

ORIGINAL PAPER

The Iranian Parents of Premature Infants in NICU Experience Stigma of Shame

Haydeh Heidari¹, Marzieh Hasanpour², Marjan Fooladi³

Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran¹

Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran²

Florida State University, College of Nursing, USA³

Introduction: To explore experiences of Iranian parents with a hospitalized premature infant in Neonatal Intensive Care Unit (NICU) and examine socio-cultural factors associated with having a less than perfect infant. **Methods:** Purposely selected 21 participants in this study were 6 fathers, 7 mothers, 5 nurses and 3 physicians specialized in neonatology. Semi-structured in-depth interviews using inductive approach and content analysis helped obtain and analyze data by open encoding for classification and theme abstraction. **Results:** Findings revealed that parents of hospitalized NICU infants in Iran experienced: job and income loss; shattered confidence in parental role; challenges to family dynamics; shame as a social stigma; loss of control; overwhelmed with uncertainties; and stress induced physical and emotional problems. **Conclusion:** Unique and outstanding finding of this study was the social stigma of shame for parents of an NICU infant which directly explained the socio-cultural aspect of Iranian society where families place great importance on having a healthy and strong infant. Having a premature infant with anomalies is viewed as a family flaw. Physicians and nurses must focus more on communication with parents and fulfill an important role to educate, assure and comfort parents. Establishing support system for parents of NICU infants seem urgently needed to improve parent-infant bonding. **Key words:** Shame, Social stigma, NICU, Content analysis, Culture.

Corresponding author: Assistant professor Marzieh Hasanpour, Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Iran. E-mail: hasanpour@nm.mui.ac.ir

1. INTRODUCTION

In Australia approximately 8.2% of infants born every day are admitted to the NICU. Therefore, a considerable number of parents require early professional interventions by health care providers to facilitate their needs for emotional support as they learn a new way to care for their infants. In an intensive care environment for neonates, stabilizing and helping infants survive by appropriate treatments are the main priority and often parental needs for social and psychological support take a lesser degree of importance or at times are

even forgotten (1).

Giving birth to a premature infant, which is soon transferred to NICU for long-term hospitalization takes a heavy emotional and financial toll on families. Neonatal nurses providing care for infants in NICU face the challenge of providing immediate care for a neonate as well as attending to the parental needs for assurance and comfort to see the best neonatal health outcome (2). Study by Lee and Kimble (2009) revealed that mothers of NICU infants recovering from postpartum period experience fatigue and exhaustion and justifi-

ably unable to provide adequate care for their infants requiring long sleepless hours (3). In another study, parents described caring for their hospitalized infant in NICU as their worst life experience. Parents of premature infants in NICU have significant needs for education to reach some level of readiness to care for their infants (4).

Hutti (2005) highlighted the importance of parent-infant relationship and discussed the nursing role as a major part of support system for parents (5). Currently, nursing role in NICU is heavily focused on the care of neonate. Interventions to appropriately improve infant's overall wellbeing often take precedence over educating and training parents on specialized infant care before discharge (6). In developed countries, NICU parents are an important part of healthcare team in providing infant care. Hospital becomes a small world for parents to interact with experts and specialists and often professional's behavior toward parents influence parents' experience in a positive or negative way. A supportive environment helps parents gain confidence and cope effectively, while a critical and blaming attitude delay parent adjustment to the situation (7).

Nurses are required to prepare a supportive environment for parents to assume a supervised caregiver role in a safe environment. Parents should feel comfortable in NICU and begin to participate in infant care from the moment of admission until discharge. In an environment with advanced technol-

ogy such as NICU, recognizing human needs of parents is necessary (8). Therefore, forming a family-centered NICU culture and an environment managed by effective leadership benefits everyone involved (9).

In Iran, current vital statistics on infant mortality rate shows reduction from 19.1/1000 infants death in 1992 to 15.6 in 2004. In the city of Isfahan, the infant mortality rate decreased from 19/1000 infants in 1992 to 13.11 in 2006 (10). In recent years, the morbidity and survival rates of low birth weight infants have increased. Thus, in February of 2008, the Iranian Supreme Council for Ministry of Health and Medical Education approved the degree of Masters in Neonatal Nursing and the first group of students began their classes in October, 2009. With appropriate education, Masters prepared neonatal nurses can play a significant role in improving the support system for parents of NICU infants. Developing this important nursing role and the move toward family-centered care is a positive step toward better neonatal health outcomes. Paucity of research studies examining the parent experiences of a hospitalized infant in NICU, initiated this study. Researchers used holistic approaches to look at socio-cultural issues when examining parent's perspectives.

