The Experiences of Making Infant Feeding Choices by African, Caribbean and Black HIV-Positive Mothers in Ontario, Canada

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Abstract

Mothers in HIV-endemic countries are advised to exclusively breastfeed their babies until six months because of lack of resources and better chances for child survival, while in developed countries, replacement feeding is advised. What are the experiences of HIV-positive women who migrate from HIV-endemic countries to developed countries, when making infant feeding choices?

Methods: In-depth interviews and focus group discussions with a total of 25 women living with HIV in Toronto and Hamilton, Ontario.

Results: Free infant formula alleviates the practical constraints in making infant feeding choices. However, cultural beliefs and social expectations constrain HIV-positive mothers' decision not to breastfeed. This is further complicated by the different policies. Service providers should understand the psychological and emotional experiences of the mothers in order to provide the appropriate support. Peers could be potential sources of support. The differences in policies are issues of global justice that need to be addressed.

Background

Breastfeeding has been considered a normal and optimal infant feeding practice globally. While the World Health Organization (WHO) recommended that infants be exclusively breastfed for a minimum of six months (Kramer et al. 2001), the discovery that breastfeeding significantly increases the risk of mother-to-child transmission of HIV changed this policy. Children born to HIV-positive mothers have a 5% to 20% risk of contracting HIV through breastfeeding in the absence of any intervention (WHO et al. 2007). The risk is lowered with exclusive breastfeeding, breastfeeding for a short time, reduced viral load (e.g., mother receiving antiretroviral treatment [ART]) and with prompt treatment of mastitis (Burge et al. 2003).

Given the risk of vertical transmission, the WHO made the following recommendations, which were adopted globally: (i) When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), mothers are advised to use replacement feeding exclusively; (ii) When replacement feeding is not AFASS, mothers are advised to breastfeed exclusively until the baby is six months old, then stop and use replacement feeding exclusively (WHO et al., 2007). These recommendations were revised in 2010 (see Table 1) (WHO et al. 2010).

While there is a new push to encourage breastfeeding in Canada (Ontario Ministry of Health and Long-Term Care 2013), Health Canada's strategies for preventing vertical transmission of HIV/AIDS include exclusive replacement feeding. According to this policy, "breastfeeding should be avoided irrespective of antiretroviral therapy, as this practice is contraindicated for HIV-infected mothers..." (Burge et al. 2003: 1673). Since mothers are provided with free infant milk, one would assume that their decision not to breastfeed, within the Canadian context, is relatively easier (Palda et al. 2004). However, the situation is different in low income countries (LICs).

Breastfeeding is perceived as a cultural norm in many Afro–Caribbean and black communities and most of the low income countries, and adoption of formula feeding is not widespread. Furthermore, unhygienic conditions, lack of supplementary food and lack of safe water make alternative feeding unsafe (Nogueira 2002). Moreover, mixed feeding in the earlier months has been found to increase the risk of HIV transmission

Table 1. Summary of WHO principles and recommendations on HIV and infant feeding of relevance to this paper

Principle	Explanation	
Setting national recommendations for infant feeding in the context of HIV	Mothers should be counselled and support to either: (i) Breastfeed and receive ARV intervention OR (ii) Avoid all breastfeeding	Basis of decisions: • Mother's socio-economic and cultural context • Availability and quality of health services • Prevalence of HIV among pregnant women • Main causes of infant mortality and malnutrition
Informing HIV-positive mothers about infant feeding alternatives	Mothers should be informed about: (i) The national recommendations (ii) Availability of alternatives they could adopt	
Providing support services for mothers to appropriately feed their infants	Skilled counselling and support in appropriate infant feeding practices and ARV treatment to reduce PMTCT should be available to all mothers	

