

# The experiences of parents with infants in Neonatal Intensive Care Unit

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## ABSTRACT

**Background:** In recent years significant medical science advances have been made in the field midwifery and infant care. The premature, low birth weight and ill infants are admitted to the technologically advanced NICU for care and they often require long-term stay. This study addresses parental experiences with the infant care in NICU, explores their concerns regarding nursing supports for parents and offers nurses' perspectives on performing duties.

**Materials and Methods:** A qualitative inductive content analysis method was applied in 2011 that included a purposely selected group of parents, nurses and physicians from neonatal unit at the Medical Science University of Isfahan. Participants were surveyed and interviewed according to the institutional ethics committee approval and signed informed consents.

**Results:** The content analysis identified two main categories: 1) the definition of stress, which consisted of misgivings, nervous pressure, imbalance, separation and 2) the parents' reaction to stress, which revealed emotional, psychotic and behavioral reactions as subcategories.

**Discussion:** The medical team awareness of NICU parent experiences is essential to the quality of care. Recognizing the type of parents' reaction to the whole process by the healthcare team seems essential to the optimum outcome.

**Key words:** Content analysis, NICU, nursing support, parental experiences, stress

## INTRODUCTION

Most women experience a difficult physical and emotional evolutionary change when giving birth. A woman evolves into motherhood as a natural process and requires a significant adaptability.<sup>[1]</sup> Having a premature or low birth weight (LBW) infant adds additional stress to a difficult phase in the mother and infants' life.<sup>[2-5]</sup>

The majority of infants in neonatal intensive care unit (NICU) are premature and low birth weight. Seven and a half percent (7.5%) of the new born are LBW and one out of nine infants born in the United States (U.S.) is premature. One of the U.S. public health organization objectives is to reduce the infant death rate to 4.5 per 1000 by 2010. In fact, prematurity and LBW are two of the main causes of infant mortality. The hospital admission of infants weighing

below 2500 g varies from 7.29 to 10.15 percent.<sup>[6]</sup> LBW rate is 7% in Iran. Of course 31% of mortalities have been due to prematurity.<sup>[7]</sup>

The hospital admission of a premature infant could pose emotional and practical challenges for parents when maternal bonding and interaction with newborn is interrupted.<sup>[8]</sup> The ability to recognize the expectations and stress provoking factors for parents in NICU helps the healthcare team better manage and care for infant. Stress is a stimulus like pain that disturbs balance. Stressful situations are created from out of control circumstances that lead to emotional imbalance in people involved such as parents. The need recognition could prevent stress. The unfulfilled needs of the parents lead to stress and escalate into a critical situation. The NICU nurses should have a greater awareness of the parental needs and try to fulfill them within their possibilities.<sup>[9]</sup> Today, parents in Norway are considered as the helping hand for NICU nurses and providing support to parents is an important part of nurses' duties.<sup>[10]</sup>

To address the cultural components of parent's experiences, researchers in Taiwan used grounded theory and explored the socio-cultural backgrounds and reported on the way cultural differences could affect healthcare planning and implementation of health promotion strategies by nurses. Researchers in Iran conducted a descriptive cross-sectional study titled "The sources of stress in mothers with infants in

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NICU” and surveyed 50 mothers using a questionnaire to measure parents’ stress. The findings showed the apparent stress provoking factors for parents involved in their infant’s behavior such as: Infant being in pain, interruption in birthing process, intravenous or tube feeding; watching the infant in a dreadful mood and having their infant in an isolate.<sup>[11]</sup> Researchers found the stress creating sources with respect to the infant–parent relation were separation, non-feeding, not having free time to spend with the infant and a sense of being unable to help the infant who was in pain. Researchers indicated that in spite of the variety in the sources of stress, a family-centered instead of infant-centered NICU could help reduce stress. Researchers only evaluated mothers’ feelings and reported that a family-centered approach will enhance fathers’ contribution to the family stability as a vital caregiver.

Another Iranian study by Valizadeh, Akbarbeglou and Asad (2009) used descriptive method to find the effects of stress on mothers with premature infants in NICU. They sampled and surveyed 300 NICU mothers in 2009 and found for parents NICU was a stress provoking environment. Parents identified noise from monitor and special devices and placing two infants in one isolate very stressful. Parents experienced high stress level when their infant was in distress during medical procedures and treatments as they watched abnormal breathing pattern, medical accessories and devices surrounding and attached to infant, sudden skin color changes, the helplessness of a tiny infant making facial grimaces indicating pain. Other stressful factors included the parent–infant relation such as separation, a sense of not being able to help the infant and not being able to protect the infant during painful procedures.

