

The impact of the maternal experience with a jaundiced newborn on the breastfeeding relationship

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Key Points for Clinicians

1. Interactions with medical professionals emerged as the most important factor mediating the impact of the maternal experience with neonatal jaundice on breastfeeding.
2. Encouragement or lack of encouragement to breastfeed plays a large role in whether women continue to breastfeed after their experience with jaundice.
3. To minimize feelings of guilt and enhance maternal understanding about jaundice, health care professionals need to be aware not only of what information is given to mothers, but how mothers receive and interpret this information.
4. Medical professionals must provide consistent information and ensure that mothers understand how jaundice relates to breastfeeding and the purpose of any breastfeeding instructions given during the experience.

- **OBJECTIVE:** To examine the process by which mothers' experiences with neonatal jaundice affects breastfeeding.
- **STUDY DESIGN:** We used ethnographic interviews with grounded theory methodology. Audiotaped data were transcribed and analyzed for themes using ATLAS/ti qualitative data analysis software (Scientific Software Development, Berlin, Germany).
- **POPULATION:** We studied a total of 47 Spanish- and English-speaking breastfeeding mothers of otherwise healthy infants diagnosed with neonatal jaundice.
- **OUTCOME MEASURED:** Our outcomes were the qualitative descriptions of maternal experiences with neonatal jaundice.
- **RESULTS:** Interactions with medical professionals emerged as the most important factor mediating the impact of neonatal jaundice on breastfeeding. Breastfeeding orders and the level of encouragement from medical professionals toward breastfeeding had the strongest effect on feeding decisions. Maternal reaction to and understanding of information from their physicians also played an important role. Guilt was common, as many

mothers felt they had caused the jaundice by breastfeeding.

- **CONCLUSIONS:** By providing accurate information and encouragement to breastfeed, medical professionals have great impact on whether a mother continues breastfeeding after her experience with neonatal jaundice. Health care providers must be aware of how mothers receive and interpret information related to jaundice to minimize maternal reactions, such as guilt, that have a negative impact on breastfeeding.

key words Neonatal jaundice; breastfeeding; physician-patient communication. (J Fam Pract 2002; 51:465)

Neonatal jaundice is the most common condition for which newborns are tested, treated, and often rehospitalized, resulting in millions of dollars of annual expenditure.¹⁻³ Two types of jaundice are associated with breastfeeding⁴: early jaundice, or breastfeeding jaundice, caused by the infant receiving insufficient breast milk^{5,6}; and breast milk jaundice, which develops later in a thriving breastfed infant and is thought to be caused by a substance in the breast milk.^{7,8}

Diagnosis and treatment of jaundice can begin within the first few days after birth, while the breastfeeding relationship is being established. Despite the ongoing debate on the appropriate protocol for jaundice management⁹⁻¹¹ and a wide variance in physician practice,^{12,13} little research has examined the effect of the jaundice experience on the newborn's mother. The few studies to directly examine the influence of jaundice management on breastfeeding show that protocols such as maternal-infant separation for phototherapy or temporarily suspending breastfeeding are associated with a shorter duration of breastfeeding.¹⁴⁻¹⁶

What remains unclear is how jaundice management affects breastfeeding. Our study adds to existing knowledge by exploring the process by which the maternal experience with a jaundiced newborn affects the mother and her breastfeeding decisions. Qualitative methods, guided by grounded theory, were used because of the paucity of information on this topic and the study's focus on process.¹⁷⁻¹⁹

■ METHODS

Settings

Two distinct sites in Chicago were chosen to increase the heterogeneity of experiences: a community hospital serving a mixed-income and ethnically diverse population, and an urban teaching hospital serving primarily low-income Latino and African American patients. Breastfeeding initiation rates, tracked by the University of Illinois at Chicago breastfeeding task force, were 70% and 40%, respectively. Institutional Review Board approval was obtained from both sites.

