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## **“Why Aren’t You Breastfeeding?”: How Mothers Living With HIV Talk About Infant Feeding in a “Breast Is Best” World**

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*Infant feeding raises unique concerns for mothers living with HIV in Canada, where they are recommended to avoid breastfeeding yet live in a social context of “breast is best.” In narrative interviews with HIV-positive mothers from Ontario, Canada, a range of feelings regarding not breastfeeding was expressed, balancing feelings of loss and self-blame with the view of responsibility and “good mothering” under the current Canadian guidelines. Acknowledging responsibility to put their child’s health first, participants revealed that their choices were influenced by variations in social and cultural norms, messaging, and guidelines regarding breastfeeding across geographical contexts. This qualitative study raises key questions about the impact of breastfeeding messaging and guidelines for HIV-positive women in Canada.*

According to the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS, women account for 50% of global HIV infections (WHO, 2008). Many women living with HIV reside in the province of Ontario, Canada, where prevalence has increased by 80% from 2001 to

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2006 (Remis, Swantee, Schiedel, Merid, & Liu, 2006). Women of childbearing years are the fastest growing group of persons to be infected with HIV (Public Health Agency of Canada, 2008), with an over-representation of Aboriginal women and women from countries where the prevalence of HIV is 1% or greater, for example, Zimbabwe, South Africa, Uganda, and Jamaica (Public Health Agency of Canada, 2008, 2010a).

All pregnancies to mothers living with HIV in Canada are reported through the Canadian Pediatric AIDS Research Group (CPARG). The CPARG annual reporting for the province of Ontario noted an increase in children born to women living with HIV from 52 in 2001 to 91 in 2011. Across Canada, according to CPARG, between 50 and 80 infants were perinatally exposed to HIV each year in the early 1990s; this had increased to 238 infants in 2008 (Public Health Agency of Canada, 2010b). Recent studies indicate that rates of pregnancy amongst HIV-positive women may increase over time as a result of the success of combination antiretroviral therapy with undetectable viral loads, vertical transmission rates being less than 1%, and a normalization of pregnancy for HIV-positive women (Chen, Phillips, Kanouse, Collins, & Miu, 2001). A survey of women living with HIV in Ontario found that 69% wanted to have children and 57% fully expected to conceive in the future (Loutfy et al., 2009). Having children is a growing reality for women living with HIV, highlighting the need for increased research exploring their diverse experiences of pregnancy and early motherhood.

Although there has been an increase in the clinical and social supports available to HIV-positive women who wish to become pregnant, HIV-related stigma continues to have an impact on the perinatal experiences of HIV-positive women. Researchers have reported that HIV causes a great amount of disruption in the family environment and that women living with HIV are particularly vulnerable to rejection and the loss of important familial and social relationships (Corea, 1992; Murphy, Marelich, Stritto, Swendeman, & Witkin, 2002; Owens, 2003; Winstead et al., 2002). Sandelowski and Barroso (2003) conducted a research synthesis to integrate findings from qualitative studies focusing on motherhood in the context of maternal HIV infection. Out of the 56 studies reviewed that contained findings related to motherhood, the authors found that becoming a mother intensified women's concerns related to HIV disclosure, perinatal HIV transmission, care for children, stigma, and worry about the negative effects of maternal HIV on children (Sandelowski & Barroso, 2003). The findings presented in this article align with Sandelowski and Barroso's (2003) metasynthesis and highlight how concerns associated with infant feeding practices could potentially intensify some of the social effects of HIV.

### Infant Feeding, HIV, and the Prevention of Vertical HIV Transmission

As rates of HIV in women of childbearing years have increased, it has become progressively more important to prevent vertical transmission of HIV

