Persistence of Maternal Concerns Surrounding Neonatal Jaundice

An Exploratory Study

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Objectives: To explore whether mothers currently express concerns about neonatal jaundice and perceive it as a serious condition; if so, to identify factors influencing these perceptions; and to elicit maternal recommendations for improved health care interactions.

Design: Ethnographic interviews using grounded theory methods. Audiotaped data were transcribed and analyzed for themes using a qualitative data analysis software program.

Setting: University and community hospitals.

Participants: Forty-seven Spanish- and English-speaking breastfeeding mothers of otherwise healthy infants with a diagnosis of neonatal jaundice and treated in inpatient and/or outpatient settings.

Interventions: None.

Main Outcome Measure: Qualitative descriptions of maternal experiences with neonatal jaundice.

Results: Mothers continued to voice concerns about jaundice and perceive it as serious. They expressed misconceptions, wished to have jaundice explained further, and offered suggestions to improve communications with medical staff. Guilt was common, with mothers believing that they had caused the jaundice. Mothers voiced alarm about the yellow skin and discomfort about jaundice management and worried about perceived short- and long-term effects. Maternal perceptions were exacerbated by cultural differences, language barriers, and subtlety of language and its meaning. Key factors in creating perceptions of jaundice as serious included unexpectedness of and lack of knowledge about jaundice, quality of information received, levels of intervention, and prolonged duration of illness and yellow color. Interactions with health care professionals and other mothers with personal experience with jaundice were important mediators in the way mothers reacted to information.

Conclusion: Practitioners need to address these persisting misconceptions and concerns about neonatal jaundice with mothers.


JAUNDICE COMMONLY occurs in term newborns, with 15% to 30% of breastfeeding newborns having elevated bilirubin levels requiring medical intervention. Clinicians treat jaundiced breastfeeding neonates in a variety of ways, including observation only, blood tests, modification of infant diet, and/or phototherapy. Although jaundice typically has a benign course in otherwise healthy newborns, clinical experience and a previous study have revealed that mothers have an inadequate understanding of this condition and perceive it to be far more serious than it is. In 1989, Kemper et al demonstrated that at 1 month postpartum, mothers of healthy, formerly jaundiced infants expressed distress at jaundice management, perceived jaundice as a serious medical problem, demonstrated separation difficulties and higher use of health care resources, and prematurely discontinued breastfeeding.

The findings by Kemper et al are consistent with previously published literature demonstrating that stresses created by medical issues early in childhood create parental anxieties and insecurities about infant health that can have lasting effects on the mother-child relationship. Medical professionals must understand why parents react in this manner. To develop a substantive understanding about the current maternal experience with neonatal jaundice, we designed a qualitative study guided by grounded theory methods. The study’s purposes were to explore mothers’ current perceptions regarding neonatal jaundice; to identify factors influencing these
SUBJECTS AND METHODS

SETTING

The following 2 sites were chosen to increase the heterogeneity of mothers’ experiences: a community hospital serving an economically and ethnically diverse population, and an urban teaching hospital serving primarily low-income African American and Hispanic patients. Breastfeeding initiation rates were 70% and 40%, respectively. Local prevailing physician adherence to the American Academy of Pediatrics hyperbilirubinemia practice parameter was not available. We obtained approval of the institutional review boards.

SAMPLE

Qualitative studies seek to describe the range of experiences in the population and capture variability of responses. We used purposeful sampling by means of criterion and maximum variation strategies to identify Spanish- or English-speaking mothers of term infants who exclusively or partially breastfed their infants at postpartum discharge and who represented a range in age, parity, ethnicity, language, and treatment. Infants were otherwise healthy, term newborns who had a bilirubin level of at least 10 mg/dL (≥171 µmol/L) within the first 4 weeks of life and who received jaundice management through a study site in a newborn nursery, outpatient clinic, hospital ward, and/or home. Medical record abstraction for all jaundiced infants at study sites determined eligibility. Eligible mothers were recruited using a script describing the study. If mothers agreed to participate, an interview was scheduled for approximately 4 weeks after recognition of jaundice. Sampling continued until theoretical saturation, when no new relevant data were emerging. Final sample size was 47.

