

Women Living With HIV in High Income Countries and the Deeper Meaning of Breastfeeding Avoidance: A Metasynthesis

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Abstract

Background: Recommendations to avoid breastfeeding for women living with HIV in high income countries has resulted in a gap in the literature on how healthcare professionals can provide the highest standard of lactation counseling.

Research aims: (1) Describe social and emotional experiences of infant feeding for women living with HIV in high income countries; (2) raise ethical considerations surrounding the clinical recommendation in high income countries to avoid breastfeeding.

Methods: A systematic literature search was conducted between January 1, 2008 and June 20, 2019. A total of 900 papers were screened and six met the inclusion criteria: (a) the sample was drawn from a high-income country regardless of the nativity of participants; (b) some or all participants were women living with HIV. Metasynthesis, according to Noblit and Hare (1988), was used to synthesize the experiences of women living with HIV in high-income countries and their experiences in infant feeding decisions.

Results: Participants in this sample suffered a substantial emotional burden associated with infant feeding experiences potentially leading to risk of internalized stigma, suggesting that infant feeding considerations may contribute to HIV stigma in unique ways. Four overarching themes were identified expressing the meaning of avoidance of breastfeeding: maternal self-worth, deculturalization, surveillance, and intersectionality.

Conclusion: Women in high-income countries living with HIV deserve the highest standard of lactation care and counseling available. Healthcare professionals in high-income countries are ethically obligated to provide evidenced-based lactation care and counseling to women living with HIV.

Keywords

Access to care, breastfeeding, breastfeeding experience, ethics, lactation counseling, mother-to-child transmission

Lactation and breastfeeding are complex, biologically and socially, and provide extensive preventive lifelong effects for women, children, and society (Horta et al., 2015; Rollins et al., 2016; Victora et al., 2016). Thus, breastfeeding is recommended for women and children both in low income (LICs) and high-income countries (HICs), with rare exceptions (Victora et al., 2016). One exception where breastfeeding recommendations diverge is for women living with human immunodeficiency virus (WLWHIV). Because HIV is transmissible through human milk, the presence of HIV infection is considered incompatible with breastfeeding in HICs (World Health Organization, [WHO] 2016a). The longstanding recommendation to avoid breastfeeding for WLWHIV has led to a dearth of literature related to how healthcare professionals (HCPs) practicing in HICs can best meet the unique counseling needs of families in this population. To our knowledge, HIV is the only condition for which breastfeeding recommendations differ according to resources, leading to

ethical questions surrounding parental autonomy in decision-making (Gross et al., 2019) and the role of HCPs in the clinical counseling of WLWHIV in HICs globally.

Background

In LICs, the contemporary standard of practice is to initiate treatment with combination antiretroviral treatment (cART) at the time of HIV diagnosis (WHO, 2016b), and breastfeeding is

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recommended for WLWHIV. Conversely, in HICs where rates of infectious disease are lower, and alternative feeding is generally considered affordable, feasible, acceptable, sustainable, and safe, the greater risk to infants is exposure to HIV (American Academy of Pediatrics, 2013). In these settings, families are generally counseled to avoid breastfeeding.

Evidence from LICs demonstrates that with effective cART for pregnant women and their infants, rates of transmission during exclusive breastfeeding may be reduced to 3–4% at 6 months (Bispo et al., 2017). Based on studies from countries where HIV mother to child transmission (MTCT) risk is high, the evidence supports exclusive breastfeeding for 6 months if women and infants have access to and use cART as directed (WHO, 2016b).

The recommendation for exclusive breastfeeding with concurrent cART has been successful in LICs (WHO, 2016b). Yet, the scarcity of data in HICs presents ongoing challenges to standardizing those recommendations for WLWHIV in HICs. To our knowledge, there is only one published report of the clinical management of WLWHIV ($N = 2$) in a HIC wishing to breastfeed that did not result in HIV transmission to the infants ($N = 3$; Nashid et al., 2019).

Although evidence may be insufficient to recommend exclusive breastfeeding for WLWHIV in HICs, as a matter of reproductive health justice all WLWHIV deserve the highest standard of care available, including infant feeding counseling. Most WLWHIV will experience lactation following birth. Lactation is part of the reproductive continuum and counseling should be available to manage, at the very least, potential discomfort that may be associated with the avoidance of breastfeeding. Ongoing assessment of women's social and emotional well-being is also critically important.