2. METHODS

Qualitative approach and content analysis included inductive and deductive methods. In both methods, the three main steps of basic, organizing and reporting were used. Inductive content analysis method consisted of open encoding, classification and abstraction. Open encoding means inserting headings to classify pieces of information to help make sense of qualitative data. Responses to open-ended questions were categorized to enable researchers to organize large amounts of text and discover common patterns which would be difficult to identify by reading alone. Raw data was given headings after two rounds of transcription and careful reviews. Marginal headings described the text's main points and later collected for encoding and classification.

The classification step included

grouping categories aimed at reducing the number of classes by recognizing the differences and similarities in each class. However, data classification was specifically arranged according to affiliations of each class. The purpose of classification was to simplify categories and describe the phenomena in order to generate new knowledge from within the human experiences and studied phenomena. At the time of forming classifications through inductive analysis, researchers interpreted data to decide where to place various concepts to match similar classes.

Abstraction step helped form general descriptions from classifications. Each class was named by certain descriptive words. The codes were introduced as the classes were grouped into the main categories (11).

2.1. Participants

The 21 purposely selected participants were 6 fathers, 7 mothers, 5 nurses and 3 physicians. They were recruited from NICUs located at various hospitals spread across the city of Isfahan. Physicians and nurses were employed at both teaching and non-academic hospitals in Isfahan. The inclusion criteria for parents consisted of: 1) having an admitted infant in NICU within the past 24 hours, and 2) having no previous experiences with NICU. The exclusion criteria included: 1) previous history of NICU experience with other children, 2) identified parent history of psychiatric disorders such as anxiety, depression and obsessive compulsive disorders according to medical record or self-report. For professional enrollment, we included physicians and nurses with at least 6 months of work experience at NICU.

2.2. Interviews

Principle investigator entered the study environment after the preliminary official process was completed at each hospital and the NICU administrative team. Afterwards, volunteer participants signed an informed consent. To obtain maximum diversity, participants were selected from different parts of the city in Isfahan. The interview locations were chosen by participants and anywhere they were more comfortable which included the hospital unit, workplace, home or elsewhere.

Initially, only parents were enrolled and later physicians and nurses were included and interviewed to maximize rigor and improve diversity.

The interviews began with an open-ended question asking: "please tell me about the admission of your infant to NICU and how it has affected you?" A probing question helped deepen the discussion, promote trust, and avoid judgment if the interviewee made an error when stating the facts. Each interview session lasted 30-60 minutes or continued until saturation was reached or participants were repeating themselves without adding new information. Data was analyzed simultaneously during interviews.

2.3. Procedure

Researcher listened to the tapes several times and focused on the interview contents. Recorded materials were transcribed word-for-word and key concepts were highlighted to extract codes. Encoded concepts from sentences and paragraphs were grouped into classes based on the similarities and differences and ultimately classified into main categories according to their associations. Measures were adopted to increase data validity by reading the interview contents several times and focusing on comments and suggestions from colleagues which confirmed or suggested modification to increase accuracy of the extracted codes and classes. Researchers reached consensus on codes and classes and discussed various possibilities before agreeing on all aspects of coded data.

Researcher reviewed all the transcribed texts, encoded and classified the important concepts several times to ensure validity and reliability for each identified code and concept. After encoding, researchers interpreted a number of interviews with key concepts and reached consensus on appropriateness of assigned codes.

2.4. Ethical Considerations

This study was approved by the Isfahan University Medical Ethics Committee for the following ethical considerations: regard for privacy, confidentiality, and anonymity and this is where we mention participants were assured of voluntary participation at no risk. The participants provided written con-

sent prior to interviewing.

3. RESULTS

Demographic characteristics of study sample included young mothers with the mean age of 27 years. Three were first-time mothers (primiparous) and 4 were multiparous. Three had finished junior high, 3 graduated from high school and 1 had a bachelorette degree. Among the fathers, mean age was 37 years. One had primary education, 2 finished junior high, 1 was a high school graduate and 1 had a bachelorette degree. The mean age of nurses was 35 years with an average of 6 years NICU experience. Physician's mean age was 29 with an average of experience in NICU.

Data analysis of parent's experiences with a hospitalized infant in NICU revealed major themes listed as: 1) job and income loss, 2) shattered confidence in parental role, 3) challenges to family dynamics, 4) shame as a social stigma, 5) loss of control, 6) over whelmed with uncertainties, 7) stress induced physical and emotional problems.