DATA COLLECTION

The ethnographic interview guideline was developed using literature on neonatal jaundice and breastfeeding and included experience with jaundice recognition and treatment; mothers’ understanding of and emotional response to jaundice; perceptions of jaundice seriousness and its current effects on their infants; infant feeding decisions; interactions with and information received from medical staff, family, and friends; recommendations to improve future jaundice experience; and demographic information.

Three trained female ethnographers (including P.R.H. and S.K.W.) conducted in-depth 60-minute semistructured interviews in Spanish or English, as appropriate. Mothers were encouraged to lead the conversation, with the ethnographer using prompts to guide the discussion toward any issues on the interview guideline not brought up by the mothers. This method standardized the information collected without limiting the information given by the mothers. Audiotaped interviews were transcribed verbatim into English by bilingual transcribers and edited by the ethnographer to ensure accuracy and include field notes.

ANALYSIS

Interviews were loaded into qualitative data analysis software (ATLAS.ti). With the use of an iterative process, codes with inclusion and exclusion criteria were developed representing themes generated in the interviews. Codes were applied to interview text by a single investigator (S.K.W.). Intracoder and intercoder agreement were determined by means of regular team meetings to ensure internal consistency of data analysis and consistency of code definition. Sampling of 15% of the interview coding showed 95% agreement between investigators.

Once coded, text was retrieved using the qualitative data analysis software. Themes were analyzed in relation to key variables by all investigators. The women’s experiences with neonatal jaundice were compared and contrasted to gain insights into the range of maternal concerns and factors influencing their perceptions about jaundice and their infants. Representative quotations for each theme were selected. In a previous portion of this study, we identified important factors that have an impact on the breastfeeding relationship, so those results are not included herein (P.R.H., S.K.W., and S.C.S., unpublished data, August 1998).

RESULTS

Sixty-nine women were eligible for the interviews. Eleven mothers declined participation, citing time constraints, and 13 could not be contacted or failed to attend the interview. Of the 24 mothers who did not participate, 14 were Latina and 12 of their infants had received phototherapy. Forty-five mothers were interviewed from October 1, 1997, through April 30, 1998. To validate interview findings, investigators attempted to convene 2 focus groups, with unsuccessful attendance rates. One mother attended each session. Both women, who had never been interviewed, were interviewed individually, and the results were included in the analysis of the other interviews. Interviews were conducted 2.5 to 14.5 weeks post partum (mean, 6 weeks).

Table 1 highlights participant characteristics. Of the 47 mothers, 72% were Latina of Mexican descent. Half of them were born outside the United States and had lived in the United States from 1 to 25 years (mean, 7 years). Mean age was 27 years, (range, 16-38 years). Among multiparous women, 19 had previous breastfeeding experience, and 14 had experienced jaundice with a previous neonate. Thirty-nine study infants experienced jaundice within the first 6 days of life, with most having nonhemolytic jaundice. Eight infants had breast milk jaundice, with elevated bilirubin levels occurring after 1 week of age. Peak bilirubin levels for all infants ranged from 10.3 to 23.5 mg/dL (176-402 µmol/L), with 4 having levels above 20 mg/dL (>342 µmol/L).
functioning or biomedical explanations, i.e., bilirubin levels were too high to explain neonatal jaundice. The most common responses agreed with studies indicating that jaundice is a normal physiological process in newborns. Each woman discussed up to 10 different causes of neonatal jaundice, their reactions to jaundice management, and their responses to the yellow skin. These are discussed below, along with the interplay of these themes and the mothers’ guilt, distress, and worries regarding the effects of jaundice management. Quotations to illustrate maternal concerns are presented in Table 2.