Evidence from LICs and emerging evidence from HICs indicate that, for some WLWHIV, a substantial emotional burden may be associated with infant feeding decisions. For example, evidence surrounding experiences of WLWHIV and breastfeeding in sub-Saharan Africa describes sociocultural stigma, discrimination, trauma, exclusion from communities, fear of HIV status disclosure, and mistrust of HCPs (Tuthill et al., 2014). Similar experiences were reported for women who emigrated to HICs from countries in which HIV is endemic and infant feeding guidelines divergent. Psychosocial consequences included painful emotional loss associated with not breastfeeding and even fear of criminalization laws surrounding HIV transmission (Etowa et al., 2018).

Availability of evidence aside, there is a growing awareness by HCPs that some women may want to breastfeed given the evidence surrounding MTCT in LICs (Gross et al., 2019; Johnson et al., 2016; Kahlert et al., 2018; Levison et al., 2014; Tuthill et al., 2019; Yudin et al., 2016). Much success has been realized in the effective treatment of pregnant women and birth practices that reduce the risk of HIV transmission to infants born in HICs. Far less studied are the social and emotional consequences and ethical considerations associated with the recommendation to avoid breastfeeding for women and infants living in HICs.

Key Messages

- Divergent global breastfeeding guidelines for women living with HIV in high versus low income countries raise ethical considerations for lactation professionals and other health care professionals.
- Women living with HIV in high income countries experience a substantial emotional burden associated with recommendations to avoid breastfeeding. The intersection of culture and power may intensify emotional suffering and lead to social isolation.
- Infant feeding experiences for women living with HIV in high income countries contribute to situation-specific stigma that health care professionals have a responsibility to address.
- Evidence is limited to guide clinical lactation practice for women living with HIV in high income countries who, as a matter of reproductive health justice, deserve care and counseling for issues associated with the avoidance of breastfeeding.

Given the debate in the literature and the recent calls to update clinical guidelines in HICs for women who may wish to breastfeed (Gross et al., 2019), it is critical that lactation and healthcare professionals are armed with evidence to support parents' informed and autonomous decision-making. From an ethical and reproductive justice standpoint, guidelines should reflect the voices of WLWHIV. Due to the longstanding and strict avoidance of breastfeeding for WLWHIV, there is a substantial lack of evidence to inform counseling decisions. The aims of this metasynthesis were to (a) describe the social and emotional experiences of infant feeding for WLWHIV in HICs and (b) raise the ethical considerations associated with the clinical recommendation to avoid breastfeeding in HICs.

Methods

Design

Metasynthesis is an interpretive review process that involves the integration of multiple qualitative reports. The metasynthesis was guided by the process described by Noblit and Hare (1988). We aimed to understand and describe the social and emotional experiences of WLWHIV and their infant feeding decisions. Thus, our method most closely adhered to grounded theory by which metaphors or themes are derived from conceptual data (Sandelowski & Barroso, 2003).

Sample

We searched online databases PubMed, CINAHL and SCOPUS from January 1, 2008 to June 20, 2019, using the following key words and various derivatives: breastfeeding, HIV, high-income country, and counseling. We applied additional filters

