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Stress Management among Parents of Neonates Hospitalized in NICU: A Qualitative Study

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ABSTRACT

Introduction: Infant hospitalization is stressful event for parent in NICU. Parents think that they have lost control because of unfamiliar environment. Therefore, stress management is very important in this period. The family as the main factor of strength and protection for infant is required as the bases of standard care in NICU. Therefore the aim of this study was to investigate stress management in Iranian NICU Parents.

Methods: Using qualitative content analysis approach helped to collect and analysis data for open coding, classification, and theme abstraction. Twenty one parents with hospitalized neonates, physicians and nurses in the city of Isfahan were purposely recruited and selected for in-depth interviews.

Results: The analyzed content revealed unique stress management approaches among the parents. The main themes were: 1) spirituality, 2) seeking information, 3) Seeking hope, 4) maintaining calm, 5) attachment to infant, and 6) communicating with the medical team

Conclusion: Findings of this study highlights the importance of medical team's attention to stressed parents who are trying to make adjustment or adapt to the hospitalization of their infant. A revised management approach to address the emotional needs of parents of neonates in Iran seems essential for improving communication with physicians and nurses.

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Introduction

Admission of infants with weights lower than 2500 gr. varies from 7.29-10.15%.[1] In recent decades, the advances in science and technology has improved required facilities to better care for neonates in the neonatal intensive care unit (NICU) leading to a higher survival rate among premature and low weight infants.[2] However, technological advances have not focused on the psychosocial needs of parents of hospitalized infant in NICU.[3] Hospitalization interrupts and delays parent–infant bonding and attachment. Therefore, mothers experience anxiety and mental anguish with each specific situation regarding the vulnerable state of infant's health.[4] When parent-infant bonding is disrupted, such emotional detachment and uncertainties create the anxiety and stress among parents leading to the poor healthcare outcomes. Moreover, ignoring parental stress may lead to maternal rejection of infant, inadequate bonding and parents feeling of unskilled to raise an infant with specific growth and developmental needs.[5,6]

Research on maternal-infant bonding has revealed that contact with infant is fundamentally important for the development of maternal self-confidence, security, sentimental emotional stability, and preparation for learning about infant's growth and development. Confident parents notice infant's signs for specific needs and

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appropriately act on time to respond to any physiological and behavioral changes. Moreover, parents with emotional stability provide better infant nutrition and maternal care. [7]

With an increased survival rate of premature infants the need to address infant survival outcomes requires a closer look at parental state of emotion and its psychosocial consequences. The quality of early maternal-infant relation is an important factor with potential for long-term negative effects on the mother and her premature infant. The parental ability to cope with having a premature infant and to provide quality care is one of the most essential factors to consider when maternal-infant outcomes are assessed. Maternal-infant bonding influences the quality of care when maternal role has been conceptualized.[8]

The family as the main factor of strength and protection for infant is required as the bases of standard care in NICU. The standard care principle stands on respect, information, options to choose from, flexibility, encouragement, cooperation and support. Therefore, a mother should be given the opportunity to be a part of her infant care and the services provided for the family.[9]

Whenever there is an imbalance in the family it breeds tension in the system. Naturally, having a new born may create a family imbalance with new roles and responsibilities imposed on every family member. But, a premature birth requiring long-term hospitalization and home care obviously tilts the balance even further.[10]

The NICU environment can be stressful for parents for various reasons and they use different adaptation mechanisms to manage this stress. Therefore, staffs and the healthcare team should be prepared for repeated enquiries by anxious parents and try to support them with kindness and assurances when applicable.[11] Including parents in the decision making process regarding their infant's care may reduce parental stress and their confusion to some degree.[12]

The latest report on the Iranian annually infant mortality rate shows a significant annual drop from 19 per 1000 in 1992 to 16.6 in 2004. The same report from Isfahan province indicates a remarkable decrease from 19 per 1000 in 1992 to 13.11 in 2006.[13,14] Previous studies indicate that stress and nervousness have unpleasant effects on the infant's growth.[15,16]

According to previous studies parent involvement in infant care has positive consequences.[17] Treyvaud et al., claimed that disturbance in family management and parent's stress was directly related to the infant's situation in NICU. [18] According to the results of Patil (2014) stress management technique is very useful for parent in NICU.[19] Fotiuo et al., stated that using relaxation technique, in addition to providing information in parents of infant reduced the stress of parents.[20]