ARV = antiretroviral; PMTCT = preventing mother-to-child transmission. Source: WHO 2010

compared to exclusive breastfeeding (Lauer et al. 2004). Given the socio-economic and cultural context for women in low income countries, the 2010 WHO principles on HIV and infant feeding recommend that HIV-positive mothers on ART should exclusively breastfeed for the first six months, then introduce supplementary feeding and continue breastfeeding until the baby is 12 months old (WHO 2010). When such women migrate to Canada where different standards and policies prevail, what are their experiences in making infant feeding choices? Understanding these experiences is critical, since this population represents the highest rates of HIV-exposed infants (48.3%) (Health Canada 2011). Women may face cultural and social problems, especially if they have not disclosed their HIV status to the people they live with. In some cases, women may be forced to breastfeed and face the various repercussions this may have for the mother and baby.

There is a paucity of literature on the experiences of immigrant mothers with making infant feeding choices in Canada. This paper fills the gap.

Objectives

The objectives of this paper are:

- To describe the cultural beliefs and practices surrounding infant feeding among HIV-positive Afro–Caribbean and black immigrant women in Ontario;
- To describe these women's experiences with making infant feeding choices;
- To discuss the factors that influence the women's experiences and their implications for policy and practice.

Methods

Approach and Population

This was a qualitative study involving a total of 25 adult (21–56 years) immigrant women living with HIV. Seven were from Hamilton and 18 from Toronto in Ontario, Canada. Five were of non-African origin and two had no children. Participants were recruited through posters and snowball sampling. Interested participants contacted us. Interviewed participants gave our contact information to their friends.

Data Collection

Seventeen in-depth interviews and three group discussions were conducted by the principle investigator and a trained research assistant. Both interviews and group discussions involved themes about (i) cultural beliefs and practices about infant feeding, (ii) infant feeding choices when one has HIV and, (iii) how those choices are made and the respondents' experiences with making these choices. The interview guide was pilot-tested on two women living with HIV to ensure clarity and appropriateness of the questions. The interviews were audio-recorded with permission from the respondents. Each interview lasted for about 45minutes.

Analysis

The audio-recorded interviews were transcribed and analyzed using Nvivo10 (QSR International, Victoria, Australia). The analysis involved reading through whole transcripts while identifying key ideas and giving them code names. At the abstract level, related codes were linked together, then grouped under categories. Related categories were then grouped under emerging themes, which we present in the Results section.

The study was reviewed by the McMaster University Research ethics board, and written consent was obtained from all respondents.

Results

The results section is organized according to the themes that emerged from the interviews: (i) cultural beliefs, (ii) knowledge of dangers, (iii) making tough decisions, and (iv) contextualizing women's experiences. Illustrative quotes are provided in the text and in Table 2. Respondents are identified by age and region of origin: (A: Africa; C: Caribbean; O: Other).

Cultural Beliefs

Most of our respondents believed that breast milk was the best for the baby because it is healthy, safe, fresh, natural, easier to digest, cheap, convenient, provides immunity and makes the baby more intelligent. The act of breastfeeding was also thought to strengthen the bond between mother and baby. Because of these benefits, women in their culture are expected, and are pushed by healthcare providers and family members, to breastfeed since "... it is what mothers do...." In view of these social and cultural expectations, we asked about how women who do not breastfeed are perceived.

Not Breastfeeding: "... What Kind of Mother Are You ...?"

Not breastfeeding is perceived unfavourably in these communities. The mother would be the subject of gossip or face continual questions from friends and community members about why she is not breastfeeding. Mothers who do not breastfeed are perceived as cruel and unloving toward their baby; some group discussants reported that these mothers could be treated like a criminal. One said,

> It is [a] must to breastfeed ... if you don't breastfeed ... they think that you don't love your child ... that's why everyone will have to breastfeed ... because there is no way to escape...." (R13, 37 years, A)

Strong cultural beliefs about breastfeeding and the negative perception of people who do not breastfeed in these cultures introduce pressure and constrain how HIV-positive women make infant feeding choices. However, before examining this issue further, we explored the women's knowledge about the implications of breastfeeding if one had HIV.