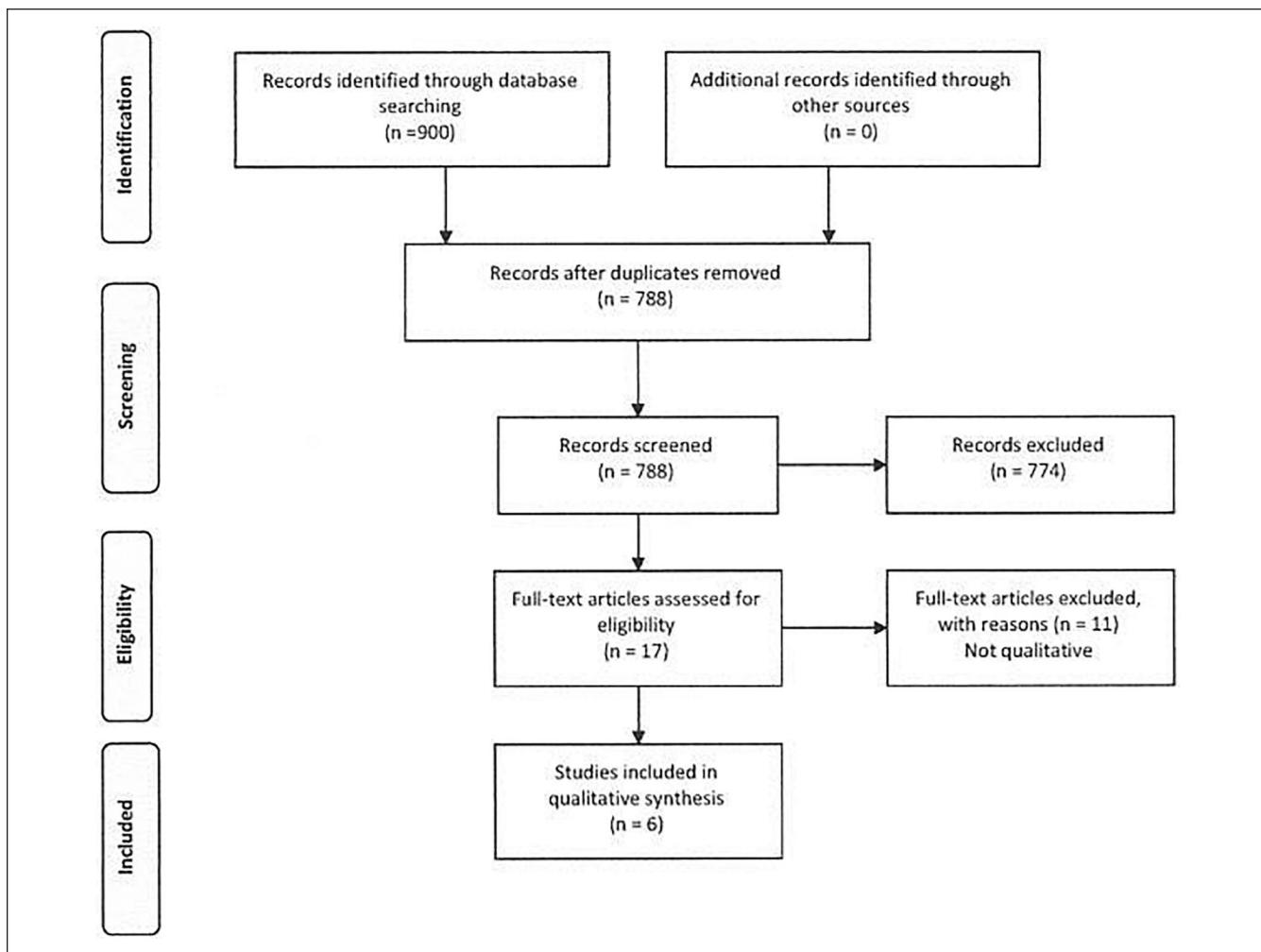


Figure 1. PRISMA Flow Diagram.

of 10 years, clinical study, clinical trial, comment, editorial, journal article, review, humans, and English (see Supplemental Materials). Breastfeeding was broadly conceptualized to mean avoidance of breastfeeding as a behavior and/or product (Noel-Weiss et al., 2012). Our preliminary search indicated that resource rich settings, high-income settings, and countries are terms often used interchangeably. Income was selected as a final search word because it returned the most relevant results to describe countries where resources are generally rich, the prevalence of HIV is relatively low, and families are usually counseled to avoid breastfeeding.

In total, 900 papers were identified, and duplicates removed according to PRISMA guidelines (Figure 1). Both authors (MG and JPT) screened all remaining titles and abstracts. We included all papers in which (a) the sample was drawn from a HIC regardless of nativity of participants and (b) some or all participants were WLWHIV. We did not evaluate the quality of research because so few published qualitative papers exist on the topic; however, we do include the reported methods of each paper in Table 1. A total of 17 papers met the inclusion criteria. We excluded

11 papers because they were not qualitative reports. We defined qualitative broadly (Sandelowski & Barroso, 2003). We considered papers to be qualitative if a specific qualitative methodology was employed, a theoretical or conceptual framework was explicitly applied, and/or participants shared their experiences as individuals or part of a group directly with the researchers. A total of six papers were selected for the metasynthesis.

The substantial volume of research that is focused in LICs compared with the relatively few qualitative studies published in HICs prompted the selection of metasynthesis so that these studies and the experiences of WLWHIV therein do not remain as “respected little islands of knowledge” (Glaser & Strauss, 1971, p. 181). Rather, the studies were synthesized to build cumulative knowledge that will inform clinical practice.

