Mothers’ experiences of neonatal jaundice: A qualitative study

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Abstract

Background & Aim: The importance of neonatal jaundice is not only for its social, economic, and psychological complications resulted from hospitalization of neonates in the hospital, but also for the permanent neurological handicaps and its consequent high morbidity. Since Iranian mothers have no, in spite of the importance of matter, appropriate approach in coping with their newborn jaundice, this study aimed to explore mother’s experiences of neonatal jaundice.

Methods & Materials: This qualitative study was carried out through in-depth semi-structured interviews with 14 mothers whose infants were hospitalized in one of the hospitals affiliated to Shahrood University of Medical Sciences with a diagnosis of neonatal jaundice. The participants were selected purposefully and the data were analyzed using qualitative content analysis.

Results: Two main themes and several subthemes emerged from the data. The main themes were as follows: mothers’ experiences of jaundice crises and its management, and mothers’ present experiences after crisis of jaundice. First theme arranged into four subthemes and second theme was grouped into three subthemes.

Conclusion: Mothers’ and grandmothers’ cultural and dietary beliefs have an important impact on mothers’ health-seeking behavior. Educational programs about neonatal jaundice and its management through prenatal care consulting and mass media is recommended as an important priority for health system of country.

Key words: mothers’ experiences, neonatal jaundice, qualitative study

Introduction

Jaundice is the most common clinical condition in the newborn that requires medical attention. On an average 50–60% of term newborns and 80% of premature become clinically jaundiced. Infants of Asian and American Indian descent are more likely to develop jaundice, African-American infants are comparatively less so (1). Neonatal jaundice is still a leading cause of preventable brain damage, physical and mental handicap, and early death among infants in many communities (2). Neonatal hyperbilirubinemia is defined as a total serum bilirubin level above 5 mg/dL. However, only a few newborns have an important underlying disease (3). Neonatal jaundice is almost due to unconjugated hyperbilirubinemia, which may, in the case of not treating, cause kernicterus (4, 5). Although the majority of neonatal jaundice is benign disorders, high level of unconjugated bilirubin will be toxic and causing adverse outcomes. Indeed the risk of hyperbilirubinemia is due to kernicterus resulted from toxic effects of bilirubin on the brain (6). The importance of kernicterus is not only for its social, economic, and psychological problems resulted from hospitalization of neonates in the hospital, but also for the permanent handicaps of neurologic system and its con-
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sequent high morbidity. Fortunately, kernicterus is preventable with medical treatment, phototherapy and exchange blood transfusion provided that the prompt diagnosis and management can be performed. Factors like earlier discharge of newborns from hospitals than before, trust in traditional treatment and treatment with herbal medicines play the essential role in delaying the treatment and neonatal adverse outcomes (7, 8). Household practices, especially of its mothers has significant role in neonatal health (9). Jaundice will be easily curable with simple and low dangerous methods such as phototherapy otherwise using more dangerous therapeutic methods is required. Different quantitative studies in Iran indicate that mothers take no proper action in management of neonatal jaundice and sometimes with treatment of home medicines cause serious damages for their babies. Based on the study done by Hosseini and Nikbakht Nasrabad (10) in the hospitals affiliated to Tehran University of Medical Sciences, the mothers are unaware of the importance of neonatal jaundice’s nature and their dominant cultural beliefs poses the challenges in newborn treatment. Getting a deeper understanding of mothers’ health-seeking approach and the reasons that govern such behaviors seems to be needed. Therefore, this qualitative study aimed to explore mothers’ experiences of a neonatal jaundice.