Sample

Two purposeful sampling strategies were employed.²⁰ Criterion sampling was used to recruit mothers, identified through medical record abstraction of all jaundiced infants, who met the following criteria: Spanish or English speaking; exclusively or partially breastfeeding at postpartum discharge; and mother of an otherwise healthy term newborn who had a serum bilirubin level of ≥ 10 mg/dL within the first month of life and received care through a study site in 1 or more of the following settings: newborn nursery, outpatient clinic, hospital ward, or home. Maximum variation sampling, which seeks heterogeneity within the sample to permit examination of common themes, was applied to achieve variation in ethnicity, language, age, parity, and jaundice treatment. Eligible mothers were invited by phone to participate in an interview. Sampling continued until data from new interviews confirmed earlier data, signifying that theoretical saturation was achieved.¹⁸

Data collection

Using the literature on hyperbilirubinemia and breastfeeding, an interview guideline was developed addressing the topics in **Table 1**.²¹ Three female ethnographers (including authors S.K.W. and P.R.H.) conducted in-depth, semi-structured interviews in women's homes. The interviews were approximately 60 minutes in length given in either Spanish or English. Women were encouraged to lead the conversation, with ethnographers using prompts to guide the discussion toward any topics not addressed and probes to elicit detailed descriptions of the women's experiences. Audiotaped interviews were transcribed verbatim, and edited by the ethnographer to ensure accuracy and include field notes. Spanish-language interviews were translated into English. Participants received no financial incentives.

Analysis

Interviews were carefully read by all investigators for themes, and codes were developed to represent these themes.^{18,22,23} A code book defining each code and listing inclusion and exclusion criteria was developed, and one investigator (S.K.W.) applied codes to the interviews using ATLAS/ti qualitative data analysis software (Scientific Software Development, Berlin, Germany). Intracoder and intercoder (with P.R.H.) agreement were determined to assure consistency of code definitions. Codes with a low level of agreement were redefined and reapplied. Coded text was retrieved and emerging themes analyzed in relation to other themes and variables. Focus was placed on comparing and contrasting women's experiences to elicit what in the maternal experience with neonatal jaundice influenced infant feeding decisions. We also focused on women's understanding of the information they received and the relationship between jaundice and breastfeeding.

■ RESULTS

Of 69 eligible mothers, 11 declined to participate, and 13 could not be reached or scheduled for an interview. Forty-five mothers were interviewed between October 1997 and April 1998 at 2.5 to 14.5 weeks postpartum (mean = 6 weeks). Investigators attempted to hold 2 focus groups with unsuccessful show rates. Individual interviews were conducted with the 2 women who attended these sessions and analyzed with the other interviews. The 24 nonparticipants had similar demographic characteristics to women in the study.

Participants represented a range of sociodemographic and jaundice management characteristics **Table 2**. Mothers were predominately Latinas of Mexican descent, with a mean age of 27 years (range = 16-38 years). Women born outside the United States had lived in the US from 1 to 25 years (mean = 7 years). More than three quarters of the women lived with the father of the baby. Peak bilirubin levels of all infants ranged from 10.3 to 23.5 mg/dL; 4 infants had peak levels of >20 mg/dL and 7 had peak levels of <12 mg/dL. Thirty-nine infants experienced jaundice within the first 6 days of life, with the majority having nonhemolytic jaundice. Eight infants had breast milk jaundice with peak bilirubin levels occurring between 1 and 2 weeks of age. More than half of the multiparous women had experienced jaundice with a previous infant (n = 14) and three fourths had breastfed a previous child (n = 19).

Though each woman's experience was unique, a pattern emerged from the women's discussions that described a process by which their experiences affected the breastfeeding relationship. This process centered on mothers' interactions with medical professionals during jaundice management and their internalization of the experience.

Jaundice management

Half the women described how their experiences with neonatal jaundice had directly influenced their breastfeeding decisions, positively or negatively, primarily discussing this impact in terms of the breastfeeding instructions they received. **Table 3** illustrates the clear pattern seen between a maternal report of breastfeeding orders received from medical professionals and a woman's feeding status at 2 weeks postpartum, directly after the jaundice experience. Breastfeeding orders were categorized as: continue, conflicting, supplement, suspend, and none. Regardless of parity, women's interactions with medical professionals related to breastfeeding orders and the level of encouragement they received had the strongest influence on whether women continued to breastfeed.

Mothers exclusively breastfeeding after their experience discussed the encouragement they received from medical staff. Mothers told to continue to breastfeed felt encouraged to breastfeed frequently to help the jaundice go away. All continued to breastfeed for at least 3 weeks, none quit because of their infant's jaundice. Mothers who returned to exclusive breastfeeding after being told to temporarily suspend breastfeeding or to supplement with formula described being encouraged not to quit breastfeeding and were reassured that their milk was good.

"Right away I wanted to stop breastfeeding, especially if it is me causing him to get that. And they were like, 'No, no. We're not telling you to stop. It's good that you are breastfeeding him.'"