MATERNAL CONCERNS DURING JAUNDICE EXPERIENCE

Mothers repeatedly expressed concerns regarding their experience with neonatal jaundice. These concerns grouped into themes that included their perceptions of causes of jaundice, their reactions to jaundice management, and their responses to the yellow skin. These are discussed below, along with the interplay of these themes and the mothers’ guilt, distress, and worries regarding the effects of jaundice management. Quotations to illustrate maternal concerns are presented in Table 2.

Perceptions of Causes of Jaundice

Each woman discussed up to 10 different causes of neonatal jaundice. The most common responses agreed with biomedical explanations, i.e., bilirubin levels were too high or “not clearing out of the system”; blood cells were “not functioning” or were “reacting to mothers’ cells”; and a liver issue involved its “prematurity” or a “development problem.” Twenty-six mothers believed that breastfeeding led to jaundice. Nineteen of them had had a previous infant with jaundice. Their understandings of how breastfeeding caused jaundice related to the quantity or quality of their breast milk (P.R.H., S.K.W., and S.C.S, unpublished data, August 1998). The next most common category of responses was uncertainty about the cause of jaundice, with most stating that they had not been given an explanation. These mothers were exclusively Spanish-speaking, young, non–high school graduates whose infants had undergone blood testing only. Many of these mothers specifi-
cally asked interviewers for more information about the cause of jaundice.

A theme of maternal guilt arose in 18 interviews, regardless of intervention type or language spoken. These mothers believed that they had caused the jaundice, using phrases like “got it from me,” “did something wrong,” “not being a good mother,” or “doing my baby harm.” Five of them had had a previous infant with jaundice. Mothers who described their neonates as being “born with it” described what they did or did not do during pregnancy. Mothers who believed they had caused the jaundice after delivery discussed their diabetes, current illnesses and medications, or, most commonly, breastfeeding. Several Latina mothers shared their belief that maternal emotions transmitted to the infant during pregnancy or through breastfeeding can cause jaundice. The term bilis means anger in Spanish. This meaning and a lack of understanding about causes of jaundice accentuated their perceptions, as seen in the following example:

Bilirubin, they are like bilis when one gets mad. I felt that when I was pregnant and had so much stress, that’s what caused it. Also, I was scared in the hospital. I thought that was affecting my milk and making him worse.

When asked if she still felt that way, she responded: “Yes, because they haven’t told me very well what happened.”

Fewer mothers explained that jaundice was normal or part of giving birth, attributing it to labor, bruising during delivery, or an adjustment to the new environment. A few commented simply that “babies are born with jaundice.” Finally, 3 mothers assumed initially that hepatitis had caused neonatal jaundice.

Reactions to Jaundice Management

Mothers expressed strong emotional reactions toward jaundice treatment protocols and the resulting mother-infant separation. Most mothers indicated that the blood testing process was difficult to watch and painful for mother and child. They noted the frequency of blood drawing and lack of success with the first attempt. Mothers used “screamed” or “suffered” to describe reactions of their neonates, and “poked,” “bruised,” “tormented,” or “tortured” to describe the actions of medical staff.

As bilirubin levels increased and higher levels of intervention were needed, mothers’ concerns increased. Mothers reported that professionals frequently referred to bilirubin levels when assessing whether jaundice was improving. Many recounted being told that high levels cause brain damage. This emphasis on the height of bilirubin levels worried them, and they recalled avidly observing these numbers. Some mothers had been given specific levels at which brain damage may occur, but most had not and were left to their own thoughts about how close bilirubin levels were to causing harm to their infants.

Twenty-three newborns underwent phototherapy. Their mothers vividly recalled their infants crying during treatment and feeling unable to comfort them. In addition, mothers worried that infants would overheat or become blind, and that the lights would be ineffective in lowering bilirubin levels. They reported lack of sleep because of their perceived need to monitor closely the therapy and eye patch. Mothers whose infants received home phototherapy expressed mixed reactions; some preferred being at home and not separated from their neonates, whereas other mothers felt it put more pressure on them to watch their infants carefully.

