



Ontario Midwifery Clients' Experiences with the Management of Hyperbilirubinemia

Expériences des clients des sages-femmes ontariennes relativement à la prise en charge de l'hyperbilirubinémie

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ABSTRACT

Hyperbilirubinemia is the most common reason for the hospitalization of a newborn within the first week of life. Very little is known, however, about the impact this diagnosis and subsequent management has on parents, particularly within the midwifery context. The Clinical Knowledge Translation department at the Association of Ontario Midwives conducted a multimethod qualitative research study in 2017 to better understand the experiences of midwifery clients whose newborns have been diagnosed with and required management of severe hyperbilirubinemia. Three focus-group discussions and one in-depth, in-person interview were conducted with midwifery clients in Ontario. Findings were analyzed using NVivo software, resulting in the extraction of key themes. Clients discussed how the transition from midwifery-led care to care being led by other health care providers in the hospital impacted them in the postpartum period. Clients also observed changes in the continuity of care provided by their midwives during management of hyperbilirubinemia, and discussed both the positive and negative impacts these changes had on their broader experience of the early postpartum period. These findings have informed the development of a series of knowledge translation tools that support midwives in providing optimal care to clients whose infants require phototherapy.

KEYWORDS

hyperbilirubinemia, midwifery, phototherapy, postnatal care, jaundice, neonatal, postpartum period

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RÉSUMÉ

L'hyperbilirubinémie constitue la raison la plus courante de l'hospitalisation d'un nouveau-né durant sa première semaine de vie. On connaît toutefois très peu l'incidence de ce diagnostic et de la prise en charge subséquente sur les parents, en particulier dans le contexte de la pratique sage-femme. Le département du transfert des connaissances cliniques de l'Association des sages-femmes de l'Ontario a réalisé une étude de recherche qualitative multiméthodes en 2017 afin de mieux comprendre les expériences de la clientèle des sages-femmes dont les nouveau-nés avaient reçu un diagnostic d'hyperbilirubinémie grave et ont eu besoin d'une prise en charge connexe. Trois discussions de groupe et des entrevues approfondies en personne ont été organisées avec des clients de sages-femmes en Ontario. Les constatations ont été analysées avec le logiciel NVivo, ce qui a donné lieu à l'extraction des principaux thèmes. Les clients ont raconté l'incidence sur eux de la transition des soins dirigés par une sage-femme à ceux dirigés par d'autres professionnels de la santé durant la période postpartum. En outre, ils ont observé des changements dans la continuité des soins prodigués par leur sage-femme durant la prise en charge de l'hyperbilirubinémie et parlé des conséquences tant positives que négatives de ces modifications sur leur expérience plus globale au début de la période postpartum. Ces constatations ont contribué à l'élaboration d'une série d'outils de transfert des connaissances qui aident les sages-femmes à fournir des soins optimaux à leurs clients dont le nouveau-né a besoin d'une photothérapie.

MOTS-CLÉS

hyperbilirubinémie, pratique sage-femme, photothérapie, soins postnatals, jaunisse, néonatal, période postpartum

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BACKGROUND

Hyperbilirubinemia is the excess breakdown of hemoglobin in red blood cells, resulting in increased levels of bilirubin in the body.¹ When bilirubin accumulates in the skin and mucous membranes, it can manifest as physiologic jaundice.² While 50%–70% of newborns in the first week of life will develop physiological jaundice (most of which will not require treatment), some newborns are at risk of developing a severe form of hyperbilirubinemia, usually defined as total serum bilirubin > 340 µmol/L anytime in the first 28 days of life.^{3–5} The short lifespan of a newborn's erythrocytes and their limited capacity to efficiently process and expel bilirubin are among the factors that contribute to a newborn's increased risk of developing severe hyperbilirubinemia.^{2,3} Increased levels of serum bilirubin can be toxic to the central nervous system and can result in neurologic and behavioural impairment.^{2,4} Newborns with severe hyperbilirubinemia require management, most commonly in the form of phototherapy, to help reduce levels of serum bilirubin.^{1,2,6,7} In Canada, severe hyperbilirubinemia is the most common reason for the hospitalization of a newborn.^{6,8}

There is a significant gap in the literature regarding the experiences of parents whose babies require management of severe hyperbilirubinemia; no information was found regarding midwifery clients' experiences of their infants' phototherapy treatment in Canada. The limited qualitative, peer-reviewed literature on the experiences of parents whose infants require phototherapy for severe hyperbilirubinemia does, however, highlight a few key themes.