3.1. Job and income loss

Having an infant hospitalized in NICU, shifted some responsibilities for the care of other children, household duties and transportation on fathers which interfered with their regular jobs and reduced their income. A mother [m2] stated:

Someone like my husband who is self-employed, all depends on being there at the job to earn income and if he is not there working, it means no income for that day.

A father [f4] mentioned:

I am concerned for leaving my job unattended. They call me to say, why aren't you here? Farming is not like working in industry with machine. Farming is season dependent and when I or any other team member doesn't go to work, things don't get done and work stops.

Data analysis showed a split sense of responsibility and double duty by fathers. Family concerns related to the loss of job and income when fathers had to be present at work in order to make a living and yet, be present in NICU with the infant or care for other children at home. Families who were financially supported by relatives (a common cul-

tural practice) were much more upset and worried as a father [f5] indicated:

I raise animals in an animal farm and had to leave those living beings unattended and come here. Those animals need food and water and someone must be there but, I left and came here; I left 60% of my livelihood behind for this infant and so far, no change has occurred in his health status and there is no one else to come here in my place; I have got many things left to do, I have no body to take care things at work nor anyone to stay here.

3.2. Shattered confidence in parental role

Giving birth to a premature infant left all parents in this study with a sense of helplessness and doubt. Mothers with a term and healthy infants often experience self-doubt⁽¹²⁾ and indeed birth of a premature infant care can shatter confidence in parenting ability as mothers have reported here. Caring for a hospitalized premature infant in NICU and meeting infant's special needs at home challenges every aspect of maternal role as a mother [m5] shared:

My infant is so small; I can't take her home, I don't know how to be a good mother to her.

Another mother [m7] said:

It's very hard, because right now I want to breastfeed him and I can't. I want to dress him or anything else...

A physician [d3] commented on the parental inability to assume role and perform tasks by saying:

Parents feel they are unable to care for infant and feel insufficiency prepared for being a parent. For instance, they think they are bad parents or they are not good enough.

3.3. Challenges to family dynamics

Data analysis showed changes in family dynamics and lifestyle where fathers had to carry a heavier burden of parental responsibilities at home when mother was attending to the infant needs in NICU. Iranian fathers who commonly leave domestic care to the mother, had to be more engaged in the care of other children and household activities after leaving the mother in NICU. Infant's hospitalization in NICU forced fathers to work double duties in the absence of mother. A mother [m6] shared:

My husband must take care of the

infant or drive me back and forth to do that.

Father's responsibility to care for children at home does not end there as he has to help support the mother as well. One of the nurses [n5] added:

If the husband comes in at the right time in the morning or evening, we can teach him how to help the mother.

Disruption in the family process related to role changes and chaos in the family system when parents had to spend many long hours at NICU, as a mother [m5] said:

I have a one-year-old child. She has been living at different places and I don't know what to do anymore. I have left my other child with my neighbor to come to the hospital and what should I do with this one?

Infant's hospitalization separates family members and especially when mother is away other children feel abundant as a father [f1] explained:

We also have a four-year-old daughter... we are far from each other. She spends a day at her aunt's, another day at my mom's house and the next day she is at her other grandma.

Having an ill infant can affect the whole family by impairing the family system. One of the physicians [d3] shared:

In fact, when an infant is ill and hospitalized, the mother is ill, the father is ill, and the whole family is ill.

3.4. Shame as a social stigma

A sense of shame, self-blame and guilt were the dominant expressions when parents referred to a social stigma associated with birthing a less than perfect infant. The Iranian socio-cultural structure is based on glorifying the perfect form and finding a reason to discard anything less than perfect. With an infant in NICU, parents' expectations for having a perfect infant were dashed and explanations to the relatives had to be made. Giving birth to a small and premature infant stigmatized parents especially mothers for giving birth to an abnormal infant.

A mother [m7] shared:

You see, my baby is so small; I know everyone could have this problem ...I told my husband I don't want this baby anymore.

In a family oriented society such as

Iran, cultural norms allow relatives and family members to get too involved in commonly considered private issues and overtly express or behave in such a way that new parents of a premature infant could feel guilty, ashamed and stigmatized. Negative remarks and stinging comments may be unavoidable when relatives come to see the newborn as one mother [m2] stated:

From the moment they walk in, someone would say "whose heart did you break to get such a punishment (pointing to the infant)?" Or they say, "what sin have you committed in your life to be punished like this?"

Regarding social stigma, one of the NICU nurses [n3] said:

Imperforated rectum which may be repaired by a colostomy where colon is temporarily opened to the abdominal surface is an unbelievable thing for the general public and when an infant with colostomy is discharged home, that family is ashamed to show the infant to relatives or in public.