Knowing Does Not Reduce the Complexity of Decision Making

All respondents knew the potential dangers of breastfeeding with HIV. Some likened it to "... giving a stone to your child ..." (R3, 45 years, O), and "... giving poison; how can you give poison to your baby?" (FGD 1).

They also knew that while in their home countries they may have been able to breastfeed their babies, in Canada, it is "not an option." They spoke of a complex responsibility, a special natural instinct and a duty to protect their babies from contracting HIV.

> ... if you infect that baby ... you are gonna live with that for the rest of your life ... that's your kid ... you are supposed to protect them ... you have to love them and you have to make the decision not to breastfeed and not to infect the baby. (R2, 45 years, C)

One would expect that respondents' knowledge of the dangers of breastfeeding and their commitment to protect their babies would make their decision not to breastfeed easier. However, their cultural beliefs about infant feeding made the decision a challenge.

Making the Tough Decision

Almost all our respondents expressed the difficulties of deciding not to breastfeed within their cultural and social contexts. Not breastfeeding could lead to alienation, unwanted disclosure and the related consequences; it also causes emotional and psychological pain. We discuss these in detail.

Table 2. Summary of themes with corresponding quotes

Theme	Quotes
Cultural beliefs	
Perceptions of people who do not breastfeed	"... the people treat you like a criminal you are a criminal because breast milk is like a food for the baby ... and so they think you are criminal and you want to kill that baby ..." (FGD2)
Tough decisions	
Unwanted disclosure: the external pressures	"I didn't breastfeed and my mother went ballistic ... it doesn't matter if you are almost dead ... you are supposed to breastfeed ... so ... it's an issue ... my Japanese grandmother still didn't talk to me till the day she died because I didn't breastfeed her granddaughter ... but I'm ok with that ... it's her issue not mine...." (FGD2) "... some breastfeed their kid even if they are HIV positive ... due to the stigma associated with not breastfeeding because if you don't breastfeed automatically (people assume) you have HIV...." (FGD3) "... The problem I think I am going to have maybe is when people come to visit me ... I am sure everyone will have questions like why ... are you not breastfeeding? ... and that maybe is going to make them start saying ... maybe she has it (HIV) ... coz we all know that you have to breastfeed a new born baby.... I am gonna have to deal with that ... it will be very hard.... (R10, 33 years, A) "... I am not going to breastfeed my baby ... even though I want but I wish there would be another way ... so far I am already protecting my baby with taking medication ... so I don't think after all these months of protecting the baby then I breastfeed ... that is kind of useless for me. I will make sure that I don't infect my baby, so I just told myself that it's going to hurt if people ask why are you not breastfeeding but ... I will not care what people will say coz this is me this how I live my life so nobody should come and judge me. (R4, 32 years, A)
Inherent pressures	"... it is very hard it's not easy to overcome ... knowing I am HIV positive and I have a child and I can't breastfeed ... [sigh] ... I don't know if something can be done to stop that because like I said it's a big loss...." (R9, 41 years, A) "... when the baby looks at the mother's eyes when breastfeeding ... the first contact that you'll be my mother ... and they recognize you everywhere you go ... no matter what can make you apart but that first sight of both parties through breastfeeding is very important. (R7, 47 years, A) "... if you are not breastfeeding, that bond will be gone ... so it will be hard coz that bond helps with their growing stage...." (RI, 49 years, C)
Contextualizing the decisions	"... I don't think it (not breastfeeding) will be an issue ... a lot of people choose to do that anyways whether or not they are HIV positive so I don't think there is any problem with it ... everybody is very accepting of formula here...." (R8, 41 years, A) "... I know my doctor will support me ... because they don't want me to infect my baby and they want the baby to be healthy...." (R11, 33 years, A)

