

Maternal experiences about neonatal jaundice: a qualitative study

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Keypoints

Mothers need to improve their information on jaundice and change their attitude towards it and its treatment.

Abstract

Introduction

Jaundice is the most common clinical condition in the newborn, requiring medical attention and hospital readmission. This study was conducted to explore maternal experiences regarding their newborn jaundice.

Material and Methods

In the current qualitative study, conventional content analysis approach was used to explain 8 mothers' experiences and perception of care provision for jaundiced infants were hospitalized in one of the hospitals affiliated to Zahedan University of Medical Sciences.

Results

According to data analysis, the following 3 main themes and 4 sub-themes emerged: the themes "Maternal awareness, a necessity in the treatment process" "The traditional medicine, a paradox in healthcare and "The challenges of treatment outcome in the main ones", and the sub-themes "Recovery in the light of correct diagnosis" "Care sensitivity" "Understanding the disease" and "Family distress and concern".

Conclusion

The findings of this study showed that mothers need to

improve their information on jaundice and change their attitude towards it and its treatment.

Keywords

Neonatal, jaundice, qualitative study

Introduction

Neonatal jaundice may first have been mentioned in a Chinese textbook 1000 years ago. Jaundice is the most common condition in infants, requiring medical attention and hospital readmission (1). Neonatal jaundice is common in neonatal period due to the adaptation of bilirubin metabolism occurring during this time. (2) It is also considered a major cause of neonatal morbidity globally, and is estimated to be present in 60% of term infants, and 80% of preterm ones (3) (4). During the neonatal period, the health beliefs and practices influenced by the local culture are frequently practiced in many countries (5).

The practitioners in developing countries still encounter kernicterus frequently, whereas it has been described as a re-curring disease in most developed countries. The recurrence of kernicterus may have different causes such as poor adherence to universal guidelines on jaundice management, early discharge of infants from hospital before jaundice could be detected, an increase in breastfeeding practices, poor knowledge of the early signs of bilirubin

encephalopathy and the lack of parental information about the dangers of neonatal jaundice (6, 7).

Neonatal jaundice is usually noticed during the first 3–5 days of life and may lead to kernicterus or even death. On the other hand, mothers and their newborns are commonly discharged within 48 hours after vaginal delivery or 96 hours after cesarean delivery (8) as a result of cost-containment policies implemented by care management companies.

In Ghana, delay in seeking treatment is reported to be due to factors like previous negative experience with health services, complex decision making processes, and the tendency for traditional medicine as well as regarding some diseases as *not for hospital* (9).

Infants with high blood levels of bilirubin, a condition known as hyperbilirubinemia, develop the yellow color when bilirubin accumulates on the skin. Severe hyperbilirubinemia can be toxic to the infant's nervous system, which may cause acute reversible brain damage called bilirubin encephalopathy or permanent brain damage called kernicterus.(10)

Since mothers are the primary care giver for the infants in most societies, their perception of understanding and dealing with neonatal jaundice would significantly affect the disease's outcome. This would, in turn, help healthcare providers in making proper treatment decisions for the infant, and more importantly, in counseling the mother and her family. Mothers' perception regarding the diagnosis, severity, causes, and treatment of jaundice in their infants mostly reflects their own misconceptions about this common neonatal condition. Apparently, their experiences in providing care for children with jaundice in the neonatal period, as well as the influence of the society and their families form their perceptions about neonatal jaundice (10).

The implementation of some home-based traditional care practices might reduce the mortality rate in infants, as a result of decreasing the risks of infection and hypothermia (11).