Parents of infants with more obvious anomalies dread going home and face the difficult moments with relatives and family members who pass judgment or the society at large which considers anything less than a perfect infant a curse or divine intervention to punish misdeeds. Thus, parents hide their infants and silently suffer from feelings of shame and guilt. They fear visitor's comments and reluctantly show their infants.

3.5. Loss of Control

According to analyzed data, management of a hospitalized infant in NICU separates parents from home routines and most parents feel the loss of control over their lives. Once a woman who functioned as a person in charge of her home environment is removed from home to spend endless hours in NICU, she begins to feel out of place and without any control over her life. A mother [m4] explained:

Here, I can't tell anyone not to come into my room, when to leave, ... I can't tell anyone don't touch my stuff,...my whole life is exposed and many of my belongings are lost. I feel as if I have lost everything...what happened to my life?

One of the fathers [f5] said:

Just waiting here and all that work

is waiting to be done...and there is no one to take my place for me to leave...

3.6. Overwhelmed with uncertainties

Participants felt overwhelmed and confused with uncertainties related to their infant's health status in NICU. A mother [m4] in distraught stated:

How long can I stay here? What am I supposed to do?

Parents wanted to know more about their infant's progress and lack of information, direct communication with the healthcare team or periodic updates on their infant's health status, made them feel overwhelmed with uncertainties, confused and helpless. A mother [m6] in distress indicated:

I don't know any more what I should do?

Uncertainty is a major source of stress and parents were feeling restless with the unknown state of their infant's health as one of the nurses [n4] mentioned:

The worst thing for a family is, not knowing what to do.

3.7. Stress induced physical and emotional problems

Mothers suffered from extreme stress leading to breast milk reduction and postpartum hemorrhaging as a father [f3] said:

My wife had so much stress and the bleeding wouldn't stop.

Muslim women in Iran consider breastfeeding and providing nutrition to their infant as an important religious and maternal duties and the reduced amount of breast milk was devastating to them as a mother [m7] stated:

I am very sad that for the past two days I have had no breast milk.

Often, insufficient rest and stress contribute to breast milk reduction as one of the nurses [n5] stated:

If a mother doesn't get enough rest, her milk can gradually decrease.

In addition to physical problems, most of the parents had psychological symptoms such as crying and breaking down. An infant in NICU is an unexpected incidence for parents with tremendous emotional upheaval as a father [f3] indicated:

Well, honestly that was a miserable feeling, I got so tired emotionally and my wife cried a lot.

Parents of a hospitalized infant in

NICU have to assume increased responsibilities which affect their physical, psychological and mental health. One of the physicians [d3] elaborated:

Parents are confronted with the major event of having an infant in NICU and many aspects of their own health may be at risk, thus closer attention to parents' emotional state is most essential.

4. DISCUSSION

Although Iranian culture places the family management responsibility on the mother's shoulder, the findings of this study, identified that fathers of a premature infant hospitalized in NICU also experienced the heavy burden of attending to the mother's emotional needs, sharing in the care of infant and other children and worrying about the loss of job and income as the family bread winner. Previous studies to some extent have found similar results. For instance, Hollywood & Hollywood (2010) reported job was the primary factor which interfered with fathers' involvement and participation in infant care. Having to work and earn income for financial support of family created much stress and pressure for fathers as they could not concentrate on work or leave to be with their infant hospitalized in NICU (13).

This study showed that having an infant in NICU disturbed family structure by changing routines. Parents had to leave home for long periods of time and function in an environment without having any control over their lives. Board (2004) asserted that parental role at the time of infant's hospitalization is very stressful for fathers when they cannot help manage the crisis, feel incapable of caring for the infant and loss of control for protecting the infant from uncertainties (14). In contrast, our study found mothers having difficulties with the stress of sensing inadequate to care for the infant and fulfill their maternal responsibilities.

We found that parents suffered from unknown prognosis and similarly De Rouck & Leys (2009) reached a conclusion that parents repeatedly seek information on their infant's progress in NICU to relieve feelings of shock, disbelief and uncertainty (15). Study by

Gavey (2007) showed that admission of an infant in NICU was a stressful experience for parents and mostly for insufficient information to alleviate their concerns and suggested frequent update on the quality of infant's progress to prepare parents for any changes (16).

This study revealed birth of an infant associated with new maternal responsibilities and how difficult it is when parents are unable to assume their parental role for a hospitalized infant in NICU because of many special needs. Another study showed that NICU hospitalization of an infant influences maternal role negatively where a mother feels unable to care, support and alleviate pain for her infant (17).