Data Analysis

Noblit and Hare (1988) recommend seven phases to the process of metasynthesis: getting started, deciding what is

Table 1. Characteristics of Studies and Individual Study Participants Included in Metasynthesis (N = 6).

Study	Method	Framework	Country	N	Age	Sample Characteristics
Kapiriri et al. (2014)	Individual interviews & focus groups	Not reported	Canada	25	21–56 years	Afro-Caribbean and black immigrant women living with HIV
Treisman et al. (2014)	Semi-structured interviews	Interpretive phenomenology	United Kingdom	12	23–41 years	African women living in the UK with HIV diagnosed during pregnancy
Greene et al. (2015)	Narrative interviews	Social determinants of women's health	Canada	33	21–42 years	Over half identified as black or African; 48% originated from Canada and 45% originated from Africa
Hufton et al. (2016)	Focus groups & semi-structured interviews	Not reported	United Kingdom	30	Not reported	Large proportion of mothers are black African refugees or asylum seekers living with and without HIV.
						Five health care providers working with refugees in maternal health settings
Kapiriri et al. (2016)	Individual interviews & focus groups	Not reported	Canada	27	21–56 years	Afro-Caribbean and black immigrant women living with HIV
Tariq et al. (2016)	Semi-structured interviews	Risk as a social construct framework	United Kingdom	23	Not reported	African WLWHIV from larger study of engagement with HIV care during and after pregnancy

relevant, reading the studies, determining how the studies are related, translating the studies into one another, synthesizing translations, and expressing the synthesis. Each of these steps in the process is detailed below.

Getting Started. Noblit and Hare (1988) suggest that the value of a metasynthesis resides in its interest to the authors. In this case, we were compelled to understand *how* to provide the highest standard of care to our patients in practice. To do this, it is critical to understand how WLWHIV in HICs experience recommendations to avoid breastfeeding.

Deciding What is Relevant. Noblit and Hare (1988) emphasize the importance of a valid justification. As practice statements are revised and clinicians in HICs explore the possibility of breastfeeding for WLWHIV (Gross et al., 2019), HCPs will be ethically obligated to provide the highest standard of care available. We selected a review of qualitative research because qualitative research guides clinical interventions that are grounded in the “particularities of human experience” (Sandelowski & Barroso, 2003, p. 158).

Reading the Studies. Metasynthesis is the result of an approach that uses ethnographic techniques (Noblit & Hare, 1988). Thus, meta-ethnography precedes synthesis. For the

purpose of our study this required reading and re-reading the studies so that the meaning of each study was understood as a whole and not solely through the findings reported by the authors. Throughout the process, both authors discussed each study to reach agreement on the meaning of individual studies before determining the relationship of one study to another.

Determining how the Studies are Related. After multiple readings of individual studies, both authors met to discuss initial interpretations. By focusing on key quotes and statements made by study participants, we identified and coded preliminary concepts in preparation for translating the studies into one another.

Translating the Studies Into one Another. The translation of studies in meta-ethnography aims to “protect the particular, respect holism, and enable comparison” (Noblit & Hare, 1988, p. 28). We used initial interpretations of the data extracted from individual studies to compare and contrast concepts across studies, specifically looking for commonalities and differences.

Synthesizing Translations. Synthesizing the translations is about making a whole of the parts. Noblit and Hare (1988)

Table 2. Lines of Argument Synthesis According to Themes.

Lines of Argument Synthesis	Themes			
	Maternal self-worth	Deculturalization	Surveillance	Intersectionality
Expression	Guilt Loss Disappointment Devastation Hopelessness/Helplessness Self-neglect Suicidal ideation Strength Resilience Children gave them reason to live	Avoidance of breastfeeding resulted in feeling less of a: Woman Mother Revisiting avoidance of breastfeeding resulting in painful reminders of HIV status	Emotional energy on devising lies for family members Guilt and humiliation from lying to family members Distrust of HCPs	Social isolation
Formal structure	Good vs. bad mothers Breast is best Best nutrition Bonding	Immigration	Fear of disclosure of HIV status to loved ones, community	Insecure Immigration status Fear of disclosure and related marginalization of children from the community Criminalization laws
Substructure	Past experiences: Rape Trauma Violence	Surrendering mental and physical abilities to continue cultural practices	Thoughts of relocation Partially breastfeeding child to avoid disclosure Pressure to breastfeed by family members Pressure not to breastfeed by HCPs	Lack of resources to meet recommendation to avoid breastfeeding Insecure immigration status prevents seeking social assistance Not knowing criminalization laws creates risk due to duplicity of global standards