Therefore, a supportive environment helps parents to cope to the situation. [21] In 2009, in an effort to further reduce infant morbidity and mortality in Iran, some universities launched a graduate nursing degree in neonatal nursing to improve infant care quality in NICU and increased research efforts in neonatal medicine. Paucity of published research in neonatal nursing establishes the significance of this work in NICU investigating perceptions of Iranian parents and healthcare providers. [22]

Researchers used holistic approaches to look at socio-cultural issues when examining parent's perspectives. Naturalistic paradigm assumes that there are multiple interpretations of reality and that the goal of researchers working within this perspective is to understand how individuals construct their own reality within their social context.[23] Therefore, this study aimed to explore the stress management approach among parents of neonates hospitalized in NICU, in Iran.

Materials and methods

In this study, conventional qualitative content analysis was used which consisted of open coding, classification and abstraction.[24]

Following to institutional review board approval from Isfahan University of Medical

sciences (Code number: 389294), verbal and written informed consents were obtained from all participants and they were interviewed. Data was collected using 25 semi-structured interviews with 21 participants based on the study objectives. Purposive sampling was used for selecting of participants. Parents were the key participants and the physicians and nurses were the secondary informants. Participants included 6 fathers, 7 mothers, 5 nurses and 3 physicians.

They were recruited from NICUs located at various hospitals of Isfahan, Iran. Physicians and nurses were employed at both teaching and non-academic hospitals in Isfahan. The inclusion criteria for parents consisted of: having an admitted infant in NICU within the past 24 hours and having no previous experiences with NICU. Parents with previous history of NICU experience with other children, and identified history of psychiatric disorders such as anxiety, depression and obsessive compulsive disorders according to medical record or self-report were not included in the study. For professional enrollment, we included physicians and nurses with at least 6 months of work experience at NICU.

Selected participants were from different hospitals and they were interviewed by first researcher at the hospital, participant's workplace or other locations agreeable to both parties. First researcher entered the study environment after the preliminary official approval was received at each hospital and the NICU administrative team. Afterwards, volunteer participants signed an informed consent form. To obtain maximum diversity, participants were selected from different parts of the city in Isfahan. The interview began with the question asking: "please tell me about your infant from the time he/she was hospitalized?" When you feel stressed what do you do during hospitalization? The interview with nurses and physicians began with the question asking: "please tell me when parents are experiencing stress in NICU what they are doing?"The interview continued with probing questions and data collection continued until researchers reached data saturation.

The average interview time was 45 minutes. Data was peer reviewed by colleagues to confirm accuracy in coding process and data allocation to each classification with respect to participants' expressions and researcher understanding for data analysis.

The inductive analysis was applied in this study that includes open-coding, categorization and abstraction.[24] Data analysis began with open coding when taped interviews were heard several times to find common themes in perspectives. The interviews were transcribed verbatim by first researcher to extract key words/terms to support initial open coding. In the classification phase the extracted concepts and codes were grouped based on similarities and differences and eventually were combined into main classes as they correlated. For precision and accuracy of the data, prolonged visits and interviews were given and conducted with the participants by the interviewer and in depth re-reading and reviewing of the inscription that constituted the data was done by the same. During peer review, colleagues' views were considered with respect to the accuracy of the codes. For the review of the participants, some of the coded inscriptions were reviewed by the participants (member checking) and the researcher for the level of consent regarding data coding.

Results

In this study, the mean age of the mothers of infants hospitalized in NICU was 27 (6.8) years. Three mothers had elementary education, while four had high school diploma**.** The mean age of the fathers was 37(7) years. Two fathers had elementary education, three had less than high school diploma and one had a BS degree. The mean age of the nurses was 35 (7) years, with an average NICU experience of 6 years. Moreover, the mean age of physicians was 39 (4) years, with an average NICU experience of five years**.**

The final analysis of the data indicated that parents experienced stress and needed some measures to overcome their emotional distress through stress management. The emerged main categories were: 1) spirituality, 2) seeking information, 3) finding hope, 4) maintaining calm, 5) attachment to infant, and 6) communicating with the medical team.