Methods

This qualitative study was conducted using content analysis method. Prior to commencing the study, ethical approval from Ethics Committee of Research Center of Shahrood University of Medical Sciences was obtained. The research was begun on May 2010 and completed in April of 2011. Sampling took about 3 months and the left time was spent on data analyzing and reporting the findings. Participants of 14 mothers, who were volunteers to participate in the study, underwent in-depth semi-structured interviews to explain their experiences of their newborn jaundice. Mothers whose babies were hospitalized with the diagnosis of neonatal jaundice in the hospitals affiliated to Shahrood University of Medical Sciences at least 2 days prior to the study, was considered as inclusion criteria. Prior to each interview, the researcher explained the purposes of the study to the mother and their written and informed consents were obtained. The mothers were assured of confidentiality of their name, answers and comments and their right to withdraw from the study whenever they want. The environment of research was real and natural one and interviews was conducted anywhere the mothers were available and felt more comfortable like the neonates wards of above-mentioned hospitals.

Each woman underwent individual interview and the interview lasted between 30 and 50 min. The questions of interview were completely objective centered ones. At first, the individual information such as age, level of education, the women’s and their spouses’ job and the date of delivery were asked. Then, the interview continued with probing and main questions such as “when was your baby born? What is your perception of jaundice’s nature? Who recognized the jaundice of your baby at first? What were the danger signs of the jaundice? Who encouraged you to use herbal medicine?”. The samples’ answers directed interview’s procedure. Sampling was continued up to reaching saturation of information and lack of access to new data. Audio taped interviews were transcribed verbatim together with observed nonverbal communication such as gesture, facial expression and eye contact and the tapes were blanked out after being written on the paper. Conventional content analysis, being valuable method for analyzing qualitative studies (11), in which coding categories are derived directly from the text data (12), is used for analysis. The content of interviews was read repeatedly, word by word and finally the codes were emerged by merging into content of the text. This process steadily continued from codes extraction to naming the codes. After coding sort done through reconciliation of codes, the codes were arranged into categories according to similarities and differences in related codes across distinct original contexts. Finally after emerging concepts, one or two quotation was cited for each themes or concepts (13). To be precise and to increase the data objectivity, combination of some methods including deep
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Interview, spending of adequate time, good communication, member check, further interviewer revision and consulting faculty members of university who were familiar with analyzing qualitative studies, authenticity of interpretation and coding processes were used in the study.

Results

Among 14 mothers who participated in the study six were from Fatemieh, five from Imam Hossein and three from Khatam Hospital, age ranging between 18 and 39 years, with educational level of high school to bachelor’s degree; four were multiparous and others primiparous; the age of infants ranging from 5 to 12 days old and all babies were breastfed and other than one newborn who received phototherapy, others discharged from hospital without any specific therapy, but came back to readmission. Except one neonate, whose mother was health provider, having sufficient knowledge of neonatal jaundice, other babies were treated with traditional herbal medicines resulted in consequent phototherapy. Exchange blood transfusion was required for two newborns. Analysis resulted in two main themes including: mothers’ experiences of jaundice crises and its management, and mothers’ present experiences after crisis.

First theme: Mothers’ experiences of jaundice crises and its management

Facing neonatal jaundice imposed a crucial situation for parents especially for mothers. Mothers’ misunderstanding of jaundice’s nature and family centered decision affected their jaundice’s management.

The subthemes of the first theme and its good illustrations were as follows.

Feelings of stress and tiredness

The majority of mothers felt helpless of having a jaundiced and sleepy baby. Physical exhaustion in the result of the delivery process and postpartum complications like bleeding and tension of delivery went from bad to worse with the readmission of babies in the hospital.

Participant number 3 said: “Just the time I thought that I got rid of the hospital, I had to take my baby to the hospital for the treatment. I was completely shattered. You don’t know. It is so hard”.

Psychological tension of mothers due to concerns for newborn’s health, their husband and other children who were alone at home, was even more intolerable than physical exhaustion.

Participant number 6 said: “As I previously experienced the stress of a neonatal jaundice, I was so worried. Leaving my honey under the heat of phototherapy setting for hours alone bothered me (furrowing of forehead). On the other hand, if I took him to the hospital, my husband and my other child would be alone. I felt completely miserable.”