Our study found increased parental responsibilities and special infant needs generated a feeling of inadequacy to care for infant and fulfill parental duties. Hutti (2005) indicated that prolonged hospitalization and the separation of parents from their infant disturbed their family life. Parents felt detached from their parental role and could not bond with their infant as an essential part of postpartum maternal bonding (5). Other researchers have reported that infant care in NICU is highly specialized and mother does not seem to be a part of the team to care for her infant. She experiences a sense of loss and deprivation when the healthcare team care for her infant as if her baby belongs to the hospital (18).

The highly specialized NICU environment is prohibitive to performing parental role, and fulfilling the emotional needs of parents. This aspects of hospitalization negatively effects maternal-child bonding with long-term influence on infant development (19). Ward (2011) believed parents in NICU are incapable of listening to the explanations, caring from their infant and recognizing the importance of attending to their own health (20). Another study reported at the beginning, maternal feelings are strong and over time mothers recognize the severity of infant needs for specialized care. Mother's experience to perform her maternal role would require skills training as a challenge for most mothers (21).

Parental stress was found as a risk factor for behavior problems in siblings

of premature infants hospitalized in NICU and if parents managed to decrease stress, their infant and child had less behavior problems in the first year after birth (22). We found parents had difficulties being separated from their children while attending to the infant hospitalized in NICU.

In support of our study reporting most parents experienced physical and psychological problems due to having their infant hospitalized in NICU, another study has also showed that admission and hospitalization of an infant in NICU can be a very stressful experience for parents. The anxiety associated with infant's health generates emotional responses in parents described as the "worst thing ever" (23).

The stigma attached to having a premature infant with some anomaly or abnormal appearance stems from cultural beliefs and karma. This study identified unique experiences with shame, guilt and self-blame associated with having a premature infant in Iran. Similarly, Lee, Norr & Oh (2005) reported self-blame among mothers whose infants had a certain health problems. Authors indicated in South American countries, anger was the most common maternal response to birthing a premature infant while Korean mothers experienced guilt and self-blame (24). In our study we found a strong sense of shame associated with giving birth to a premature, developmentally delayed or infant with anomalies. Parents faced negative responses from relatives on both sides which added to the parental stress or maternal rejection of infant. Such cultural practices raise concerns and highlight the importance of necessary individual, family and community training to prevent and reduce shame stigma. Parents at such a difficult time need support and understanding and Feeley, Gottlieb, & Zerkowitz (2007) emphasized providing information to key family members in order to help parents develop confidence and self-efficacy to care for infant. Mental anguish prohibits learning and reduces self-confidence (25).

5. CONCLUSION

This study supported findings of previous research and found new in-

formation on human experiences from cultural perspectives regarding Iranian parents with a hospitalized infant in NICU. Researchers interviewed participants and identified physical, psychosocial, emotional, economic and cultural views on infant hospitalization in NICU and how it affected the family dynamics. We found paternal concerns with job and financial loss, family disruption in daily routines, parenting role challenges when the burden of responsibility was shifted to fathers, dealing with shame stigma, losing control over life decisions and experiencing physical and psychological health problems due to extreme stress associated with uncertainties.

Providing multilayered support for parents of an infant in NICU seems essential as nurses and physicians confirmed how uncertainties affected parent's lives. Encouraging and promoting parent involvement in infant care can strengthen maternal-child bonding and help build confidence. In such a system, the healthcare team not only uses expertise to stabilize and care for the premature infant, but also includes parents in every effort with greater emphasis on parent education and training. Family members must be included and made aware that certain cultural health beliefs could be modified to help build hope and offer kind support to parents.

Medical team could be more engaged in providing infant health updates to parents to reduce their concerns. Physicians and nurses in NICU must be sensitive to the parents' needs for information and help educate family members to prevent and reduce shame stigma associated with infant anomalies and prematurity. In a family oriented society such as Iran, where families of parents are in close relation, it is necessary to hold debriefing sessions with the whole family and inform them of the infant's condition. This may help reduce negative and hurtful comments by relatives and leave room for parents to attend to their infant, family and themselves. Moreover, our findings indicates the importance of establishing an Association for supporting parents of NICU infants in Iran with the help of pediatricians, social workers, nurses and other medical team members.

Acknowledgements

The authors would like to acknowledge the kind co-operation and support of all participants at the units involved in this study, Alzahra hospital, Shahid Beheshti hospital, and Amin hospital.

Conflict of interest: The authors have no conflicts of interest to declare.

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Izet Masic is Professor of Family Medicine at the Medical Faculty of the University of Sarajevo and Professor of Social Medicine, Health Care Organization and Health Economics at the Faculty for Health Sciences at the University of Zenica in Bosnia and Herzegovina.