Spirituality

Data analysis indicated that NICU environment was stressful for parents and created a condition where parents searched for hope and calm through faith by asking God for help. Parents are looking to find hope and talk to the doctors and nurses. Unfortunately, the NICU conditions are not met the needs of parents, and then they resort to God and spirituality and prayer to cope with stress.

Majority of parents expressed spirituality and prayers as helpful for reducing anxiety and gaining self-control. A 43 year old mother [M1] said:

All night long I watched him and prayed. I thought God will help my infant get better soon.

Prayer and reading the Quran (Muslim holy book) meant direct contact with God to seek blessing, find hope and calm the anxious soul as two fathers expressed:

The fact is that when we prayed and read Quran we felt calmness. (Aged 48)

"*Sometimes we felt hopeless but, we are human and this might be God's will if our infant survives and gets released from here, (Father, aged 41)".*

During one interview a 30 year mother [M2] was rolling the worry prayer beads and non-stop prayers and said:

"*Whenever I want to enter the NICU I recite Quran verses. I ask God to cure my child*".

In Iran, there are prayer rooms in all hospitals for people to pray in private.

Seeking information

Hospitalization of the infant in NICU happens very suddenly, the parent were not informed about what or even where the NICU. Lack of sympathy is one of the main factors that give way to stress in parents. One of the main reasons for parents to experience anxiety was related to lack of information on infant's condition, uncertainties regarding prognosis and surrendering parental control to NICU healthcare team without the ability to seek information or finding the desired answers to repeatedly asked questions on the infant's health status. A 24 year old mother [M3] stated:

"*When we ask the nurses about the baby, nurses say we need to ask the doctor and it all depends on the infant's illness severity…*"

Parent's questions mainly evolved around the recovery period, hospital discharge date, the infant's health progress, treatment effectiveness and prognosis. Parent's questions often overwhelmed the nurses, as a 26 year old nurse [N3] with 2 years of NICU experience shared:

"*Almost every parent wants to know when the baby would go home*".

Parents usually ask about the hospitalization period and search to find an answer to the unknowns. The medical staff responses effectively calm parents and again any uncertainty adds to their anxiety as a mother [M4] aged 20 expressed:

"*Why is my infant here, what is wrong with him? It does not matter…just tell me the reason for me to understand*".

A 40 year old nurse [N5] with 9 years of NICU experience voiced:

"*In NICU parents have such high levels of stress that their questions never stop*".

A 38 year old nurse with 13 years of experience [N4] says:

"*NICU is full and we are so busy, preoccupied and overworked that we could not respond to the parent questions. We really need one person for this task. When we say 'we do not know' the parent get annoyed"*

Seeking hope

Parents of sick infants experience more stress than parents of healthy term infants. Since an important part of the responsibility of nurses are supports to the parents. They are finding hope. Data analysis supported one of the main categories in this field of research as seeking to find hope. After observing the infant's

condition parents often begin to search for hope and eager to hear a hopeful comment from the nurses and physicians as a mother [M3], age 24 stated:

"*Nobody gave me hope while I was standing behind the door so I had to force myself in*".

Hopelessness was one of the most stress provoking factors that majority of parents emphasized and any glimpse of hope gave them emotional strength to go on waiting for another day as a father [F2], age 28 expressed:

"*We were in constant state of hopelessness wishing to hear any hopeful news. A 28 year old mother says the physician told her*".

"*Do not be very hopeful, cases like these are tricky, you do not know whether they would recover or not. You should not be happy, you could not count on their becoming better or worse, sometimes the worse cases end up cured and the best cases end up in death" (mother 6, 28aged).*

The unstable and fragile health status of NICU infants prohibits nurses from offering hope to parents and this initiates dissatisfaction among parents who are too anxious to understand the explanations given by the medical team. A mother [M1], age 43 voiced:

"*Give me hope on the way to the hospital and tell me that this is not the first or the last treatment or procedure done for my baby and I will thank God that there are new facilities for this type of medical treatment. Tell me this may take a while for my infant to be cured and discharged from NICU. But somehow I hear no such words…"*

Maintaining calm

The parents need to know about their infant's status. Hospitalization of infant is very stressful event and they seek calm. Based on the analyzed data, we found maintaining calm was an effective approach to overcome stress for parents, staff and infants in NICU. Finding a way to keep parents calm could help change the entire dynamics of NICU experience. A mother [M1], age 43 mentioned:

"*I was waiting to hear a supportive comment from the doctor before getting anxious*".