(Bulterys, Ellington, & Kourtis, 2010). For some, the low risk of transmitting HIV to their child is the reason they opt to get pregnant, resulting in increased rates of planned pregnancies among HIV-positive women (Loutfy et al., 2012). In combination with prenatal HIV testing, antiretroviral therapy (ART) for mother and newborn, and caesarean section delivery, formula feeding has decreased rates of vertical transmission of HIV to less than 1% (Horvath et al., 2009). A systematic review by Horvath and colleagues (2009) demonstrates that breastfeeding almost doubles the risk of HIV transmission from 21% in formula-fed infants to 37% in infants who were exclusively breastfed (Horvath et al., 2009). In settings where access to clean water for infant formula cannot be guaranteed, practice guidelines have balanced HIV prevention with meeting the nutritional requirements of the infant while ensuring protection against non-HIV morbidity and mortality (WHO, 2010). In low- to middle-resource settings where access to clean water cannot be guaranteed, exclusive breastfeeding is recommended to optimize infant survival (WHO, 2010). In high resource settings including Canada, the United States, and Britain, where women may have access to infant feeding alternatives and clean water, exclusive formula feeding is recommended (WHO, 2010). As the risk of HIV transmission through the consumption of breast milk is not zero, and it is assumed that mothers living with HIV in Canada have access to clean water and infant feeding alternatives, the World Health Organization infant feeding guidelines have been adopted in Canada without question. Clinical practice guidelines in Canada recommend mothers living with HIV avoid breastfeeding regardless of plasma viral load and ART (Burdge et al., 2003). There appears to be no clinical or social science literature, policies, or practice guidelines from a Canadian context that explore this issue in greater depth, or that create an opportunity for discussion and commentary beyond the fact that breastfeeding is contraindicated for women living with HIV in Canada.

It should also be noted that breastfeeding recommendations for women living with HIV vary across high-resource settings. In 2010, the British HIV Association and Children's HIV Association released a position statement outlining a harm reduction approach to infant feeding (British HIV Association, 2010). In the United Kingdom, breastfeeding recommendations incorporate new research evidence from low-resource settings showing low rates (0–3%) of HIV transmission during breastfeeding from mothers on ART (British HIV Association, 2010). Women living with HIV are still encouraged to formula feed, but “under exceptional circumstances . . . a highly informed and motivated mother might be assisted to breastfeed” (British HIV Association, 2010, p. 2). As mothers living with HIV in high-resource settings are recommended to avoid breastfeeding, there is a need to provide education and support to these mothers regarding alternative infant feeding practices. Furthermore, it is imperative that health and social care providers understand the complexity of educating and supporting mothers around infant feeding guidelines and the promotion of formula feeding. This includes an awareness of the

historical, social, and cultural aspects of breastfeeding and the impact this has on women living with HIV in Canada.

### Living in a “Breast Is Best” World

In Canada, at the same time HIV-positive women are told not to breast-feed their newborns because of best practice guidelines to prevent vertical transmission of HIV, they bump up against Health Canada’s promotion of breastfeeding as the “normal and unequalled method of feeding infants” (Health Canada, 2013a). In a recent joint statement of Health Canada, the Canadian Paediatric Society, the Dietitians of Canada, and the Breastfeeding Committee for Canada, breastfeeding was promoted “exclusively for the first six months, and sustained for up to two years or longer with appropriate complementary feeding—for the nutrition, immunologic protection, growth, and development of infants and toddlers” (Health Canada, 2013b). Knaak argues that Health Canada’s claim that breastfeeding promotes mother–baby attachment is not supported with sufficient evidence, however, “suggesting they may be driven more by ideology” (Knaak, 2006, p. 413).

Understandings of breastfeeding have dramatically changed over time and have been influenced by a number of factors including current scientific knowledge regarding advantages of human breast milk, the medicalization of infant feeding practices (i.e., moving childbirth and childrearing from the home to the hospital), and the development of the formula feeding industry (Thulier, 2009; Wall, 2001). This is evident in late-twentieth century government-sponsored social and educational campaigns that spread across North America, which positioned breast milk as “nature’s perfect food” (Wall, 2001, p. 596), implying that breastfeeding is “an extension of the natural, embodied, and intimate connection” (Faircloth, 2013, p. 168) that presumably begins between mothers and babies during pregnancy.

The educational campaigns of the past continue to prevail in the current North American context. Consequently, breastfeeding is positioned as the optimal infant feeding practice (Murphy, 1999), rather than acknowledging the social, practical, and cultural challenges to breastfeed (Schmied & Barclay, 1999) and alternative infant feeding practices that are relevant and available to mothers living with HIV. These messages are complicated by the presence of HIV in breast milk and the subsequent debates surrounding infant feeding practices, particularly in the resource-poor context of the global south (Hausman, 2011).