Since mothers and their infants are discharged early, the importance of their ability to recognize neonatal jaundice increases. In Sri Lanka, there is little data on the mothers' level of knowledge, attitudes and behaviors regarding neonatal jaundice (12). A major problem with the traditional care for jaundice is the fact that following bilirubin levels is more difficult. It is recommended to closely monitor bilirubin levels in all jaundiced infants while being bottle-fed and hospitalized in the nursery for several days. Bilirubin levels were lower and usually peaked while the baby was still in the hospital, making the recognition and follow-up of jaundice a relatively simple matter.(13)

In regard with the management of neonatal jaundice, the results demonstrate health education prior to childbirth significantly improved the diagnosis of neonatal jaundice by first-time mothers. Most mothers chose to consult with a pediatrician as soon as the jaundice was detected, while many mothers in the control group sought other approaches such as stopping breast-feeding, putting infants under sunlight, practicing traditional Chinese medicine, or even waiting until neonatal jaundice becomes clearer. Thus, antenatal health education needs to focus more on the knowledge of biliary atresia, and infants with jaundice need to be closely monitored and require immediate medical attention. In addition, there are some limitations in this study (14). Many cases of neonatal jaundice pass unnoticed or are not timely identified by mothers who take their infants to hospitals late (12, 15).

Mothers' role regarding care provision for infants, or in some cases, adopting traditional approaches is highly affected by cultural issues. Cultural and ethnic variances can influence these experiences. On the other hand, due to the fact that few qualitative studies have been conducted on mothers' perceptions and care experiences in Iran, concerning the neonatal jaundice and care provision, the current research aims to explain mothers' experiences in providing neonatal care.

Material and Methods

In the current qualitative study, conventional content analysis approach was used to explain mothers' experiences and perception of care provision for jaundiced infants. Content analysis is used as a systematic approach to deeply and extensively explain phenomena which results in revisions, making valid conclusions from data, and creating new knowledge and awareness, and is appropriate for assessing individuals' experiences and attitude towards a specific topic. Therefore, this approach was implemented to explain mothers' experience and perception (16).

The participants in this research were 8 mothers with jaundiced infants who were included through purposive sampling and based on their experiences in care provision for their infants. The sampling continued until data saturation was achieved. The participants' information consisted of their experiences in care provision for jaundiced infants, tendency to participate in the study, having verbal skills and the ability to speak Farsi.

After obtaining an informed consent from the participants and setting interview appointments, the researcher conducted the interviews at the time and location of the participants' choice. Data was collected through semi-structured interviews. The length of interviews varied from 45 to 60 minutes. Prior to the interviews, a primary instruction was prepared to help the researcher ask more questions for doing examinations in the relevant area. At the beginning, the interview started with general questions on the mother's experience in care provision for jaundiced infants, such as "Tell us about your first encounter with your child's jaundice" or "Express your experience in providing care for the infant after the diagnosis of jaundice". Then the interview was continued according to the interview guide and the participants' responses. Moreover, other questions were asked such as "Could you give more explanations?" or "What do you mean by saying ...?" The interviews were conducted by the researcher and the responses were recorded with the participants'

permission. The responses were then typed word by word and each interview was analyzed immediately after the text was prepared. Indeed, the analysis was continuously done concurrent with data collection. For data analysis, conventional content analysis was used. In this approach and based on the various stages of content analysis process, at first, each interview was studied several times to obtain a general and primary comprehension, and important phrases were underlined. Then the meaning units in the text were determined, which were related to the participants' experience and perception in care provision for jaundiced infants. In the next stage, these meaning units became more abstract through text condensation and labeled with codes. Coding was done using the participants' own words and implicit codes. The codes were compared in terms of differences and similarities, and were categorized into several themes and sub-themes.

In the present study, the findings were validated by devoting sufficient time to data collection, reviewing the interviews with participants and peers, and reviewing data analysis with the help of the researchers familiar with the qualitative research method. Several experts coded some of the interviews in order to address the reliability of the findings. Moreover, the researchers carefully documented the details of the study so that external reviewers could assess it. The researcher also provided rich descriptions of participants and the research status.

The study was approved by the Ethics Committee of Zahedan University of Medical Sciences under the code IR.zaums.rec.1394.319 Ethical considerations were observed by obtaining both written and oral informed consents from the participants and explaining the purpose of the study to them. The participants were also assured that their information would remain anonymous and confidential, and that they have the right to withdraw from the research at any stage without having to bring any excuses.