Almost all mothers discussed their distress and guilt about separation from their infants during blood testing or phototherapy, and how this separation within the first few weeks lessened their ability to bond with, touch, or breastfeed their neonates. These feelings were most strongly expressed by mothers who were discharged from the maternity ward without their child and mothers whose neonates returned for hospitalization. Several mothers asserted themselves to minimize the impact of separation. One negotiated phototherapy at home rather than in the hospital, and another negotiated an extended maternity ward stay.

Responses to Yellow Skin

Mothers commented that the yellow skin at jaundice recognition was alarming and raised concerns about the color’s significance and its potential effects. Several said the yellow eyes caused them to worry about their infant’s vision. Sixty percent of mothers reported that their concerns about jaundice dissipated as their infants’ yellow color faded within 2 weeks. Mothers whose infants continued to have yellow skin, however, described how persistence of the color created further worries that bilirubin levels had increased and would require hospitalization, that jaundice would last a long time, and/or that their infants were at risk for future diseases. These concerns were accentuated because some of these mothers had heard that jaundice typically lasts only 10 days or had experienced jaundice differently with a previous child.

These mothers handled their concerns in several ways. They admitted to watching their infant’s skin color closely and frequently pressing down on their infant’s skin to look for the yellow color as they had seen physicians do. A number of mothers, regardless of whether the infant was still visibly yellow, reported asking their physicians for reassurance about the skin color through telephone calls or additional appointments.

Maternal Perceptions of Jaundice as Serious

Twenty-seven mothers in this study perceived neonatal jaundice to be a serious condition and described the following 5 important factors that had an impact on these perceptions: (1) unexpectedness of the yellow skin; (2) lack of knowledge and understanding about jaundice; (3) severity of the course and management; (4) concerns about the effects of jaundice on their neonate, especially brain damage; and (5) a prolonged duration of the yellow skin. Mothers stated that if treatment for jaundice had been completed before the nursery discharge, their perceptions of jaundice seriousness would have been lessened (Table 3).

Of the 20 mothers who never perceived jaundice as a serious condition, 10 explained that despite the yellow skin, their neonates breastfed well, appeared healthy, and re-
Maternal Perceptions of Their Infants at Interview Time

At the interview, 33 mothers described their infants as currently healthy, with no further worries about jaundice. They were reassured by the passage of time, their infants' normal skin color, and physicians' assurances that their infant was healthy. They then perceived neonatal jaundice to be a normal event.

Fourteen mothers expressed concerns that jaundice may return and/or that jaundice management may cause long-term effects on their infants. Eight of these mothers spoke only Spanish, with 3 of them having previously experienced jaundice. The 8 mothers described a language barrier that contributed to these perceptions and their lack of understanding about jaundice. The remaining 6 experienced frequent and prolonged interventions. One mother, whose infant had phototherapy in the nursery, home, and hospital ward stated:

I am concerned about aftereffects. Will it affect him in another way? Maybe it will stunt his growth. I asked my husband, do you think jaundice can come back? Even though he is cured and is 2 months. If he doesn't get enough fluids, can it return?

Several women questioned why blood monitoring had been stopped despite persistence of the yellow skin. They recalled their discomfort at follow-up visits when physicians assessed jaundice by "just looking" at the infant. One mother stated:

My doctor reassured me that’s fine. What would’ve really reassured me is if they would’ve taken a final blood test. I didn’t want him to go through it because it’s painful. . . Do you want pain or is he okay?"