Unwanted Disclosure: A New Culture, a New Location

Since breastfeeding is a cultural expectation, the decision not to breastfeed was perceived as acquiring a "new culture." With this new culture, the women no longer fit within their ethnic groups and have to seek new communities. The new communities are either people living with HIV (where community service organizations play a big role), or, in some cases, a new geographical location where no one would question their new culture. One respondent reported,

> First off, if a person is living with HIV ... she runs away from the people in her community ... she avoids all contact with them because she doesn't want to show people she is not breastfeeding. (R14, 32 years, A)

The physical relocation is an effort to avoid disclosing the mothers' HIV status. Within their communities, not breastfeeding automatically raises questions. People would guess their HIV status, which, in many communities is followed with stigmatization and alienation. A discussion group participant reported,

> ... at that point you are forced to tell them that it's because I'm not well I cannot breastfeed this child ... and then as you tell them you've just opened a flood gate ... no one is coming to visit you ... no one will ever carry that child; that child will never visit anyone's house ... so that is the dilemma of this breastfeeding issue. (FGD2)

The emphasis on breastfeeding in the community, in health units and on public advertisements further increases the women's sense of guilt and complicates their ability to make the decision not to breastfeed. They are chastised for not fulfilling their maternal functions and stigmatized by their families and community members. Respondents feared that the continuous external pressure and fear of discrimination and abandonment could force some of those mothers to breastfeed, at least in front of others, to hide their HIV status. In the words of one respondent,

> They know they are positive but they want to feed the baby to show their families [that they are ok], because if they don't feed their baby the husband can ask, why you don't feed my baby? So she breastfeeds the baby, yet she knows she has HIV. (R3, 45 years, O)

It is clear that the socio-cultural expectations and cultural beliefs negatively impact the women's decision not to breastfeed to the extent that it is a source of worry and distress long before the baby is born. This was expressed by some respondents who were pregnant at the time of the interview. One such respondent reported,

> I think this is going to be a tough decision not to breastfeed. [However,] at the end of day, I don't want to pass it [HIV] on to my child ... so what I will do, I am just going to do mostly what my doctor says." (R10, 33 years, A)

The stressors were not only external. Some respondents reported that they face inherent pressures entrenched in their socialization as mothers.

Inherent Pressures: "What Kind of Mother Am I?"

Another source of psychological and emotional pressure related to how these women are socialized. Not breastfeeding makes them question their ability to be good mothers since they "fail" to provide the "best food" for their babies. Furthermore, since breastfeeding was perceived as what "real" mothers do, there were feelings of guilt and loss, of missing out on the real maternal experiences of a "mature" woman. In the words of one respondent,

> "Now if somebody can ask me, why don't you breastfeed, I would have this guilt[y] conscience. I really want to breastfeed ... now I think I am a real mum ... mature, and I know what breastfeeding is ... I really want it, this pregnancy. I really wish I could breastfeed. (R4, 32 years, A)

Another internal factor that made the decision not to breastfeed emotionally painful was the loss of the chance to bond early with the baby through the physical and emotional experience of breastfeeding. This was affirmed by respondents with older children who, comparing their children who had not breastfed to those who had, believed they had a weaker and more difficult relationship with the former. One respondent said,

> If I am in bed, my son will climb in bed with me ... my youngest daughter will do that too. My other daughter, the one I didn't breastfeed, she'll sit on the bed, and I keep thinking this is because I didn't breastfeed her. It's stuck in my head because we don't have that bond. Not having that bonding makes me feel really guilty for not breastfeeding. (FGD1)

While the majority of respondents narrated the conflict of reconciling their duty to protect their babies as mothers with what they have learned about being a good mother in their cultures, a few respondents contextualized these experiences.

Contextualizing the Decision Making

Five respondents thought that the pressure to breastfeed was less in Canada, where not breastfeeding is less stigmatized than in their home countries. Furthermore, these respondents thought that the free medical care, social services and infant feeding formula in Canada would contribute to making the decision not to breastfeed easier. One respondent reported,

> You know in Canada they make sure that you really don't get tempted; they help in that way ... there's no way that you can infect your baby. (R4, 32 years, A)

It is important to note that of the five respondents with these perceptions, only one was pregnant at the time of the interview; the rest had older children.