Women exclusively formula feeding because of their experience with jaundice shared 2 separate reasons for not resuming. The first related to not wanting to "take anymore chances" with their infant receiving insufficient milk.

"At the time she was in the hospital they told me to stop breastfeeding her. They wanted to formula feed her. They just said that they think she wasn't getting enough. They said since they can't measure how much she drinks that they don't know how much she is drinking. So I decided, well, I'll just continue formula feeding her."

The second related to physical difficulty in reestablishing lactation.

"I breastfed my other three children. ... That's why I tried more to see if he'd latch on, but he didn't. ... Since the beginning, I had the idea that I was only going to breastfeed him, but no."

Women who continued to supplement with formula because of their experience expressed fear that jaundice would return if they quit supplementation.

"I am still on formula now [7 weeks after experience]. The doctor said he wanted to wait until it is 3 weeks after he is released to wean down. ... I think it caused some damage for me because I am still frightened to really let go of the formula. I may be wrong and maybe it can't come back at this stage, but I think that something could go wrong and I am still giving formula to make sure that he is getting enough."

Although mothers whose infants did not receive phototherapy were more likely to be told to continue breastfeeding or to be given no feeding orders than mothers whose infants received phototherapy, there was not a clear pattern between feeding method at 2 weeks postpartum and form of jaundice treatment. Although a few mothers expressed concern about breastfeeding during phototherapy because of having to remove their infant from the light, no mother quit breastfeeding or began supplementing specifically because of treatment. However, many mothers discussed the strong emotional impact that blood work, phototherapy, and the mother-child separation had on them.²⁴

The majority of mothers had prior exposure to neonatal jaundice, approximately one third through personal experience with previous children. Although a few mothers had previous experience with jaundiced infants undergoing phototherapy, only one had been told to stop breastfeeding a previous infant because of jaundice. Even though this mother was not told to stop breastfeeding her current infant, she supplemented with formula because she felt her milk was "no good."

Maternal internalization of experience

Mothers who received breastfeeding orders to suspend or supplement, or who were given conflicting orders, repeatedly expressed confusion or discontent with these instructions. They commented on the conflict between the medical professional's advice and their own understanding that breastfeeding was healthier for babies, and on not receiving sufficient explanation to justify changing their feeding method.

"She [doctor] just told me to stop breastfeeding because.... Actually she didn't tell me why. Which got me confused. I remember I was thinking why did she tell me to stop breastfeeding if breast milk is better for the baby?"

Mothers also shared concerns about nipple confusion affecting their ability to exclusively breastfeed, and feeling that decisions were out of their control.

Lack of understanding about causes of jaundice and feelings of guilt over their role in the etiology were common among

all women. More than one third of women expressed guilt that they had caused jaundice either during pregnancy or while breastfeeding.

"I was afraid I did something wrong... that my milk wasn't coming in right... that I wasn't feeding her enough or I wasn't feeding her the right things. Or that my milk was broken ... that I wasn't making enough or it was wrong somehow. Like it wasn't meeting her needs."

Several mothers also expressed belief that their infant may not have gotten jaundice if they had not started breastfeeding.

"I wonder if she would've started with the formula, if we would've started to supplement with formula from the very beginning, I wonder if it would've happened."

More than half the women discussed breastfeeding as a cause of jaundice. Those women had experienced early neonatal jaundice. More than one third had a previously jaundiced infant and approximately half had previously breastfed. Those who received breastfeeding orders to suspend or supplement, or who were given conflicting orders, were much more likely to discuss breastfeeding as a cause of jaundice than were those who received no breastfeeding orders. Mothers told to continue breastfeeding were least likely to discuss breastfeeding as a cause. No pattern was evident among women by language spoken, parity, bilirubin level, jaundice treatment, or feeding at the interview.

Women's perceptions of what it is about breastfeeding that causes jaundice related to either quantity or quality.

The causes related to the quantity of breast milk included:

- Insufficient feeding. The infant is not receiving enough breast milk because he or she is not eating enough or the mother is not feeding infant enough.

"I remember that a nurse in the hospital told me it was because of lack of feeding. That I wasn't feeding the baby well."

- Insufficient milk. The mother is not producing enough breast milk.

"I was trying to figure out what was it that I wasn't doing. Was I not feeding him correctly? Was my body not producing enough?"