The review of Iranian published literature on parents’ stress in NICU has mainly focused on the issue quantitatively with limited holistic approach. An in-depth examination deemed necessary to adequately address the socio-cultural dimension and researchers in this study have made the effort to fill-in the information gap by presenting a qualitative perspective on the subject. The stress causing elements regarding parent–infant relation are multidimensional. In Iran, the traditional approaches to healthcare prevail and due to the socio-cultural differences, some of the study findings from other countries may not apply to the population we studied. Therefore, effective parent involvement with nurses and other healthcare team members should be considered with cultural sensitivity to reach the desired understanding.

Stress disturbs the infant–parents relation and interaction and often leads to emotional maladjustment in parents. The healthcare trend and nursing care has had a greater

focus on the infant survival with less attention to parental experiences. What makes this study unique is the qualitative approach to reveal the personal difficulties of parents with an infant in NICU and retrieve the healthcare teams’ views and experiences on the issue. Studies such as this have contributed to the recent curriculum development and approval of a Masters of Science degree in NICU in Iran. There is a promise of a greater effort for parent-centered NICU care, more parental involvement in infant care and increased nursing team awareness of parents’ experiences. The results of this study may contribute to better NICU experiences for Iranian parents and reaching a desired health outcome for infants.

## MATERIALS AND METHODS

Content analysis is one of the qualitative methods<sup>[12]</sup> and was found most appropriate for this study for its use of inductive and deductive process.<sup>[13]</sup> We applied the inductive approach in eight stages listed as: 1) the formation of main question, 2) sample selection, 3) definition of applicable categories, 4) coding/recoding process, 5) coding implementation, 6) strengthening validity, 7) outcome analysis after coding and 8) reporting the findings.<sup>[14]</sup> This method has not been vastly used on the topics similar to this study to explore related issues.<sup>[15]</sup>

This study was approved by the ethics committee in 2011 at the Isfahan University of Medical Science (IUMS). The 21 participants were 6 fathers, 7 mothers, 5 nurses and 3 physicians. The sample selection took place at several training and non-training hospitals affiliated with IUMS.

The inclusion criteria for parents were: Willingness to participate in the study, having an infant at the NICU for at least 24 hours and no record of previous experience with NICU.

The exclusion criteria for parents included: Having had prior NICU exposure with another child and past history and diagnosis of emotional disorders such as stress, anxiety, depression, irritability due to the infant’s health status.

The inclusion criteria for the physician and nurses were willingness to participate in the study and having had at least 6 month of NICU experience.

Participants were surveyed and interviewed after signing an informed consent. Participants were selected from different districts in the city of Isfahan. The individual interviews were held at the hospital and in mother’s room. All 21 participants consented to data recording and interviews continued to reach data saturation or no more new data was presented

by participants. The interviews began with an open-ended question asking “please tell me about your baby in NICU” and followed by probing questions in the course of the interview which lasted between 30 and 60 min. Researchers listened to the tape recorded interviews several times to extract a deeper meaning of concepts and gain a general perspective. The recorded interviews were transcribed verbatim in order to retrieve the key concepts and highlight for coding. The repeated sentences and paragraphs were classified based on their similarities and differences and later combined for interrelations and meanings.

Data validity was established by following specific procedural steps such as thorough and repetitious reading of raw data for a deeper understanding and assessing the supplemental comments from colleagues to correlate and reach consensus to approve extracted codes and categories. After coding and classifying the data by the principal researcher, other team members reviewed and approved the coding/recoding process. In some cases, coded data from the transcript had to be clarified by participants for more accuracy.

## Findings

The demographic survey identified the average age for mothers, fathers, nurses and physicians as 27, 37, 35 and 29, respectively. Three mothers and two fathers reported junior high school education. Three mothers and one of the fathers obtained a high school diploma. One mother and one father graduated with a BA degree. As listed in the content analysis identified two main categories: The definition of stress and the parents’ reaction to stress. The sub-categories consisted of: Misgivings, nervous pressure, imbalance, separation, emotional reaction, psychotic reaction and behavioral reaction.