The management of severe hyperbilirubinemia through phototherapy can be a discomfoting experience for parents, as it can take a physical and emotional toll in the early postpartum period.^{7,9–11}

Although phototherapy is non-invasive and poses little to no harm to infants, the separation of parents from their infants, due to the time required under the lights, can result in parents feeling distressed over the process.¹¹ The literature also indicates that parents benefit greatly from infant feeding support during the course of phototherapy; the positive impact of this support continues long after phototherapy has ended.^{12,13}

A qualitative, multimethod study was developed to better understand the experiences of midwifery clients whose newborns require management for severe hyperbilirubinemia and to provide midwives with a better understanding of how to best support these clients' families during this period. Client focus-group discussions and one in-depth interview were part of a larger primary research study to inform the development of a midwifery-specific clinical practice guideline on the management of hyperbilirubinemia.

METHODS

Sampling and Recruitment

Participants for this study were initially recruited through online invitations sent out through social media accounts associated with the Association of Ontario Midwives. Past or present midwifery clients who had a baby that required phototherapy were invited to participate in a survey to determine eligibility. Due to geographic and scheduling constraints, an in-person focus-group discussion [FGD] with only two participants was held in July 2017, in Toronto. An online FGD with four participants was also planned for July 2017. However, only one participant attended; the discussion turned into an individual interview in order to allow the participant to share her experience.

A second round of recruitment resulted in one four-person FGD in Toronto and one three-person FGD in Ottawa. The Community Research Ethics Board reviewed and approved this study's protocol. All identifying information has been redacted.

Data Collection and Analysis

Researchers used discussion guides to facilitate the group discussions and the interviews, which consisted of open-ended questions to allow participants to reflect on their experiences. Researchers recorded the FGDs and transcribed them verbatim, with the consent of study participants. Throughout the FGDs, researchers also took notes; these and transcripts were used to analyze study findings.

A series of a priori (predetermined) codes were developed to guide the analytic process. Throughout analysis, researchers developed a subsequent series

The hospitalization of a newborn for the management of severe hyperbilirubinemia can be physically, emotionally, and psychologically discomforting for parents.

of codes to capture concepts as they emerged. Second- and third-level analyses were conducted to identify key patterns and later themes to allow meaning to be extracted from study findings.

RESULTS

Ten midwifery clients participated in this study. Seven participants gave birth in hospital, two in birth centres, and one at home. Eight were first-time parents. All participants' babies received phototherapy treatment in hospital; one client's baby required further intravenous immunoglobulin G therapy. The key themes of this study were clients' experiences when their care transitioned to hospital care and the ways in which their midwifery care changed during the management of their newborns' hyperbilirubinemia.

Transition of Care

Many participants discussed how the transition from being cared for predominately by midwives to being cared for primarily by hospital health care providers affected them. Participants discussed the transition's positive and negative impacts on their infant-feeding practices, postpartum care, skin-to-skin contact, and ability to make informed choices.

Infant Feeding

Many clients discussed the effect of this transition on their experiences of—and decision making around—infant feeding. Some clients said that the advice and practical support they received from hospital health care providers were consistent with what they envisioned they would have received from midwives:

"Every 2 hours [the nurse] would just show up with all this pump stuff and coach me... to help me learn how to pump and make sure that my breast milk came in."

Other clients, however, reported feeling unsupported or dissuaded from nursing during their infant's phototherapy. Several participants described feeling pressured to supplement with formula or to formula-feed exclusively.

"She [the nurse] was very aggressive and pushing this little bottle. And I was expressing amazing colostrum, so much of it, and she still wanted to put formula in the little bottle."

"[The nurse] said 'what we really need is for her to poop a lot, and the formula—because your milk's not in yet—the formula will help her sort of flush it out of her system.'"

Participants also discussed the restrictive hospital policies that limited the number and length of their feeding sessions.

"The second nurse that came in had said, 'No, we're on a strict schedule of feeding her every 3 hours. You taking her out after an hour and a half or two hours for a 30- or 40-minute breastfeeding session is gonna prolong how long she's under the lights.'"

"They did recommend that I only keep her out for half an hour at a time for feeds, so that she could stay under the light as much as possible."

Midwives can and do play an important role in meeting a range of clients' postpartum needs.