The parents collectively shared that supportive staff had a positive effect on their ability to maintain calm as a father [F3], age 48 said:

"*We feel calm when we see how nurses are working hardly and it gives us hope that their hard work and God's will are going to help our baby get better".*

Similarly, a nurse [N4], age 38 with 13 years of NICU experience said:

"*We know that for every family the most heartwarming and assuring statement come from the doctor*".

Difficulties in managing infants care

Stressed parents have a great need to connect with the infant. Parental state of emotion is heightened by enduring anxieties and worries while trying to maintain calm and hope for the best infant health outcome. Parents try to make attachment and yet hold back their emotions due to uncertainties. Emotional self-control at so many levels is exhausting for parents as two young mothers expressed:

"I have sold all my belongings to pay for my infant's care and there is nothing left in my home. It does not matter that I have done it all for my infant with low birth weight. All that is gone can be regained, but how do I replace my infant (mother 5, aged 26)".

Attachment and staying with the infant helps parents experience less stress when they can learn how to care for the infant and yet, parents continue having anxiety for not being there with their other children. This is a vicious cycle of emotional turmoil for NICU parents as a mother and father stated below:

"*I stay here dusk till dawn, at night I go home to care my other children and when I want to return in the morning I am highly stressed (Mother6, aged 28)".*

"*What can I do when I spend 18-20 hours of my time here in order to be with my baby for a few minutes every 2 hours (Father1, age 30)".*

Communicating with the medical team

The parents need to talk to physicians but parents think they have no desire to talk with parents. They do not pay any attention to the parent. This lack of interest in parent leads to dissatisfaction towards the physicians. Analyzed data revealed that NICU parents try to have a face-to-face talk with the physician in order to reduce their anxiety and stress. A few encouraging words from the physician can

have a significant effect on parent's emotional state to calm down. Majority of parents prefer direct talk with the physician when nurses are disallowed to share information with parents and their main complaint related to lack of communication, availability and unwillingness of physicians to communicate with parents. The following expressions samples common perceptions by mothers, fathers, nurses and doctors in this study:

"*I was looking at the doctor to see whether he would have any regards for my presence and he didn't even notice me let alone respond to my greeting or bother answering my questions. It was my biggest wish to ask the doctor about my infant's condition [M1, age 43]".*

"I told doctor B that this is a good place provided my child is healed and I took a flower basket to his office but, what all I saw is him was disrespect towards me and other parents,…even yell at them [F1, age 43]".

"The parents insist to talk to the physician [N2, age 28 with 2 years of NICU experience]".

Other than nurses even the physicians can reduced tension among parents by answering their questions with patient and explain the situation [N4, age 38 with 13 years of NICU experience].

"*When I ask the infant's situation from the mother, I get a sense of security by realizing the problem. This is true for the parents as well, since a contact has taken place this time from the physician's side [D1, age 41 with 4 years of NICU experience]".*

A 43 year old mother says: "*I stared at the physician so he would look at me as a valuable being worth talking to, but he even did not notice my presence for even greeting him and asking a question; the desire for asking about my infant's condition was killing me" [m1].*

Discussion

This study showed that parents experienced stress and needed some measures to overcome their emotional distress through stress management. The findings of Gavey showed that just the admission of an infant to NICU is stressful enough for parents to create immense anxiety. Most parents look for information to reduce their anxiety and they want to know the latest update on the infant health progress. The medical staff has the delicate responsibility of explaining to parents about the infant's condition in a manner that they would understand and feel prepared for possible changes in the outcome.[25,26]