Results

The participants in this study consisted of 8 mothers with the experience of caring for a jaundiced child, and had a

mean age of 32. They had bachelor's degrees and a year of care experience, and their infants had no special diseases, were diagnosed with jaundice, and were hospitalized in the neonatal ward of the hospital affiliated to Zahedan University of Medical Sciences. According to data analysis, the following 3 main themes and 4 sub-themes emerged: the themes maternal awareness, a necessity in the treatment process, the traditional medicine, a paradox in healthcare and the challenges of treatment outcome in the main ones, and the sub-themes recovery in the light of correct diagnosis, care sensitivity, understanding the disease and family distress and concern, each of which will be discussed in detail.

Maternal Awareness: the Missing Link in the Treatment Process

This theme, stated by all mothers, expresses the lack of awareness of the prevention, treatment, and potential complications of jaundice, which subsequently leads to anxiety in mothers. Therefore, awareness, or the lack of it, can be considered a major factor. The participants were eager to receive training in this regard.

"I always worry that it does not get well, because I have read somewhere that jaundice can affect the baby's mind because. For example, I didn't know what percentage or number determined by doctors is critical or dangerous, or what is the standard range."

Another participant asked for jaundice training before pregnancy and said, *"You know, it was my first pregnancy and I did not have enough information. They told me that jaundice may affect your blood. I didn't have enough information, so gynecologists should emphasize a dietary program if I don't want my baby to get jaundice."*

Moreover, most mothers reported a lack of knowledge on the therapeutic interventions, complications, and the outcomes of treatment. Fear and worries of harm to the infant were evident in some of them, *"What would happen if the jaundice is severe? I just think that it will highly damage the liver. I've got no more information. What if*

it's mild? Will it be treated by this light therapy and stuff like that? I don't know any of these."

Traditional Medicine: A Paradox in Treatment

One of the major themes in mothers' experience was the acceptance or rejection of traditional treatments in providing care for their children. Some of them, based on the traditional understanding of the disease and their relatives' suggestions and belief in traditional treatments, chose these approaches to treatment and follow-ups. On the contrary, the experience of some participants indicated a lack of confidence in traditional treatments.

"I knew that cotoneaster I fed him/her on was good. For example, eating hollyhocks was good. I have experienced its positive effect. I asked my doctor and he/she said it's cold in nature which is ok."

What developed this paradox were mothers' doubting the effectiveness of traditional treatments. One mother said: *"They told us to use herbal medicines. For example, they said pussy willow distilled water is good to drink. Then some others said that it's good to give them two drops of pomegranate juice. Now, I'm not sure how true they are."*

In some cases, the mothers' lack of confidence in traditional therapies had made them not follow the relatives' recommendations. Although the participants remained skeptical of the effectiveness of these therapies, their distrust prevented them from applying traditional therapies. One of the mothers said, *"Well, not much can be really done for jaundice. Of course, if we had taken grandmas' advice, we could have fed him/her on cotoneaster and stuff like this. I myself didn't believe it at all, but many would tell me to feed him/her on cotoneaster. They told me not to eat hot foods, fat, and things like that, but I really did not believe in such things. They might be true, but I didn't really believe in it."*

The Challenges of Treatment Outcome

One of the issues referred to by the participants is the challenges of treatment outcome. This theme consists of the three sub-classes recovery in the light of correct

diagnosis, understanding of the disease and family distress and concern.

Recovery in the Light of Correct Diagnosis

Research participants pointed to the sensitivity of care, the importance of laboratory tests, and even the lack of timely diagnosis. One of the participants stated, "...we took him/her to the ultrasound room, only for our peace of mine. The doctor also said his/her jaundice is mild. I asked if an examination is necessary. But the doctor told me that examination is not necessary in mild cases, why do you want him/her to have a redundant blood test? But then again, can't they give the baby a blood test when they judge from his/her appearance?"

Another participant told us, "They say that these devices they just brought here are not accurate enough. So we had him/her undergo an examination."

Understanding the Disease

Research participants emphasized that one of the challenges of treatment outcome depends on their understanding of their infant's jaundice. From their point of view, the disease is of little importance according to common people, while they considered it dangerous and worried about the outcome of the treatment and the infant's future. They expressed their experiences in pursuing the treatment of the disease.