Note. Adapted from Noblit, G. W., & Hare, R. D. (1988). *Meta-Ethnography: Synthesizing Qualitative Studies*. Newbury Park, CA: Sage.

suggested that with large amounts of data, secondary synthesis might be indicated. As such, as highlighted by Noblit and Hare, the reciprocal translation required us to go further with constant comparison, as used in grounded theory. In contrast to studies that refute one another, the studies we reviewed essentially told the same story. The greater whole of individual studies allowed us to address our aims by using what Noblit and Hare (1988) refer to as “lines of argument” synthesis (p. 62), the purpose of which is to make clinical inferences, in this case regarding the counseling of WLWHIV.

We constructed a synthesis table (not shown) to analyze relationships between studies using the initial list of key concepts. Initially, we worked from the top down. Next, we worked from the bottom up (Table 2) to determine the “substructure” or deeper meaning of individual studies using words and phrases expressed by participants in the studies (Noblit & Hare, 1988, p. 50). We then applied the deeper meaning to the formal structure of the findings and, finally, to how WLWHIV in this sample expressed their experiences. Lastly, we reached agreement on the final concepts and themes.

Expressing the Synthesis. Noblit and Hare (1988) urge authors to consider methods of expression that are true to the intent of the information described. We view the results of this metasynthesis as an opportunity to further open the dialogue surrounding clinical care of WLWHIV and the deeper

meaning of their experiences in navigating infant feeding decisions.

Results

Characteristics of the Sample

Notably, many of the study participants were immigrant women and only two countries were represented by the systematic search, Canada (3) and the United Kingdom (3). Table 1 describes the characteristics of studies and participants

Aim 1: Social and Emotional Experiences

The synthesis of qualitative data surrounding the experiences of WLWHIV and infant feeding in the HICs resulted in the identification of four overarching themes for this sample. These were maternal self-worth, deculturalization, surveillance, and intersectionality.

Maternal Self-Worth. Participants expressed the importance of breastfeeding as part of their maternal identity or self-worth. Despite some of the participants not specifically being asked about breastfeeding, many expressed that breastfeeding was inseparable from their role as a mother (Greene et al., 2015).

Some of the painful guilt and loss resulting from having to avoid breastfeeding was expressed through historical myths of motherhood. Specifically, “good” mothers breastfeed, and “bad” mothers do not (Tariq et al., 2016, p. 333). Externally imposed social and health-related messaging including “breast is best” contributed to internal feelings of guilt for not being able to provide what they perceived to be the best nutrition and bonding experience for their infants (Greene et al., 2015; Kapiriri et al., 2014).

The participants in the sample expressed powerful emotional responses to receiving a diagnosis of HIV and the inability to breastfeed their children. Participants expressed emotions ranging from guilt and disappointment (Hufton & Raven, 2016) to “devastation” (Tariq et al., 2016, p. 333). Treisman and colleagues (2014) reported that for some WLWHIV, the circumstances under which the virus was contracted preceded the emotional burden of breastfeeding loss. Experiences reported include rape, trauma, and violence leading to a sense of hopelessness, self-neglect and, for some, suicidal ideation (Treisman et al., 2014). Simultaneously, a sense of strength and resilience was realized through connections to others with similar experiences, and through feeling that their children gave them reason to live (Treisman et al., 2014).

Deculturalization. Many participants in this sample were WLWHIV who had emigrated to HICs, mainly from African countries. We highlight the specific challenges expressed by the participants as these may have unique implications for infant feeding counseling. In contrast to “acculturalization,” whereby over time cultural practices are voluntarily relinquished, “deculturalization” can be understood in the context of infant feeding as surrendering the “mental and physical abilities to continue the practices” (Hufton & Raven, 2016, p. 309).