### The definition of stress

Participants defined stress as a significant experience which provoked a great sense of misgiving, nervousness, emotional tension or pressure and separation anxiety. Parents and especially mothers expressed that unexpected hospitalization of a newborn was highly stressful after 9 months of anticipation to give birth with hope to celebrate a new life. An unfulfilled sense of loss for having their newborn admitted to NICU overwhelmed parents in this study. Most parents agreed that experiencing stress was combined with restlessness, fear and emotional imbalance.

A 43-year-old mother said: “... What about anxiety, my heart is not at ease, my thoughts become confused, all I think about at home is my infant in NICU, I cannot rest. I was not ready for this nervousness is overwhelming for me and everything bad happened hand-in-hand.

When I saw my newborn taken to NICU, I had a nervous breakdown.” [m1]

According to parents, anxiety and fear provoked stress and for majority of parents stress was defined as nervousness and an overwhelming sense of restlessness.

A 30-year-old mother said: “... It is indescribable. For me it was frightening with a sense of anxiety, stress...when a baby gets sick. I think my baby felt the same.” [m2]

A 26-year-old mother said: “... That is fear, the physicians express contradictory statements regarding my baby’s health status and this adds to my stress. When the physician says “pray to God” my stress rises. Fear is a part of me now...” [m3]

A 41-year-old father said: “... Stress means worrying about our infant, why can’t I take him home, God forbid, what if he dies, all these expenses, all this stress...” [f1]

The stress level doubles in a hospital since the atmosphere is unfamiliar to the parents especially in NICU where the environment is enclosed.

A 28-year-old nurse with 2 years of experience in NICU said: “... It is an emotional journey that doubles in a hospital compared to other places. In general, the first stressful moment experienced by people is during entry and admission to the hospital.” [n1]

A 43-year-old physician with 4 years of experience in NICU said: “In fact after nine month of pregnancy, upon delivery the mother expects to keep her infant next to herself and if this does not occur for any reason that could mean stress for the parents. In the last month of pregnancy a close relationship is established between the mother and the unborn and this relation is disturbed when the infant is transferred to NICU right after birth.” [p1]

After facing stress all parents react with anxiety and worries about their infants’ condition.

A 26-year-old mother said: “... Upon his hospitalization I cried, I cursed myself...my infant is innocent, why is this so.” [m4]

A 28-year-old nurse with two years of experience in NICU said: “...What worries a parent is the infant’s condition, the cause of the illness, how would it be cured, his future, the manner of treatment, the physicians and the nursing crew’s approach to treatment.” [n2]

Constant thinking about the infant's hospitalization and possible worsening of the condition, as time goes on, enhances the stress level.

A 30-year-old father said: "... If we leave here with no reassuring results, what would worry us is that our child is sick with a specific or incurable disease." [f2]

### Parents' reaction to stress

This category is related to psychological state of mind leading to emotional and behavioral reactions.

### Psychological reactions

Upon the admission of infants to NICU, some of the vulnerable participants behaved irrational and showed severe emotional reactions by crying, restlessness, physical discomforts and mental instability by constantly walking in front of NICU.

A 24-year-old mother said: "... I cannot rest on the bed, go home or go for a drink of water; I have to check the NICU door every 5-10 minutes." [m5]

A 26-year-old mother said: "... I like to be free...not confined here with my infant...after all we are at God's mercy ... this phenomenon is either happy or sad; I am in the sad phase now. On my previous delivery I was happy and free but this one is something else." [m6]

### Emotional reaction

Here a sense of guilt and fear masked the expression of feelings. Mothers who became pregnant unexpectedly and wanted to have an abortion felt guiltier than those who wanted a baby.

A 26-year-old mother said: "... I cried, I cursed myself and said I wish it were me not my baby, I did not want to become pregnant, when I went to the health center they said I was two months pregnant." [m7]

Fear was the other emotional reaction for losing the infant by worsening of health condition.

A 23-year-old mother said: "... I am afraid of seeing him, fear for his health condition and how he looks now..." [m8]

Suppression of feelings was more common among the fathers.

A 28-year-old father said: "I cannot say much about my feelings." [f2]

A 43-year-old mother said: "... Men suppress their feelings to prevent crying, a man's cry is full of emotions..." [m9]

This reflects on cultural aspect of Iranian men holding back their tears to be socially appropriate.

