here all the time."*

Participants stated that the lack of staff responding to their questions about the neonate can increase anxiety and fear, also lead to inappropriate communication with the staff. For example:

*"To get a chance to ask my question about my baby, I pass by twenty of them but it makes me feel more anxious when they don't answer my questions. I think there is something wrong with my baby which is scary."*

#### *Need to exchange support with spouse*

This subcategory includes two codes: "Need to be understood by spouse" and "Need to interact with spouse". Most parents are eager to exchange supportive roles with their mate. This concept is expressed in the words of one of participants as:

*"The first thing I do is to take care of my wife because she becomes very weak after her delivery. I have heard this is because a mild depression that she might have gotten after her delivery and she needs me to talk to her and understand her. I do my best to take care of her."*

Or:

*"They need their husband's emotional supports. For example, bad attitudes irritate them really bad which is very common in our busy hospitals. Nurses and physicians don't have enough time to listen to mothers as much so spouse should take care of themselves."*



*Need to get help from others*

In this study need to get help from others was considered as a subcategory. This subcategory includes two codes: "Need to get help from family" and "Need to get help from significant others". Most parents, especially mothers, could not do all things related to themselves or neonate due to critical situation of infant, fatigue and need recovering from labor. So they need to get help from other person and kin to perform the duties and parents' roles. One participant said:

"The only person who is allowed to take care of the baby is his mother, but the mother herself needs someone else to take care of her. It would be great if someone else like my baby's grandmother or aunt could help me to take care of him."

*Discussion:*

The present study is one of the limited qualitative studies that compile the needs of parents of premature infants. According to the results of this study, supporting-emotional needs of parents of premature infants admitted in NICU were categorized in 4 categories. The results indicated that all parents in this study wanted to be close to the neonate as much as possible. Separation from their baby is experienced as the most stressful part of having a preterm birth.

Some studies (14-15) show that mothers experience frustration when separated from their neonate. When separation occurs, mothers and their neonate have no opportunity to experience mutual bonding. The results of this study are in consistent with the study of Valizadeh et al (2007). Valizadeh et al pointed out that restricted contact with neonate is one of the resources of stress and influence on infant-parent interaction (16). Therefore, there might be a delay in the process of attaining maternal role identity, while this process must be initiated as soon as possible (14). Participants in this study pointed out that they want to be close to their neonates and have the possibility of caring directly and contact with baby at any time. Neu et al stated that kan-

garoo-care, as a way of establishing close relationship and contact with infant, was perceived by mothers as a positive and pleasant experience (17).

Participants noted the importance of receiving empathy from medical staff and establishing a respectful and empathic relationship with them. Reviewing previous studies showed that parents of premature infants emphasized the importance of proper communication with the medical team (18). Valizadeh et al pointed out that giving hope and support by nurses can cause development and promotion in the mother-infant attachment and relationship. Also, mothers use it to cope with the event of sudden preterm birth as a preventive strategy to solve this crisis (16). When parents feel to be supported by the staff, their concerns will be reduced. Being understood by staff is also very important which causes parents feel that their neonate receive good and appropriate care (14), also their negative feelings may be controlled. Arockiasamy et al pointed out that giving information to parents can cause increasing their understanding and control over the situation. Furthermore, he emphasized on consistency of information content which can be provided by the staff (18). According to Van Rooyen, providing accurate and understandable information to parents is necessary to overcome negative emotions of parents (19).

Parents devote a plenty of time to thinking about their neonate and are interested in receiving support to find a way to meet their needs (20). Parents stated that although they do not receive enough support from staff in some cases, it may be provided to them in other ways. Since attaining support is one of their fundamental needs, parents seek for alternatives to meet it. They look for it in all available resources in their context to feel being protected. It seems that most available resources of support for Iranian parents are: their spouse, other mothers who are in the same situation, therapeutic staff, family members, and God.

Parents said that whenever they have an encouraging and loving conversation with their spouse, they feel better. In addition, when they see that their mate, especially husband, is happy and have a good relationship with the neonate, they feel supported. Moreover, talking with other mothers in NICU or receiving help from them make mothers more powerful to face problems. They announced the same experience with their family member. According to Lindberg's study, mothers stated that support can be obtained from infant's father and/or from speaking with other mothers who were in unit (14). Short-daily conversations and talks can be an important tool for the support of parents, especially mothers. These talks will help them feel confident in the care of the infant and give better care to their infant (21). Valizadeh et al pointed out to the role of husband and family supports on attachment development, also its influence on improving mother's morale and empowering her on facing the crisis and coping with it (16). The relationship between family members and support for the family is one of the main sources of adaptability (16). In addition, in the Lindberg's study, fathers noted to importance of relationship with their wives and conversation with other parents who were in unit (1). Hughes et al (1994) reported that fathers often cope with this situation by interaction with others and seeking social supports but mothers cope with it by talking to their husbands as an emotional and psychological support (15). Mothers use some strategies to decrease risk and increase safety of their newborn in the NICU. These strategies include negotiating with the medical team and creating a strong relationship with the mothers, their husband, family, and friends (22-23). Receiving support from staff, husband, other family member, and significant others are factors which enable mothers to manage the critical situation they are exposed to it (11). If parents receive incorrect or incomplete information about their infant, they will feel stress and anxiety (23). Since traditional re-

sources of support including family and other nonprofessional persons may present incomplete or even wrong information to parents, medical team's role in this area seems to be very important.

### Conclusion

Participants in this study announced that resolving these needs can help parents to feel more confidence in infant's care and reduce their negative feelings such as anxiety, depression, inefficacy, and guilt feeling.

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