Cultural beliefs on disease’s nature

There was a variety of cultural beliefs in disease’s nature. Except one mother, others had misunderstanding of disease’s nature.

Participant number 1 said: “I only know jaundice is very dangerous. I heard that the neonatal jaundice is a blood disorder and occurred when the parents of a baby are close relatives. I and my husband are cousins, therefore…”

Participant number 4 said: “I don’t know what the jaundice is. It is said to be related to mother’s feeding and her hot temperament. Since I’ve eaten so much pastry and cacao, my baby became yellow. I’m guilty. I took neither my mother’s advice nor my mother-in-law’s. If I consumed the chicory extract, my baby might not be yellowed (sadly)”.

Fairly good knowledge about jaundice’s signs and symptoms

The majority of mothers knew alarming signs of the jaundice. The knowledge acquired by various sources such as physicians or nurses of neonatal units or previous experiences of grandmothers and relatives.

Participant number 5 said: “The baby was pretty white when I took her home but then she gradually became yellow. The nurse had instructed me about checking my infant’s jaundice. At first her abdomen skin became yellow, then her eyes and finally I understood that she had completely yellowed.

Participant number 10 said: “When we were
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in the hospital, the doctor asked us to return if the jaundice got worse. The day after going home, I felt at first his nose and face and afterwards his hand and legs yellowed. His jaundice had an ongoing process. I wondered why the process was progressing so rapidly. However, we quickly took him to the hospital.”

Decision making under others influence

Although many mothers were informed of the risk of situation through the information given by the physician or nurses, used the traditional treatment for about one-and-half to 3 days at home before taking the baby to the hospital. Cultural beliefs governing all family members of husband, mother, mother-in-law, relatives and neighbors affected mothers’ decision making.

Participant number 3 said: “I myself don’t believe in the traditional medicines. My husband, mother-in-law and others advised me to give glucose drink, purgative manna and the extract of chicory to him. I reduced breastfeeding and exchanged it for these substances (shaking his heads). Although we had realized that his bilirubin was going up, unfortunately we continued the juices for 2–3 days until the baby seemed not to wake up. As a matter of fact Almighty God was merciful to us for taking him timely to the hospital. Since his blood exchanged, his bilirubin has decreased by 5.”

Participant number 1 said: “Surprisingly my mother hadn’t used this kind of substances even for us. However, since others gave different advices to her, she was finally influenced. One day after giving the extracts to the baby, we found that the mixture of the pomegranate juice, manna and purgative manna taken by the baby had soured (grief in her voice). When I remember, despite of 7 years of infertility and great expectation for a healthy baby, how I treated my baby, I become so upset and thank God as he is healthy now.”

Second theme: Mothers’ present experiences after crises of jaundice

The subthemes of the second theme and its some phrases were as follows.

Feeling of blame and guilt

The mothers felt guilty and continuously blamed themselves for they deeply believed that their warm blood or warm food in terms of attribute had caused their neonatal jaundice. They also thought if the traditional medicines were used before appearing the jaundice in other words in the preventive form, it could be surely effective.

Participant number 4 said: “If I had taken advice of the elders and given manna before yellowing the baby, this misfortune would not have happened to him. If I had started the herbal treatment sooner, it could have been prevented. I shouldn’t have eaten warm food like eggs and honey. It is all my guilt. I thought that I understand more than others because of being literate (placing special emphasis on the word of literate).”

Cod 13 said: “In old times, there were no medical remedies. I never believe in chemical medicine. If I had drunk more chicory and manna immediately after delivery, my baby would not have been with jaundice. These substances don’t work anymore when jaundice has appeared and should be given earlier.”

Traditional approach verses common medical treatment

“How will you treat your babies in future?” was the question asked from 14 mothers who experienced the newborn jaundice and experienced its risks. Eight mothers preferred medical treatment in the hospital, but six mothers preferred herbal medicine and extracts either for themselves during pregnancy or for their babies.