### The Present Study

This qualitative analysis is part of a larger, observational, mixed methods research initiative titled The HIV Mothering Study, which explored the

psychosocial experiences and needs of women with HIV in pregnancy and the first year of motherhood. From March 2011 to December 2012, HIV-positive pregnant women from across Ontario, Canada, enrolled at HIV or obstetrical care centers and were followed to 12 months postpartum. The purpose of this qualitative analysis was to explore and highlight the emotions and experiences related to infant feeding across the pregnancy–motherhood trajectory from the third trimester to 3 months postpartum. Through participant narratives, we hope to raise key questions about the impact of breastfeeding guidelines and messaging more generally for women living with HIV in Canada.

## METHODS

### Theoretical Framework: Social Determinants of Women's Health

Health differences among women both globally and in Canada result primarily from experiences of qualitatively different environments associated with the social determinants of health. In Canada, these social determinants include ethnicity, Aboriginal status, early life education, employment and working conditions, food security, health care services, housing, income and its distribution, and social safety net and support (Raphael, 2004, 2006). They also include culture, HIV stigma, and discrimination, all of which have been found to contribute to HIV infection and disease progression (Ontario Advisory Committee on HIV/AIDS, 2002). Wuest and colleagues (2002) build on Raphael's work in their development of a social determinants of women's health (SDoWH) framework that positions gender and race at the center of their analysis of women's experience. For us, this includes attending to the variations in how women experience HIV in the context of pregnancy and motherhood, and how these experiences are linked to socio-structural forces and within particular sociocultural contexts (Benoit & Shumka, 2009).

Social determinants of health such as poverty and gender (Hobfoll, Ritter, Lavin, Hulsizer, & Cameron, 1995), race, culture and immigration (De Souza, 2006) and HIV-related stigma (Logie, James, Tharao, & Loutfy, 2011; Parker & Aggleton, 2003; Sandelowski, Lambe, & Barroso, 2004) greatly impact the well-being of HIV-positive women who become pregnant and give birth. These social determinants result in barriers to accessing appropriate health and social care resources, increased isolation, and a negative shift in psychological health (Roer-Strier, Strier, Este, Shimoni, & Clark, 2005).

The SDoWH framework recognizes the importance of gender as a determinant of health, as well as "differences between and within groups of women based on a range of social factors including sexual and gender identity, race, class, geographic location and access to key material resources" (Greene, Chambers, Masinde, & O'Brien-Teengs, 2013, p. 119). It also recognizes that although women play multiple roles in society, including

mothering, they continue to have unequal access to power. Given the racial, ethnic, and cultural diversity of the HIV Mothering Study participants, the SDoWH framework is a critical approach to deepening our understanding of the social and cultural contexts in which HIV-positive mothers talk about their infant feeding experiences, while at the same time moving toward action in both the practice and policy arenas (Wuest et al., 2002).

### Narrative Methodology

This article focuses on narrative interviews conducted with HIV Mothering Study participants in their third trimester of pregnancy ( $n = 33$ ) and again at 3 months postpartum ( $n = 32$ ). Across Ontario, six mothers living with HIV were hired and trained as peer research assistants (PRAs) to meet with participants and complete the data collection including narrative interviews. Face-to-face interviews were conducted in a space that was agreed to by both the participant and PRA, for example, the clinic where care was received, the participant's home, or HIV/AIDS service organizations; interviews lasted 30 minutes to 1.5 hours depending on the narrative the participant chose to tell. We used a narrative methodological approach to listen to and represent storied interpretations of life experiences and events of a marginalized and traditionally silenced population (Hendry, 2007). This approach was chosen to reflect our commitment to community-based research and to position women's voices at the center of the research process. We echo Connelly and Clandinin's (2006) assertion that "narrative inquiry is the study of experience as story and is a way of thinking about experience" (p. 375) in addition to Riessman's (2002) approach to narrative inquiry that focuses on "large sections of talk and interview exchanges that signal stories" of experience that emerge from participant narratives (p. 78).