In some cases, participants reported being presented with conflicting views on infant feeding throughout the treatment process.

"The nurses there really were on the same page as me about not [supplementing with] formula...and then once we got to [another hospital], the first nurses that we encountered there were very pro-formula and so they didn't want me to take her out [from under the phototherapy lights to breastfeed] at all."

"[Some] nurses say, 'we feed babies every 3 hours and that's the end of it', and then you have some that are saying, 'yeah, no, whatever; whatever works for you works for us.' So, it's confusing."

Postpartum Care

Many clients recalled the significant changes they experienced with regard to their experience of their own postpartum care following their baby's hospital admission for phototherapy. Participants, who were receiving postpartum assessments alongside their baby by a midwife before their infants developed severe hyperbilirubinemia requiring phototherapy, described how their postpartum care was interrupted due to their now being in a hospital that prioritized the care of the newborn. Although a midwifery client remains in the care of their midwife regardless of their baby's hospital admission for the management of hyperbilirubinemia, participants described a shift in care provided by their midwives. This change was especially pronounced for clients who felt that their midwives were absent during phototherapy:

"It's very much about the baby; she's the one with the hospital bracelet on, she's the patient...we do often kind of get brushed aside."

"And when I went to the hospital, I felt like they were just dealing with my sick kid and that's all it was. And so the emotional support that was so great with the midwives was just gone."

Despite this primacy placed on care provision for the newborn, nursing staff sometimes continued providing care to participants alongside their babies.

"The nurse would wake me every 2 hours to pump, and then she would feed him. 'She was like, you sleep, you rest, your milk needs to come in. So I felt really supported."

"There was this one nurse who came in and sat probably an hour with me just helping me set up the feeding tube. She [was] rubbing my back and just making sure that I was as okay as I could be, and she was incredible. I'll probably never forget her help during that time."

Other participants, however, reported receiving little to no postpartum support from nursing staff in hospital. One participant recounted her experience of asking for a bed to lie down on.

"They were like, 'uh, we don't really have that here because it's not a hospital for adults.' So they said we could go into

one of the breastfeeding rooms, and there was a bench in there, like a padded bench, so we ended up sleeping in there on a padded bench."

Another participant stated,

"I ended up [with] so many stitches, and it got infected because I couldn't take care of myself....I hadn't really been able to take it easy at all for those first couple of days and was sleeping in chairs and on the floor and stuff, for 6 days."

Skin-to-Skin Contact

Many participants lamented the valuable skin-to-skin time lost in the early days of their newborns' lives as a result of phototherapy. Hospital protocols concerning phototherapy prevented many clients from being able to spend uninterrupted skin-to-skin time with their babies.

"All I wanted to do was just hold her, and it wasn't a choice that I got to have until she was 6 or 7 days old."

"I think the hardest part for us with the phototherapy was that we couldn't hold [him]....it was very difficult because they were so rigid about who could take him out."

Informed Choice

Many clients reported being unable to make informed decisions following their infant's diagnosis of severe hyperbilirubinemia requiring phototherapy, because they felt that hospital staff rarely prioritized providing them with the necessary information and time required to make decisions.

"In the hospital, they would prick his heel and take the blood away for, like, 8 hours... and then when they come and give you the update, it's so quick, and it's...without questions or anything, and then they leave."

"I felt sort of abandoned in the first day or two. Basically, they wheeled in the light box, said 'hey, you have to put him in here,' but they didn't really give us more information."

Changes in Midwifery Care

For the majority of clients, the nature of their midwifery care changed considerably as a result of their newborns' severe hyperbilirubinemia requiring phototherapy. Participants outlined the various ways this affected their experiences as midwifery clients in the early postpartum period.

Continuity of Care

A number of participants lamented the limited support they received from their midwives in the early postpartum period following the hospitalization of their newborns for severe hyperbilirubinemia management.

"The thing I wanted most in that time was just to have my midwife there...I think that and the advocacy, [be]cause I didn't."

"I actually felt relatively unsupported from the midwives. Not [that they] didn't support me but...it wasn't their area [of expertise,] and they just didn't know what to do except pass me off."

Conversely, other participants reported experiencing increased support and involvement from their midwives during this time.

"My midwife was there every single day. She came every day to the hospital to check in on what was going on with her numbers and talking to the doctor that was in charge of us."

"[Our] midwives joined us for that 24 hours we were in hospital for the phototherapy [and] kept checking in on us."