According to Lau, Hurst et al., maternal participation in infant care during NICU stay is so crucial that it can influence the lactation process by increasing the amount of mother's milk and her emotional wellbeing. Awareness of maternal emotional state is essential to breastfeeding mothers.[27] The majority of parents seek information and reassurance on their infant's condition. May and Hu asserted that mothers with better understanding of their infant's health were more confident about the treatment modality and experienced less stress.[28] The negative feelings about the infant's health and mistrusting the medical team can lead to increased stress for parents.[27] Rouck and Leys, claimed the most essential need for NICU parents is information and direct communication. The initial shock of having an infant in NICU, lack of trust and misinformation are the main reasons for parental stress and concerns. Seeking information is manifested with repeated questions due to the parental desire to take care of the infant. Having some knowledge of infant's condition helps parents better adapt and cope with the situation.[29] Published studies indicate that lack of time among the medical staff contributed to the amount of information given to parents[29] and while shin and White-Traut reported that having an infant in NICU was stressful for families. As a universal phenomenon, explaining and understanding the illness acuity were found difficulty for staff and families under stress and informing parents and including them in the decision making process regarding treatment was effective to reduce stress. To reduce and diminish the fear factor, a shorter period of separation between the infant and parents are as crucial as offering frequent medical updates on the infant's condition.[30]

We found literature supports for findings of our study especially when parents identified getting information on the infant's condition very effective to feel calm and less anxious. Reid et al., also indicated how parents perceived the nurses role as a great contributing factor to adapt and cope with having an infant in NICU.[31] Valizadeh et al., reported that using orientation program through watching a film or reading a booklet for mothers who had preterm delivery, before entering to NICU; is an effective strategy for reducing the maternal anxiety. [32]

Participants in this study sought hope and reassurance from the healthcare providers. Similarly, Yuen reported that healthcare providers should be aware of the parent's emotional needs in order to adequately respond to their queries and help reduce the parent's anxiety. Yuen found physician's sympathy gave a sense of satisfaction to the parents. [33]

We found that stress caused by having an infant in NICU generally increased the parent's desire and urge to stay near the infant to make attachment and help them calm down. Cooper et al., referred to the "Kangaroo care" or direct contact with the infant to calm the parents and encouraged nurses to be more aware of this essential need to bond and nurses believed that this method of caring supports developmental care.[9] The study known as "Kangaroo care" has shown dual effects by increasing breast feeding success and enhancing the physiological stability of the infant.[34,35] Our data analysis revealed that when parents become anxious for having an infant in NICU they automatically seek alternative ways to improve their infant's health and chance for survival. This action in itself helps parents cope better and gain some control with the situation at hand.

For many parents, constant prayer and citing verses from the holy Koran offered calm, hope and acceptance. Five important factors has been identified by mothers with critically ill infants: 1) ask for help and sympathy from others, 2) not losing hope, 3) believing that the best care is being offered by the people in charge, 4) being informed about infant's condition and 5) reasonably remaining close to the infant.[36] Although these findings support the results of our study, we also found that speaking to the healthcare team was very important to parents. Based on various studies regarding the level of spirituality, nurses are interconnected to provide spiritual care.[36,37]

These findings can help improve clinical performance and care quality by considering parents' emotional states and allow nurses to communicate with parents according to their behavior and spiritual needs.

Conclusion

Findings of this study highlight the importance of medical team's attention to stressed NICU parents who are trying to make adjustment or adapt to the hospitalization of their infant. A revised management approach to address the emotional needs of NICU parents in Iran seems essential for improving communication with physicians and nurses.

Based on our results parents are looking to find pope and talk to the doctors and nurses. Unfortunately, the NICU conditions do not met the needs of parents; then they resort to God and spirituality and prayer to cope with stress. Nurses and doctors should communicate with parent in NICU.

Relationships in the context of the NICU need to be based on respect, spiritual, and religious beliefs, as well as the caregivers' ability and willingness to connect emotionally, listen carefully, and communicate effectively. It is necessary for nurses to recognize parent's spirituality and belief system as they conceptualize having an infant in NICU. It is also necessary for the healthcare providers to evaluate the positive behaviors in parents trying to adapt and learn how to manage their emotional state. Direct contact with the healthcare team helps form a relationship and come to for reliable information regarding infant's health condition. This qualitative research study is not generalizable to all communities. It is suggested to study the relationship between spiritual health and

parental stress in the neonatal intensive care unit. This study revealed parent experiences but it is necessary to study the nurse's experiences of spirituality in NICU. Although further research is needed in spirituality, incorporating spiritual support in the NICU which could decreases family's stress.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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