We asked participants one question: "Can you tell us what your pregnancy/birth/mothering experiences have been like for you as an HIV-positive woman?" As participants shared stories, we listened, seeking clarification or an expansion of the stories they shared within the larger narrative. The narrative interview enabled a more fluid and flexible process for the stories to be told and retold, for the data to emerge, and for our team to make sense of the stories that were shared with us, including a reflection and discussion of our assumptions as HIV-negative and HIV-positive researchers and health and social service providers. The narrative interviews were audiorecorded and transcribed verbatim. Our approach to narrative analysis most closely reflected Riessman's (2001) process of unpacking, interpreting, and analyzing the story with close attention paid to the uniqueness of time and environment in which the story was told. We engaged in this process through hiring and training PRAs who were mothers living with HIV to engage in narrative interviews with HIV-positive women during their pregnancy and beyond, and to contribute to the narrative analysis. Narrative informed content analysis

was conducted to fully unpack and reflect on the stories within the narrative interviews. Research team members including the PRAs participated in a process of reflexivity that incorporated the PRAs' reflections of their experience of the narrative interview and their interpretation of the stories that were being told. We also drew on Bal's (1997) trilevel analysis by (a) reflecting on the series of events encompassed in the narrative, (b) paying attention to how the story was told and plot described, and (c) focusing on the text and the manner in which the stories were portrayed through verbal and nonverbal communication and language used. Through this process, stories and experiences about infant feeding emerged. NVivo8 software was used to search, code, and organize the text related to infant feeding or breastfeeding. The HIV Mothering Study protocol was reviewed and approved by the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board (REB) in addition to the REBs of study coinvestigators at multiple universities and hospitals across Ontario. All participants were given a pseudonym to protect their privacy.

### Participants

Women in the HIV Mothering Study ( $n = 33$ ) reflect a range of cultures, ethnicities, ages, and experiences. Participants included in this analysis had a mean age of 32 years, ranging from 21 to 42 years. The majority of participants (53%) identified as Black or African followed by White (33%), Aboriginal (10%), or Other (4%). Almost half (48%) of the participants indicated Canada was their place of origin followed by Africa (45%), the Caribbean (5%), and South America (2%). The majority of participants were Canadian citizens (63%), while others identified as permanent residents (23%), refugee claimants (7%), or other (7%). The majority (65%) were in a relationship at the time of the interview (i.e., common-law, married, or in a relationship, but not living together), whereas 35% were single, separated, or divorced. This was the first baby for 27% of participants; other participants already had one (29%), two (26%), three (9%), or more than three (9%) children. The majority of HIV Mothering Study participants (78%) resided in urban areas around the Greater Toronto and Hamilton area. Narratives related to infant feeding including perspectives of breastfeeding and alternative feeding practices were shared in 94% of interviews conducted in the third trimester (31 out of 33) and 56% of interviews conducted at 3 months postpartum (18 out of 32).

## RESULTS

Narratives about breastfeeding emerged as a central story in the women's overall experience of becoming and being a mother. Although a few women



in our study were clear that they did not want, nor did they miss, the opportunity to breastfeed, many women had something to share about their thoughts and feelings on this topic and most of the women talked about the challenges of infant feeding in the context of living with HIV. These themes included concerns about the impact of not breastfeeding on their role and identity as a mother; feelings of loss and guilt; the surveillance of their infant feeding practices; concerns about HIV-related stigma and disclosure; and the need to develop a plan for how to confront the surveillance of their infant feeding practices as a response to concerns about stigma and disclosure.

### “It Makes Me Feel That I’m Not Performing My Full Womanly Duties as a Mother”

The quote above from Claire, a 35-year-old Canadian-born mother of six, echoes the experiences of many women by highlighting how social and cultural breastfeeding discourses impacted mothering identities as a result of not being able to breastfeed, as Kathy, a 32-year-old Canadian-born mother of two, poignantly reflected:

It was important, it is important. I mean that is what we are equipped to do, you know, it’s just part of mothering . . . and all those books that I read, the pregnancy books they always say breastfeeding is way better than bottle-fed babies, I wish they would just split it in half to make us feel better, you know?

The “breast is best” mantra is certainly not unique to Canada, and this was reflected in the narratives of mothers who came to Canada from African and Caribbean countries as, for example, Estelle, a 33-year-old, French-speaking first-time mother from Central Africa shared:

It hurts. . . . I am not sure if White women share my opinion, but for African women if you can’t breastfeed, it’s hard. It’s like you abandon your child or it feels like your child won’t love you. I think a lot about that, it’s hard. But what is important is the baby’s health.