Deculturalization was noted across studies, and was manifested in deep emotional responses to the loss of breastfeeding. Women expressed the cultural importance of breastfeeding and associated feeling “unnatural” and “not womanly” with avoidance of breastfeeding (Treisman et al., 2014, p. 152). Of note, WLWHIV also expressed that the avoidance of breastfeeding was not an isolated decision but rather one that they revisited often. Revisiting their decision resulted in painful reminders about their HIV status (Tariq et al., 2016).

Surveillance. In several studies, participants reported perceptions of feeling under surveillance. In the health care setting, some lactation professionals were perceived to be “overzealous” (Greene et al., 2015, p. 891) in recommending lactation support. HCPs are obligated to know each patient’s history. Not knowing the individual’s history required WLWHIV to disclose their status sometimes with family members in the room (Greene et al., 2015). WLWHIV often reported feeling pressured to breastfeed by family yet pressured to avoid breastfeeding by HCPs. Fear and concern about disclosure of

HIV status prominently influenced emotional responses. Feeling constantly under surveillance, some WLWHIV expressed thoughts of relocation to avoid disclosure to family (Kapiriri et al., 2014).

Internal conflicting feelings were reported about the painful choice between disclosure of HIV status to family members versus the emotional energy spent on devising lies (Hufton & Raven, 2016; Kapiriri et al., 2014; Tariq et al., 2016). Greene et al. (2015) reported that “some women went to great lengths to conceal the fact that they were feeding their baby formula” (p. 893). Relocation and familial disclosure further marginalized and isolated WLWHIV and, for a few, the pressure may have resulted in them partially breastfeeding their infants (Kapiriri et al., 2014; Tariq et al., 2016).

Intersectionality. Intersectionality refers to how social and political landscapes intersect with gender (Crenshaw, 1991). Greene et al. (2015) acknowledged the complex intersections of “sexual and gender identity, race, class, geographic location, and access to key material resources” (p. 887). Here, we use the concept of intersectionality to also reflect how social and political factors for WLWHIV intersect with infant feeding experiences. Socially, several researchers reported that decisions surrounding infant feeding intensified the influence of HIV for WLWHIV, particularly for lower income women and for immigrant women (Hufton & Raven, 2016; Kapiriri et al., 2016; Tariq et al., 2016). Lower income women may lack resources necessary to exclusively formula feed to meet the recommendations in HICs. The costs associated with buying formula and even basic equipment may be prohibitive. Social assistance programs may be available, but for women who may be concerned with insecure immigration status, seeking assistance may not be viewed as a safe choice (Tariq et al., 2016). Navigating complex healthcare systems, while balancing concerns about disclosure and the marginalization of one’s children, may alienate low-income women from receiving necessary care.

Political landscapes may also be of considerable concern. Criminalization laws pertain to the willful transmission of HIV and at least 60 countries have enacted related laws (Kapiriri et al., 2016). Because women bear the reproductive burden of birth and breastfeeding, current criminalization laws as they pertain to HIV disproportionately affect women (Kapiriri et al., 2016). WLWHIV who leave their home countries where exclusive breastfeeding is recommended and arrive in countries where the avoidance of breastfeeding is strongly recommended, face the additional burden of possible criminalization simply because they may not know about the laws (Kapiriri et al., 2016).

Aim 2: Ethical Considerations for HCPs

We aimed to describe the ethical considerations surrounding the clinical recommendation to avoid breastfeeding. WLWHIV in our sample expressed social and emotional

experiences related to infant feeding that may increase risks of social isolation, depression, and compromised quality of life. Syndemic risk, a framework that historically described a biomedical model of comorbidity, is gaining popularity for describing “mutually reinforcing health and psychosocial problems that generate increased health risk and burden on vulnerable populations” (Batchelder et al., 2015, p. 229). We suggest that infant feeding dilemmas may demonstrate compounding risk for WLWHIV in HICs. The WHO (2016a) recommends skilled lactation counseling and support for all pregnant WLWHIV. Yet, it is unclear in HICs if WLWHIV receive counseling that addresses their concerns about breastfeeding or if they receive infant feeding support and counseling at all.

The scarcity of research and counseling guidelines regarding infant feeding, coupled with an increasing awareness from HCPs that WLWHIV in HICs may want to breastfeed (Tuthill et al., 2019), is at best concerning and at worst a potential breach of ethical responsibility on the part of HCPs. HCPs are in a position to build trust with WLWHIV, provide skilled lactation care, and assess and address psychosocial concerns (Tuthill et al., 2014; 2019). Without attention to these considerations, HCPs may reinforce risk by implicitly isolating WLWHIV who might benefit from their ongoing skilled support.