Participant number 1 said: “The hospital is safer and more comfortable. The bilirubin comes down easier in the hospital (wave in hands). If an event happens in a hospital, you will know who is guilty, but not when you are at home. I will take my baby to the hospital as soon as I see yellowness.”

Educational expectation from authorities

The majority of mothers requested from authorities to provide them with proper educational programs, about the management of jaundice through mass media, prenatal education and postpartum hospital stay.

Participant number 3 said: “I have not heard of jaundice before. Although I’m a recent university graduated, but my education is in the
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field of humane science. I wish the required information could be given through premarital educational classes.”

Participant number 12 said: “I have education but not more than high school. My husband is a rural simple worker and none of us had heard of jaundice. So others made decisions for us. The authorities had better give the instruction via radio, television or some other mode which we could understand. Please convey our regards and messages to the authorities (fondness and hopefulness in his voice).”

Discussion

Results of the study indicated that mothers’ physical and psychological status of postpartum was aggravated in the presence of neonatal jaundice. This situation can contribute to improper decision making. This result was in keeping with reports of Brethauer and Carey’s study (14) in which the mothers of newborn with jaundice suffered from mental and physical exhaustion. This finding was in disagreement of Hannon et al.’s study (15) in which mothers’ stress and concern lessened by providing them with good information about jaundice and its treatment. Similar to the studies done by Amirshaghaghi et al. (16), Hosseini and Nikbakht Nasrabadi (10) and Khalesi and Rakhshani (8) there was misunderstanding of disease’s nature due to cultural beliefs. Except one mother, others were influenced by traditional and dietary beliefs, and believed that eating warm food in terms of attribute was the cause of their newborn jaundice. In agreement with the study of Hannon et al. (15) misconception of disease’s nature aroused mothers’ feeling of guilt and default. They continuously blamed themselves for eating warm food such as coca and honey. Their misconception resulted in them stopping breastfeeding. Cultural and dietary beliefs are more difficult to address, especially because they are so commonly and widely upheld among people. Willis et al. (17) showed that related instruction given to the mothers by health providers motivated them to continue purposefully breastfeeding. Seemingly grandmothers, friends and others in the woman’s social network have an important impact on mothers’ decision making (18). Though the mothers diagnosed the jaundice promptly, due to be instructed by the physicians and nurses of neonates ward, they postponed taking their babies to the hospital. Their strong trust in traditional remedies caused them to treat their babies with traditional healing home remedies and herbal medicines at least one and half day at home. In agreement with the study of Awasthi et al. (19) these preferences and negligence in the treatment were more due to mothers’ unawareness of adverse complications of hyperbilirubinemia. This negligence resulted in more dangerous therapeutic requirement like exchange blood transfusion. This survey revealed that mothers even after experiencing a neonatal jaundice and its consequences were still doubtful about their future reaction to the jaundice. The findings of present study represented that half of the mothers facing with another neonatal jaundice preferred traditional remedies. However, the results differ from the Egube’s study (20), which reported that mothers’ attitude and practice toward the medical management was good. Finally, mothers were requested to be qualified with sufficient information of newborn jaundice and its complications by health care providers.

There were two limitations for the study. Firstly, the participants were gathered from the educational hospitals of Shahrood only. Secondly, there is the probability of misreporting some bitter experiences of traditional medicine due to cultural prejudices on traditional treatment.

Conclusion

The findings of the present survey reveal that there is a misunderstanding of neonatal jaundice’s nature. The study identifies mothers’ and grandmothers’ cultural and dietary beliefs have an important impact on mothers’ health-seeking behavior. Psychological effects such as feelings of stress, blame and guilt affecting mothers’ health status, suggests requirement of psychological support, which should be provided by the treatment team. Since trust in cultural beliefs and traditional treatment brings serious consequences for newborns, there is an emergent need to enhance intervention efforts. Educational programs about neonatal jaundice and its manage-
ment through prenatal care consulting and mass media is recommended as an important priority for health system of country.

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