Hence, women in our study shared the view that breastfeeding is central to the mothering role. For Caucasian, Canadian-born women, these messages were often received via media-based and clinical discourses, for example, handbooks on becoming a mother, public health messaging about the benefits of breastfeeding, and interactions with health care providers. Women from African countries were also subject to these messages, but their feelings were intensified vis-à-vis cultural expectations and pressures. Moreover, these pressures were exacerbated for many African mothers in our study as they anticipated how family and friends would react to their decision to

bottlefeed. As Nadege, a 26-year-old mother of two from east Africa stated, “In our culture it’s, it’s, you need to [breast]feed your baby. If they don’t see it, they say you are killing the baby.”

Hence when medical, social, and cultural pressures to breastfeed collide, mothers who do not or cannot breastfeed internalize the notion that they are somehow putting their baby at risk for lower physical and emotional health outcomes and, therefore, not fulfilling their full duties as a mother. These narratives also highlight the importance of grounding these experiences within the SDoWH framework, which highlights the intersection of gender, culture, and HIV status and the impact this has on the emotional well-being of HIV-positive mothers who cannot breastfeed.

### “Everybody Asks Me Why I Don’t Breastfeed”

The social and cultural pressures highlighted above are not only embodied by new mothers, but also by health care providers, family, and friends who subject new mothers to questions about their infant feeding plans and choices, as Pamela, a 30-year-old Canadian-born, mother of one stated:

In the hospital, um, most I think it was fine, most of the time . . . we just said, “Bring us formula, we need formula” and they were, like, “Okay,” and then . . . one of the nurses [says], “Have you seen the lactation consultant?” and I’m like, “No,” and they were like, “Okay, well, I’ll send her by,” and I’m like, “Well, it’s not necessary” . . . I’m like, “Have you not read the file?” . . . There were some people just asking.

The availability of lactation consultants reflects the social pressure to breastfeed in the hospital, as well as the overzealous application of breastfeeding practice guidelines (Registered Nurses Association of Ontario, 2003). What is equally if not more concerning is the lack of awareness of infant feeding practices in the context of HIV on the part of the nurse, or the poor communication amongst the health care team regarding this woman’s HIV status and her subsequent individual care needs.

Surveillance of infant feeding practices continued after discharge from the hospital when the gaze shifted from medical staff to family and friends, as Sheila, a 32-year-old Canadian-born, mother of two shared:

It was difficult, I mean, I had so much company coming over here when I first had the baby and they all asked me why I wasn’t breastfeeding, every single person.

In describing a conversation she had with a friend who came to visit her shortly after the birth of her baby, Asya, a 27-year-old first-time mother from southern Africa further exemplified this issue:

Like, “Oh, you’re not breastfeeding?”  
 I was, like, “No.”  
 “Why aren’t you breastfeeding?”  
 “Cause I don’t want to.”  
 “Well, why?”  
 “Because I say so, what’s it to you?”

Asya’s narrative reflects a moment in time when social messaging and cultural norms that proclaim “breast is best” collide. Consequently, this subjects HIV-positive mothers to undue surveillance and interrogation by the very people upon whom they rely for support.

### “I’m Thinking, if I Don’t Breastfeed, People Will Know”

The SDoWH perspective highlights the need to prepare and support women who are socially and culturally situated in spaces where they will be subjected to pressure to breastfeed. As reflected in the quote above, this is particularly important for women living with HIV who are concerned about their infant feeding practices becoming a catalyst for unwanted disclosure of their HIV status. Many study participants had not disclosed their HIV status to anyone other than their health care providers and partners. It was very rare for anyone outside the woman’s HIV specialist and obstetrician to have knowledge of her HIV status and, thus, it was important to them that the fact they were not breastfeeding did not become the occasion where people would find out. In the context of talking about ART for her baby, Millicent, a 32-year-old mother of two from southern Africa shifted the conversation to breastfeeding and stated, “I’m more concerned about my friend’s question ‘why you not breastfeeding?’ and, uh, how am I gonna deal with that?”