The causes related to the quality of breast milk included:

- Milk composition. The breast milk caused jaundice, often because it was not good.

"When I saw him look bad, I thought could my milk be causing harm to my baby? Or since I never breastfed before, I began to think is my milk not good? Is it bad? Because I don't think that all women's milk can be good. There can be some that have less vitamins, others have more than enough vitamins, or the milk didn't come out like you hoped for. Maybe the milk is no good. So I thought about all of that. Since I saw him like that, I thought is it the milk that is making him yellow? Since the milk looked yellow, is it making him yellow?"

- Something in milk. There is something passed through the milk to cause jaundice, such as medicine, hormones, or emotions.

"I thought I was getting mad a lot. I was tense, and I wasn't sleeping because I was in the hospital with the baby. I thought that was affecting my milk that I was giving to the baby and that was making him worse."

Women who gave explanations for jaundice closer to a biomedical understanding of jaundice, such as insufficient fluid intake, received this information primarily from medical professionals and occasionally from family and friends. Many issues related to feelings of guilt came from their own thoughts, though they were, at times, triggered by something said by a medical professional or family member. Mothers interpreted the information, or lack of information, they received in

their attempt to explain why their infant had jaundice.

“The nurse said, the baby won’t be having your breast. All the time the baby will be in the hospital he will only be given formula. Since they never explained why he was that color or anything, I thought maybe my milk was no good. That’s why they told me not to give it to him.”

■ DISCUSSION

Interactions with medical professionals emerged as the most important factor mediating the impact of the maternal experience with neonatal jaundice on breastfeeding. Encouragement or lack of encouragement from health care professionals played a large role in whether women continued to breastfeed after their experience, which agrees with other findings on the influence, both positive and negative, of interactions with medical professionals on breastfeeding.²⁵⁻²⁸ Maternal understanding of and reaction to information received during jaundice management and their subsequent internalization of their experience also played a key role in mothers’ infant feeding decisions. In contrast with previous studies,^{14,29} no consistent pattern was seen between breastfeeding continuation and whether infants received blood work only or phototherapy. This difference may be due to our study’s inclusion of multiple settings for phototherapy and differences in the study populations. In addition, earlier studies did not include information on medical professional’s breastfeeding orders.

Limitations

Although the use of qualitative methods allowed in-depth inquiry from the mother’s perspective, it necessitated a small sample limiting generalizability. Generalizability was further limited because the women in the sample were predominately Latina, though study findings were consistent across ethnicities. Data was only collected from the mothers’ point of view, which likely differed from medical professionals’ perceptions. Limiting the sample to mothers who initiated breastfeeding may have excluded mothers who decided not to breastfeed because of a previous jaundice experience. In addition, women whose infants did not develop jaundice because of adequate early breastfeeding support were not interviewed. Careful structuring of the interview guideline and use of experienced ethnographers minimized potential threats to validity through interviewer bias. Regular team meetings to discuss data collection and analysis increased reliability.

Additional research is needed to gain further understanding of mothers’ emotional responses when faced with neonatal conditions like jaundice. While maternal guilt has been acknowledged as a potential problem arising from treatment for neonatal jaundice,^{4,7,8} no research has focused on the impact of this guilt on breastfeeding. How do responses like guilt influence perceptions of themselves as breastfeeding mothers and their breastfeeding decisions? The possibility that neonatal jaundice and its management may deprive future children of the opportunity to breastfeed should be examined.

■ CONCLUSIONS

Neonatal jaundice affects many newborns and their families. Besides the monetary cost of treatment, our study results indicate that treatment for jaundice is not completely benign; there are health and emotional costs. Medical professionals must weigh the perceived benefits of treatment decisions and feeding orders against the potential costs to the emotional well being of mothers and newly established breastfeeding relationships. To minimize guilt and enhance maternal understanding about this common condition, professionals need to be aware not only of what information is given to mothers, but how mothers receive and interpret this information. Identifying neonatal jaundice with terms such as breastfeeding jaundice and breast milk jaundice may cause maternal concerns that jaundice is a result of their decision to breastfeed. Medical professionals must provide consistent information and ensure that mothers more fully understand the causes of jaundice and how it relates to breastfeeding, as well as breastfeeding instructions during the experience. The neonatal jaundice experience provides an opportunity for medical professionals to encourage breastfeeding mothers and provide specific guidance on how to maintain a successful breastfeeding relationship.

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