Table 3. Contributing Factors to Maternal Perceptions of Jaundice as a Serious Condition

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<tr>
<th>Unexpectedness of yellow skin and lack of understanding and knowledge about jaundice</th>
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<td>So since my baby went home with me, they gave him to me, I thought all was well. Then on the second or third day I started to notice he was kind of yellowish. I thought, perhaps, does he have something in his blood, or was he born with hepatitis? When they [home health nurse] called, I began to think about that again. Why would the nurse visit me at home? I’ve never had one visit to see my other children. I was scared. I told her to come right away. I prefer that they tell you right there [in the nursery] that the baby is normal: “He has this and it’s not serious. It’ll go away.” If the doctor tells you before you notice it, because if you bring the baby home and he begins to turn yellow, you get scared; then you think it’s something serious.</td>
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<td>Maternal concerns about effects of jaundice and prolonged duration of jaundice and yellow skin</td>
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<td>Well, with my [older] son I didn’t think it was anything serious because it went away rapidly. But with him [new baby], it was different. Since it was more days, I was worried many days. I thought at times that something would happen to him. That’s why I was always watching him. She [healthcare professional] told me that people die because of this and that this can damage the brain also. When I saw that it did not go away, did not go away, I was afraid. [She went on to describe her reactions to a follow-up visit at 2 weeks of age, where the pediatrician told her the baby was fine and didn’t require any further tests for jaundice. In response to the question “Did you feel that he was fine?”] No. Because I still saw him yellow.</td>
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Short newborn nursery course

You know insurance companies push you out the door so quickly that chances are this wouldn’t even be an issue if it was normal to stay in the hospital for 3 days or 4 days after the birth. You wouldn’t even know if there was something to worry about. They could just take care of it. The most uncomfortable part of it is when you are ready to go home and then either saying you can’t go home or you have to come back. That makes you feel sicker. Like something is really wrong and serious.

INFORMATION AS A KEY FACTOR IN MATERNAL CONCERNS AND PERCEPTIONS

All mothers discussed how they sought information about jaundice from professionals, family, and friends, with medical staff being the most respected source. Most mothers noted that medical professionals had told them that “jaundice was normal and don’t worry.” Some viewed reassurance of normalcy as helpful, but many still worried as their infants underwent further treatment. One mother, whose neonate underwent only blood testing, described: “Of course I will worry! It’s serious when it’s your baby. But they [the physicians] must have been worried because they asked me to come back.”

Women usually expressed preferences for being informed about neonatal jaundice prenatally, although others wanted information at nursery discharge or only during their experience. Recommendations for the best format included verbal one-on-one interactions, small-group discussions, written pamphlets, and/or videotapes. Mothers recommended that more detailed information be provided about causes of jaundice, especially addressing maternal responsibilities; management procedures; potential effects of jaundice and its treatment; duration of the yellow skin; and what mothers can do for their infants preventively and during the illness. Another val-
Previously published literature has demonstrated that parental experiences with medical conditions in the neonatal period cause parental distress and insecurity about infant health and can have lasting effects on the mother-child relationship. It is important for health care professionals to understand why parents react in this manner and to identify the current range and extent of mothers’ beliefs and reactions regarding a common pediatric condition, neonatal jaundice.

This qualitative study highlights that neonatal jaundice continues to concern mothers, leading to distress, guilt, and perceptions that jaundice is a serious condition. This study identified the following key factors behind maternal perceptions of seriousness: unexpectedness of jaundice; a lack of understanding and knowledge about jaundice, often due to cultural differences and language barriers between medical staff and mothers; levels of intervention; and the prolonged duration of jaundice and yellow skin. Medical professionals must be aware of the message of seriousness they send to mothers as they order blood testing and initiate treatment for neonatal jaundice, and weigh the risk for causing maternal distress when determining what treatment course to follow.