Millicent’s questions resonated with many mothers in our study who came to Canada from African countries. These mothers were greatly concerned about being identified as a woman living with HIV vis-à-vis the act of bottle-feeding. This was further stressed by Carine, a 33-year-old mother of two from west Africa:

The challenges from not breastfeeding is the people around me, right? It’s so sad because most people, like most Africans, they know that the Moms who do not breastfeed are Moms who has HIV. They know about that, so sometimes if they come to your apartment, they’ll be watching to see if you’re gonna give the baby milk.

Hence, a fundamental issue for many women in our study is the cultural pressure to breastfeed coupled with fear that not breastfeeding will result in inadvertent disclosure of HIV. Again, this provides a strong argument for using an SDoWH framework to stimulate discussion about how to best

support women with their infant feeding needs and experiences. For women living with HIV, this would ensure that a range of social and emotional concerns, including cultural pressures to breastfeed and the assumptions that are made when a mother is not breastfeeding, would be incorporated into practice and social support guidelines.

### “We Have to Come Up With a Convincing Answer”

As highlighted above, most HIV-positive mothers are not supported in preparing for the surveillance of their infant feeding practices, in particular, their concerns regarding disclosure and HIV-related stigma. Consequently, many women began to prepare “excuses” for why they were not breastfeeding. Excuses ranged from telling people “there’s no breast milk” to saying that they “don’t breastfeed in the day” to explaining that they were on a “high dosage of iron.” Most women developed what was deemed to be “a convincing answer” as to why they were not breastfeeding. This was the case for Louise, a 30-year-old Canadian-born mother of one, who, prior to the birth of her second child, shared her process of developing an explanation for why she was not breastfeeding:

I’ll just say, like, “It’s easier now because it’s the second,” so I’m, like, “It didn’t work the first time, so we didn’t try the second time,” or “We had a lot of problems the first time, so we didn’t want to put ourselves through that stress the second time,” or, like, “We already had the bottles and the formula already prepared just in case,” and stuff like that, so it was a little bit easier to do it that way.

Some women went to great lengths to conceal the fact they were feeding their baby formula. For example Grace, a 37-year-old first-time mother from Central Africa, bought a breast pump in anticipation of breastfeeding questions. The purpose of the breast pump was “just to show them. If they ask me of what are you doing, I say . . . I don’t breastfeed, but I do the pump; I put it in the bottle for him to drink, that’s it.”

Mothers also shared the emotional consequences of “making up all these lies about breastfeeding.” As Bonnie, a 27-year-old first-time Aboriginal mother stated, “I feel bad, like I don’t want to have to tell people excuses or it’s pretty much a lie, but I also don’t think everybody needs to know.” At times, lying made the mothers feel “stupid,” and Alice, a 37-year-old first-time mother from South Africa, stated, “I hate to be made to feel that way. . . . We’re expected to be perfect.”

Women’s narratives suggest that the social and cultural pressure to breastfeed that all new mothers confront has unique implications for mothers living with HIV. This is because the social and cultural surveillance they are under raises anxiety about inadvertent HIV disclosure and the

anticipation of HIV-related stigma that may follow. This fear leads to dedicating time and emotional energy into planning excuses. For some of the women in our study, developing and enacting excuses provided a sense of relief, while for others, the act of concealment resulted in negative feelings about themselves. Consequently, HIV-related stigma must be understood as a key social determinant of health of HIV-positive mothers that intersects with social and cultural pressures to breastfeed. Together, these factors powerfully impact HIV-positive women's emotional health, well-being, and the way they experience new motherhood.

### “This Is My Take on Breastfeeding”

It is at this juncture that we come full circle. As highlighted earlier, most mothers situated their infant feeding stories relative to their social and cultural understanding of the relationship between breastfeeding and “good” mothering. As we have demonstrated, however, mothers also emotionally prepared for the surveillance of their infant feeding practices and planned ways to protect themselves from HIV disclosure and HIV-related stigma. Consequently, at the same time mothers actively planned how to manage multiple concerns, they also had to cope with feelings of loss and grief connected to not breastfeeding, as Roshni, a South Asian first-time mother from southern Africa shared:

It's sad because you see some Moms doing that and you miss that experience. You want to experience how it feels, like to, you don't get to feel that, you to touch them hold them, everything, I think that's a Mom experience, right?