Midwives As Liaisons

Many participants described how their midwives, during the management of severe hyperbili-

rubinemia, acted as liaisons between them and hospital health care providers, particularly in the case of “translating” relevant information.

“[We asked] our midwife, ‘can you help us just sort of translate from medical geekspeak to English and give us a bit of a commentary [on] what’s actually going on?’...and that worked really well.”

“Our midwives were able to explain to us far more than the medical staff at the hospital was. And that made us trust more in our midwives”

Some participants said they benefited from the advocacy and coordination their midwives provided throughout treatment.

“We really needed the midwives to advocate for us and to tell the nurses, ‘no, they’re not [supplementing with formula], unless it’s an emergency,’ because they just wouldn’t acknowledge that I was allowed to have an opinion about that.”

“I called [my midwife], and I said, ‘we’re still sitting here, and I’m getting really upset because I can’t wake [my baby] up anymore’....[My midwife] called me back and was, like, ‘it’s gonna be okay, just sit tight....’ I don’t know who she called and yelled at, but moments later, a doctor appeared.”

DISCUSSION

As we found no other research reporting on the experiences of midwifery clients whose babies have been hospitalized for the management of severe hyperbilirubinemia in Canada, our study appears to be the first to report findings on this group. Findings from this study support those from other qualitative studies conducted in North America, South America, and Europe indicating that when babies with severe hyperbilirubinemia require phototherapy in hospital, it can be a challenging time for parents and their families. Furthermore, health care providers play an important role in lessening the discomfort

experienced by parents during phototherapy by providing adequate infant feeding support, as well as consistent and compassionate postpartum care. This study, however, highlighted the unique experiences of midwifery clients with newborns hospitalized for severe hyperbilirubinemia requiring phototherapy. The transition from care provided by midwives to care provided by hospital staff proved challenging for many participants. Two of these challenges were that [1] informed choice was not prioritized by hospital-based health care providers and [2] physical and psychosocial postpartum support for the parent was not attended to. Furthermore, participants recalled having received conflicting information about infant feeding during phototherapy—some participants feeling dissuaded from nursing altogether—as well as noticeably less support from their midwives during phototherapy.

However, this study indicates that midwives can and do play an important role in meeting a range of clients’ postpartum needs. In the absence of suitable lactation support in the hospital, midwives can support their clients’ nursing throughout phototherapy. Moreover, midwives prove vital to their clients’ ability to navigate complex hospital hierarchies by advocating for and on behalf of their clients in hospitals and liaising with hospital-based health care providers to meet the individual needs of clients and their families. Furthermore, the continued presence of a compassionate, understanding, and supportive midwife can help mitigate much of the anxiety, worry, and stress parents feel during this process and can help significantly improve clients’ experiences of the management of their newborn’s hyperbilirubinemia. These findings have informed a number of midwifery best practices regarding severe hyperbilirubinemia and the development of relevant knowledge translation tools.

Although this study reports a number of important findings regarding client experiences during hyperbilirubinemia treatment, there are a number of limitations to consider. The qualitative nature of this study and the small sample size mean that our results may not be generalizable. Furthermore, as participants self-selected for this study, it is possible that those who felt most strongly about their experiences were overrepresented, thereby introducing bias into our study findings.

Demographic information—such as age, ethnicity, race, and socioeconomic status—was not collected; thus, this study sample may not be representative of all midwifery clients whose newborns require phototherapy. In addition, in-person focus-group discussions took place in two urban settings: Ottawa and Toronto. An online focus group was organized to facilitate recruitment from a more diverse geographic pool, but only one participant [also from an urban setting in Ontario] took part. Thus, the experiences of clients from rural and remote areas in Ontario were not captured.

CONCLUSION

This study reports on findings from focus-group discussions with ten midwifery clients in Ontario whose newborns required management of severe hyperbilirubinemia in the hospital. Findings from this study fill a significant gap in the literature with regard to the experiences of parents during this period and highlight some of the unique experiences of Ontario midwifery clients. As shown in the limited peer-reviewed literature, the hospitalization of a newborn for the management of severe hyperbilirubinemia can be physically, emotionally, and psychologically discomfiting for parents. Midwives, however, can help mitigate a number of these stresses by continuing to provide support throughout the early postpartum period, by facilitating the treatment process [e.g., helping their clients get in contact with a physician and communicating with physicians to commence treatment], and by acting as liaisons and advocates for clients within hospitals.

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