IMPLICATIONS FOR HEALTH CARE PROFESSIONALS

This study indicates that neonatal jaundice continues to concern mothers, leading to distress, guilt, and perceptions that jaundice is a serious condition. This study identified the following key factors behind maternal perceptions of seriousness: unexpectedness and a perceived lack of understanding about jaundice, quality of information received, levels of intervention, and the prolonged duration of jaundice and yellow skin. Medical professionals must be aware of the message of seriousness they send to mothers as they order blood testing and initiate treatment, and they should weigh the risk for causing maternal distress when determining what course of treatment to follow. These mothers seemed to take to heart statements from physicians and worried if the medical course deviated even slightly from what physicians predicted.

The data elicited through qualitative techniques offer valuable insights into the range of mothers’ perceptions about their jaundice experience that should encourage health care providers to modify and redirect their approach during diagnosis and treatment of this condition. In particular, the data suggest that care must be directed to the mother as well as to the neonate. Parental fears about children’s health are frequently not obvious to medical staff and lead to parental misperceptions.11 In addition, mothers’ reactions to illness are frequently quite different from those of physicians in quality and intensity.15 In our study, many mothers articulated that physicians’ views of jaundice as normal differed from their own views and did not seem consistent with physicians’ actions. Half of the Latina mothers came from countries where neonatal mortality is higher than in the United States.31,32 Illness in early childhood generates insecurities about infant health behavior and unwarranted, persistent fears of recurrence.8,9,11-17,33-35 Consistent with these findings, we found 14 mothers several months postpartum who still perceived that their infants would experience adverse effects and potentially a recurrence of jaundice.

Maternal reactions may be lessened by explaining more fully to mothers the diagnosis, prognosis, duration, and management options for jaundice and by addressing their infants’ future susceptibility to illness. Our data suggest that mothers need information at repeated intervals, especially to uncover and address misperceptions about jaundice. Each mother brings a different level of knowledge, spoken language, and vulnerability to the emotional stresses of infant health conditions. Given the frequent expressions of guilt, mothers need to be re assured that they did not cause the disease. Kennell and Rolnick33 found maternal guilt to be a normal reaction during a neonatal illness that often was hidden behind the question “What caused my baby’s condition?” In our study, all mothers expressed desire for additional information about jaundice and its cause.

Physicians need to be aware that maternal perceptions of jaundice may be exacerbated by cultural differences, language barriers, and the subtlety of language and its meaning. In this sample of predominately Latina mothers,browser associated with anger was blamed by some for jaundice. This finding is consistent with other research among Latina women showing that strong maternal emotions are seen as detrimental in pregnancy and during breastfeeding.31,32,36 Cultural beliefs can lead mothers to interpret illness within their cultural framework, especially when left without a clear and understood explanation.37,38

STUDY LIMITATIONS AND FUTURE RESEARCH QUESTIONS

This study has valuable strengths but certain limitations. Experienced qualitative interviewers, careful struc-
turing of interview checklists, and weekly analysis meetings among investigators minimized the potential for interviewer bias and misinterpretation of data. Qualitative methods provided rich information about maternal perceptions of their experiences with neonatal jaundice. The modest sample size, however, and our main Latina sample limit the ability to fully generalize findings to other ethnic groups. Nevertheless, the data generate important issues for future research.

First, mothers in our study experienced distress regarding the effects of jaundice and its management on their infants. What are the implications of these concerns on the long-term mother-child relationship and on reactions to future infant illnesses? Second, interactions with medical professionals and mothers with personal experiences with neonatal jaundice were important mediators in mothers’ perceptions of their experiences with neonatal jaundice. The modest sample size, however, and our mainly Latina sample limit the ability to fully generalize findings to other ethnic groups. Nevertheless, the data generate important issues for future research.

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We would like to thank the 47 women who participated in the study for their time and for teaching us about the impact of neonatal jaundice on mothers. In addition, we thank Isabel Martinez, MPH, for her assistance in scheduling and conducting interviews, Peter Donoghue for his editorial assistance, and Modena Wilson, MD, MPH, for her careful review and comments on the manuscript.

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RECOMMENDATIONS


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