Moreover, because breastfeeding is so highly connected to the overall experience of being a new mother, many women felt guilty about not adequately performing their role as women and mothers, as Lisa, a 25-year-old Caucasian Canadian-born mother of two expressed: “I feel, like, guilty and I feel inadequate because I'm a woman. This is our job as women to feed our babies.”

Feelings of loss and guilt, however, were most often weighed against the consequences that breastfeeding could have on the health of their babies. This was poignantly articulated by Samira, a 33-year-old mother of two from Central Africa:

Sometimes I feel sad not to breastfeed my child. I wish, with all the beautiful nipples, big nipples that I have that my child will be having the real flow breast flowing. Unfortunately that child, with all the big boobs I have, my child cannot enjoy my breast. . . . It's really sad, but sometimes I think about the risks of giving the child contaminated, like, contaminated milk, right, but because my breast milk [is] contaminated already there's

no need for me to, like, feel bad too much because it's better for me to protect the child because I don't want the child to live like me.

For many women, the desire, or perhaps need, to manage one's longing to breastfeed in the face of "protecting" their children from HIV was achieved by taking a pragmatic stance on infant feeding, as Sophie, a 37-year-old first-time mother from southern Africa asserted:

Of course it's hard, it's hard that you cannot do it for your child, but, again, you want the best for them and the best for them is to be protected from HIV.

In addition to using pragmatism as a clear way to cope with the loss of the breastfeeding experience, women also listened for and read about the positive aspects of using formula and bottle-feeding. Angelina, a 28-year-old first-time mother from Jamaica shared, "I realize that over time with research they've really tried their best . . . to make it a replica of the mother's milk . . . so I don't feel guilty about it . . . and I've done a lot of research on formulas."

Mothers also came to terms with bottlefeeding by emphasizing the positive aspects of bottlefeeding including the fact that their partners and older children could be involved in feeding the baby, as well as acknowledging that formula-fed children grow up to be equally as strong and healthy as breast-fed babies.

This suggests that while the "breast is best" cultural mindset that is so pervasive throughout Canadian and global contexts may impact many mothers, it may not influence how every woman perceives herself or her infant feeding choices, even in instances where "choice" is not a reality.

## DISCUSSION

The thoughts, feelings, and concerns of HIV Mothering Study participants regarding their expectations and experiences of infant feeding persisted throughout the third trimester and postpartum interviews, which highlights the importance of providing appropriate infant feeding health and social care support to HIV-positive women throughout this perinatal trajectory. Women's infant feeding stories also highlight how infant feeding is a social, cultural, and emotional issue that must be understood in relationship to mothers' social and cultural positioning and as women living with HIV. An important concern that was shared throughout women's narratives was the ongoing impact of surveillance of their infant feeding practices, which was exacerbated by fear of disclosure of their HIV status and anxiety about HIV-related stigma and discrimination. Hence, when considering how better to support HIV-positive mothers, we must take into account the ways that

gender, race, culture, and HIV-related stigma intersect with infant feeding practices and experiences (Young et al., 2011).

### Incorporating the Experiences of HIV-Positive Mothers

HIV Mothering Study participants spoke about infant feeding as a publicly scrutinized and potentially problematic aspect of their motherhood experience. This aligns with Knaak's (2006) assertion that there are serious concerns regarding the discursive trend to glorify breastfeeding including increased emotional consequences of not breastfeeding and the construction of idealized motherhood myths that do not reflect the range of thoughts and feelings that women have about their infant feeding experiences. This rings true for HIV Mothering Study participants who, in both pregnancy and postpartum interviews, anticipated or felt that by not breastfeeding, they were not performing their womanly role as a mother or were missing out on an experience that all women enjoy or want to have. Furthermore, as our findings suggest, these concerns are complicated for HIV-positive women living across Ontario who find themselves at the intersection of public health breastfeeding guidelines that state, "Breastfeeding is the normal and unequalled method of feeding infants . . . for the nutrition, immunologic protection, growth, and development of infants and toddlers" (Health Canada, 2013b); as well as Canadian clinical practice guidelines on the management of HIV in pregnancy and postpartum that endorse formula feeding to prevent vertical HIV transmission (Burdge et al., 2003).