"We took it as natural due to others' experiences and the fact that they say the majority of newborn boys have jaundice. We considered his jaundice as ordinary due to the fact that every infant has it. However, we had to do something."

While expressing their experiences, participants referred to their fear of the disease's recurrence, as a result of not understanding the sensitivity of it:

"If his/her jaundice is severe, it may recur after discharge which can be dangerous for the child."

Another finding of the study, which was a result of mothers' misunderstanding the disease, was the fear of treatment complications, regarding which a participant said, "They said that the light which reduces jaundice is

carcinogenic, if its rays enter the eyes. I was always at his/her side. They said it is also harmful to the mother."

Family Distress and Concern

Another finding of the study, which was repeated by all participants, was the distress and concern of families, which is considered as one of the challenges of treatment outcome.

"Well, it was really difficult for us. However, my worries subsided because the doctor had assured us that nothing bad would happen and that he/she would feel well within 24 hours after we give him/her the second drop. But all in all, it was so difficult because I was afraid of possible blood problems."

In this regard, another participant said, "We were worried about the incidence of brain problems in case the jaundice intensifies again. On the other hand, I spent all my time crying, and was always afraid and worried."

Discussion

In this study, maternal awareness, a missing link in the treatment process, the traditional medicine, a paradox in healthcare and the challenges of treatment outcome were the major themes, referred to by all the participants. Moreover, recovery in the light of correct diagnosis, care sensitivity, understanding the disease and family distress and concern were the classes extracted by the research data which were in line with the experiences of mothers with jaundiced children.

Consistent with the findings of this study, it is shown that mothers' knowledge on jaundice and their attitude towards it will play an important role in the outcome of the disease. Their lack of awareness of jaundice and the related care was one of the reasons for mothers' concerns in this regard. On the other hand, they demanded information on pre-pregnancy trainings and jaundice-related issues. In similar cases, the reports on the prevalence of jaundice among infants, the need for trainings and awareness in this area is emphasized (12, 17).

The participants acknowledged that they have considered traditional treatments for jaundice for long. On the one

hand, they have always heard contradictory talks about using or not using this approach in the treatment of jaundice. Despite various beliefs and information, this issue is one of the challenges addressed by the results of other studies. Some mothers regarded foods with hot nature as the cause of their infant's jaundice, while others blamed cold nature foods as the reason for the early treatment of jaundice (18, 19).

Past beliefs and attitudes appear to have a major impact on the behavior of mothers with jaundiced children. Some mothers believe that they turn to these treatments and are concerned about the unscientific use of these approaches under the influence of these traditional attitudes and even due to the lack of access to true information. Consistent with these findings, the results of some studies indicate that traditional remedies alone cannot treat neonatal jaundice, but may be effective if used alongside other methods of jaundice treatment (17, 18). Therefore, it can be concluded that culturalization in regard with the traditional approaches of jaundice treatment is an effective intervention in this field.

The experience of the participating mothers showed that there are challenges in the process of jaundice treatment, including recovery in the light of correct diagnosis, understanding the disease and family distress and concern. Similar studies have reported that after facing the disease, mothers have been doubtful about the correct diagnosis of the disease and the accuracy of treatment (20, 21). In this regard, it seems that one of mothers' needs at the time of their child's hospitalization is receiving support and assurance of proper child care. The need for information, answering mothers' questions, and support and guidance are referred to in many studies (22). Since the hospitalization of the child is one of the sources of fear and concern in the family, it seems that the awareness and understanding of the disease, making the right decisions, and supporting parents, and subsequently, the knowledgeable and professional participation of the family would facilitate health care. Parents usually expect to know the

treatment process thoroughly and even provide written information. It is recommended to use different educational strategies as well as new technologies and cyberspace.

Conclusion

The findings of this study showed that mothers need to improve their information on jaundice and change their attitude towards it and its treatment. Another notable issue is the public acceptance of utilizing traditional therapies for jaundice. Therefore, raising public awareness of how to use traditional remedies along with the conventional treatments of jaundice is of great importance.

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