### Behavioral reactions

Under these circumstances most of the parents had lost appetite and were unable to sleep. They behaved differently with increased agitation and anxiety and constant checking on the infant's health status.

A 24-year-old mother said: "... I only cried in the first and second day, I even could not drink a glass of water. I visited him and began crying when I saw all those things attached to him." [m10]

A 26-year-old nurse with two years of experience said: "... In addition to agitation from separation anxiety, most parents complain that 'we cannot sleep at night, because our heart is left here.'" [n3]

The commuting and related costs are the financial dimension of this phenomenon.

A 43-year-old physician with four years of experience in NICU said: "... 'He says I cannot sleep at night or during the day' and this means his problems are not just the infant's condition, there are other things involved." [p2]

### DISCUSSION

Trombini, Surcinelli, Piccioni, Alessandrini, and Faldella (2008) reported the NICU atmosphere could increase the parent's stress level and leave emotional scars on mothers trying to adapt to the situation.<sup>[16]</sup> Researchers found that parents were worried about their infant's health status, the treatment procedures and the prognosis. The results obtained from Ward's studies in 2001 indicated parents experienced shock, anticipation and unusual worries for their infant in NICU. Griffin (2002) is of the opinion that the infant's hospitalization could be worrisome for all family members and the relatives.<sup>[17]</sup>

In the hospital, parents feel anxious and agitated by the atmosphere in NICU, they worry about their own role as parents, have fear of consequences such as their infant's appearance, mental condition and death. In general, offering information to parents and allowing them to participate in certain decision-making process regarding their infant and treating them as a team member helps reduce their anxiety. Reducing the impact of separation period between mother and infant and providing updates on the infant's condition are essential to decreasing fear among parents.

Majority of the NICU parents experience restlessness

and insomnia. Some of published literatures support our findings. For instance, Lee and Kimble (date) indicate that NICU mothers experience sleeping disorders. Despite the NICU care that is beyond the parent's abilities, mothers still remain awake, unable to sleep and experience fatigue all day.<sup>[18]</sup>

According to the results obtained from this study the fear of losing the infant is agonizing to parents, in addition to the worries about the infants' future health. Other studies have had similar findings as Colville *et al.* found that the mothers are more afraid than fathers for their infant's death.<sup>[19]</sup> Sudia-Robinson and Freeman (2000) announced that hospitalization of the infant in NICU is a major cause of stress. The parents spend a lot of time and effort to understand what this strange atmosphere of NICU is and for many weeks or even months after the infant's hospitalization their feelings prevail.<sup>[20]</sup> Shin and Traut (2007) believe the maternal thoughts and feelings stem from separation and fear of not having a chance to reunite or interact with the infant. These perceptions are the main reasons for emotional disturbances and later maternal-infant emotional attachment.<sup>[21]</sup>

The results of this study indicate that upon hospitalization of the infant in NICU the feeling of guilt overwhelms the parents. This finding is different from previous other studies. As an example, Olshtain-Mann and Auslander (2008) claim that premature birth influences the parents' role. Parents feel guilty for a premature birth and mothers feel more guilt for their infant's prematurity. In general, fathers do not feel shame or guilt.<sup>[22]</sup> Although we had a similar finding in this study, the difference we found was in the way parents expressed their feelings. Profound and well-rooted expressions were noted from cultural and traditional perspectives involving the upbringing of boys and girls in a social context. We found parental stress was defined as separation due to hospitalization which deprived them access to their infant. Participants justified their feelings and contributed it to the lack of constant presence in NICU.

It is necessary for the authorities of the Iranian Ministry of Health and Infant Treatment to adopt policies regarding the permanent presence of parents in NICU. Nurses in NICU are instrumental for the development of a family-centered unit. We found the function and role of current Iranian nursing profession on infant treatment is limited and disease oriented. There is less attention paid to the parents' needs. Family-centered nursing care would promote the family strength and support by encouraging parental involvement. In such a system the focus is both on the infant and the family. The family is considered as a whole unit and the treatment principles would be based on the family values and believes when crucial decisions are made. With respect

to the importance of family-centered care, nurses would be responsible to support parents when providing infant care and remain fully awareness of parental responses to NICU experiences. When equipped with the knowledge and realization of the differences in parental reactions, nurses would perform their tasks more compassionately, hence, a better outcome for everyone.

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