The tension that exists between Canadian public health messaging on the benefits of breastfeeding and Canadian HIV clinical practice guidelines that recommend exclusive formula feeding for HIV-positive mothers is further complicated for women who come from countries and cultures where breastfeeding is an expectation of all new mothers, and where using formula is a sign of illness and disease. Many of the mothers in our study came from African countries where breastfeeding is experienced as a "complex relationship between mother and baby, the wider family and community" and as an "ever-changing activity influenced by the counterbalancing effects of past events, the daily lived experience and future plans" (Dykes, 2005, p. 2292). It is not surprising, then, that participant narratives also identified the emotional consequences of having infant feeding practices under surveillance. This included the anticipation of and real-time encounters with family and friends whose surveillance and questioning of infant feeding "choices" raised ongoing concerns and anxiety about HIV disclosure. Clearly, the interface between multiple breastfeeding discourses, which espouse "breast is best" in both local and global contexts, coupled with the reality of HIV-related stigma, positions HIV-positive mothers under the unwanted "gaze" of family, friends, and health professionals (Ruddick, 1989). It is at this juncture that we visualize how the SDoWH framework can attend to these concerns and address power imbalances through the valuing of lived experience.

## Where Do We Go From Here?

As many HIV-positive mothers indicated, HIV disclosure often does not occur beyond their HIV specialist, obstetrician, and partner and, thus, these relationships are critical to the emotional well-being of HIV-positive women throughout the pregnancy–postpartum trajectory. In order for health and social care providers to adequately address the needs of HIV-positive mothers throughout this time, we encourage infant feeding health and social care practices to be grounded in a SDoWH framework (Wuest et al., 2002) because of the multiple ways that social determinants including gender, race, culture, and HIV-related stigma impact the social and emotional health of mothers living with HIV in Canada. Moreover, the SDoWH framework demands that health and social care providers recognize and address the social and emotional impact of the appropriation of power regarding HIV-positive mothers' infant feeding "choices" resulting from the implementation of "best practice" guidelines in Canada. We urge health and social care providers to acknowledge HIV-positive mothers' capacity to reclaim this lost power of "choice." We also urge providers to value and support the planning and navigating practices that HIV-positive mothers employ when confronting questions and curiosity within clinical, community, and personal spaces by placing value on their lived experiences and "expert" knowledge of alternative infant feeding discourses. More broadly, a key recommendation that reflects our analysis of how HIV-positive mothers experience infant feeding in the midst of "breast is best" cultural and social messaging is to shift attention to how HIV-positive mothers can be supported by health care professionals in both hospital and community-based settings. These changes would need to consider how breastfeeding practice guidelines can be implemented in ways that reflect an understanding of the structural and cultural factors that are pervasive in the lives of HIV-positive mothers including gender, race, culture, and HIV status.

Because the SDoWH framework recognizes the centrality of gender, race, culture, and HIV-related stigma and discrimination, it has the potential to attend to both individual and collective concerns. This approach is supported by literature in low-resource settings about the importance of individualizing infant feeding care to recognize a mother's personal history and culture (Coutsoudis, 2005; Young et al., 2011). Consequently, health and social care providers in Canada, in particular those who deliver health care within institutions, must move away from universal assumptions about how pregnancy, childbirth, and the transition to parenthood is experienced and move toward practices that recognize variations between cultures (De Souza, 2004; Stewart & Jambunathan, 1996). This notion resonates with participant narratives, which highlighted how experiences of infant feeding varied by culture, concerns about disclosure, HIV-related stigma, and thoughts and feelings about breastfeeding more generally. This furthers the case to ground health and social care practices in a SDoWH framework and



provide appropriate support to mothers living with HIV, in particular around infant feeding practices.

Finally, in order for a SDoWH perspective to be an effective framework through which to provide appropriate and effective support to HIV-positive women throughout the pregnancy–postpartum trajectory, health and social care providers must initiate early discussions with pregnant HIV-positive women that promote alternative messaging about infant feeding, motherhood, and identity, and that honor the unique sociocultural experiences of women with HIV. Of particular importance is supporting women to plan for and navigate the surveillance and interrogation of her infant feeding practices by family and friends. This is a challenging endeavor given the clinical, cultural, social, and emotional tensions that currently exist for mothers living with HIV in Canada, yet one that is central to the success of supporting women throughout the pregnancy–motherhood trajectory.

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