Discussion

We have explored a sample of HIV-positive women's beliefs about infant feeding and how they impact infant feeding choices. The findings should be interpreted with caution because of the study limitations. Ours was a qualitative study; the results are not generalizable and might have been biased in sampling, interviewing and analysis. Despite these limitations, however, we maintain that the results contribute to the current knowledge and practices.

The findings that women still upheld their cultural beliefs about infant feeding, despite having moved from their home countries, was interesting. This would have been good if they were able to breastfeed. However, because their HIV-positive status prohibits them from breastfeeding, they face many challenges in making infant feeding choices, in addition to living with their diagnosis. It is of great concern that some find it necessary to relocate to avoid these challenges, more so given the difficulties they face in accessing affordable housing. Physical relocation may result in further marginalizing of an already marginalized population (Greene et al. 2013).

Moreover, since some of the pressures are from their immediate families, relocation may not solve these women's external pressures permanently. Other viable options are needed, such as education and sensitization of communities about HIV to demystify the disease and reduce stigma. Also, providing these mothers with ways to navigate these pressures would be a useful strategy in preventing them from caving in.

One suggestion from respondents was using peers to support the new HIV-positive mothers. Peers have provided social support successfully in several African countries (The Aids Support Organization 2013). The Ontario HIV Treatment Network is already training peers for research, including a module on peer support and the challenging issues faced by mothers living with HIV, would be a viable intervention.

The health and social support workers supporting these mothers have a very important role to play in mitigating the emotional and psychological difficulties that the women face. First, promotion of breastfeeding in clinics where HIV-positive mothers go may add to their guilt of not breastfeeding. In such clinics, these materials could be removed. Second, since the women struggle with questioning their motherhood, the workers could re-affirm them as good mothers who are trying to protect their children. Third, the workers can provide alternative ways for promoting mother–baby bonding without breastfeeding, for example, opportunities for skin-to-skin contact. And health workers should continue being their patients' advocates and sources of sustained support.

Since both external and internal pressures that women face are entrenched in their cultural beliefs and practices, interventions should be sensitive and culturally relevant to this community to be effective. They should also take into account the cultural underpinnings of different perceptions and practices. The need for cultural sensitivity in provision of care and design of health interventions cannot be overemphasized.

With regard to government policies, many still follow the older version of the WHO guidelines, which have since evolved (WHO 2007, 2010). Since formula is provided at no cost for mothers in Ontario (Teresa 2013), one would assume that opting not to breastfeed is easy. However, the cultural beliefs and divergent contextualized policy recommendations (Coutsoudis et al. 2008) may be confusing and potentially dangerous for women who risk criminalization (Global Network of People Living with Aids 2010), yet they may just be doing what they were told to do in their home countries. The contradicting policies for LICs and high-income countries raise concerns with regard to global justice and are a source of debate (Nogueira 2002; World Alliance for Breastfeeding Action 2013). Conversely, the current WHO guidelines on infant feeding seem to have changed positions in regard to not encouraging breastfeeding for HIV-positive mothers. This is partly due to the discovery that ART and a reduced viral load remarkably reduce the chances of HIV transmission through breast milk (WHO 2010).

Conclusions

Our sample of women expressed psychological and social pressure in making their infant feeding choices, especially since these vary between contexts. These findings, although exploratory, have policy implications within the Canadian context, more so since this population accounts for almost half of mother-to-child HIV transmission cases. Women are routinely strongly advised against breastfeeding in spite of their viral load. There is need for dialogue about this policy, in view of the new WHO guidelines and the study findings. Furthermore, at the service delivery level, providers need to be given clear messages to enable them to provide appropriate counselling on the risks and support for all HIV-positive mothers, whatever choice they may make with regard to infant feeding.

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