Discussion

We aimed to synthesize the experiences of WLWHIV in HICs and their infant feeding experiences in the context of breastfeeding, highlighting the ethical and clinical considerations involved with the recommendation in HICs to avoid breastfeeding. The experiences expressed by women in our sample are somewhat novel given that research surrounding HIV and breastfeeding is limited in HICs due, in part, to recommendations to avoid breastfeeding. Overall, the results indicate a substantial emotional burden associated with specific stigmatizing experiences of WLWHIV and their infant feeding decisions.

A large body of evidence exists surrounding experiences of stigma and discrimination and subsequent mental and physical health outcomes for people living with HIV (Clair et al., 2016). Stigma can be understood as a social phenomenon resulting in the devaluation of human beings based on a variety of social characteristics including HIV status. Stigma has been described as rooted at the intersection of “culture, power and difference” (Cuca et al., 2017, p. 46).

Stigma and subsequent discrimination operate through complex social systems including healthcare in HICs. For example, stigma has been associated with HIV medication adherence challenges in the United States (Turan et al., 2019) and lower quality of life in Finland (Nobre et al., 2018). A robust body of literature describes the effect of racial discrimination on health in the United States (Williams &

Mohammed, 2013; Williams & Wyatt, 2015). Research is limited on the specific mechanisms through which stigma operates for WLWHIV in the context of breastfeeding. However, Ion et al. (2017) have reported that HIV-specific stigma in the perinatal period predicted higher levels of depression, stress, social isolation, and racism in the third trimester of pregnancy.

The themes identified in this review tell a story of specific stigma associated with WLWHIV and their experiences of infant feeding. While we were unable to discern specific examples of externally imposed stigma for WLWHIV, it is reasonable to argue that internalized stigma was being expressed through emotional and psychological responses. Internalized stigma can affect how WLWHIV value themselves and can lead to low self-esteem and, ultimately, to WLWHIV distancing themselves from those who might otherwise provide support (Cuca et al., 2017). For example, we highlight in the maternal self-worth theme how the labels of “good” and “bad” mothers are associated with breastfeeding and not breastfeeding respectively (Tariq et al., 2016, p. 333). In one study, a participant referred to her milk as “contaminated” (Greene et al., 2015, p. 894). Another example of distancing expressed by WLHIV was a result of having to protect themselves from disclosure while simultaneously protecting their children from marginalization. WLWHIV reported being untruthful with loved ones and going so far as to consider relocation. Perceived surveillance between WLHIV and subsequent distancing has been reported elsewhere (Greene et al., 2017). Ion and Elston (2015) reported that WLWHIV perceived HIV-related stigma from HCPs surrounding access to care, lack of HCP knowledge, and HIV disclosure, leading to mistrust and disengagement from the healthcare system.

Themes describing deculturalization and intersectionality provided additional evidence of internalized stigma for WLWHIV in our sample, resulting in potential risk of social isolation. Emerging research demonstrates that social isolation may predict depressive symptoms, in turn predicting challenges with medication adherence for women in minority groups (Turan et al., 2016; 2019). WLWHIV who may be deeply connected to cultural expectations to breastfeed may be of greatest risk for social isolation and adverse outcomes. In addition to painful experiences surrounding breastfeeding, HIV diagnosis was associated with feelings of hopelessness, self-neglect, and suicidal ideation in one study (Treisman et al., 2014). Our review suggests that infant feeding concerns may contribute to WLWHIV’s distress in unique ways that are different from pregnancy. One way is feeling the need to lie to family members about feeding decisions, which contributed to feelings of shame and humiliation, as expressed by several participants. Criminalization laws provide further examples of extreme surveillance that may isolate WLWHIV from seeking infant feeding counseling.

Limitations

First, there were only a small number of qualitative research studies that explored the infant feeding experiences of WLWHIV in HICs. Second, of those studies, a large proportion of participants were born outside of HICs, so their experiences may have been different from WLWHIV who were born in HICs. We suggest that this is an important area for future research. Third, we used a broad definition of “qualitative” for the inclusion of studies in this review. We recommend that future qualitative research adhere to rigorous methodological standards to advance understanding of the infant feeding experiences of WLWHIV in HICs. Fourth, although we used a systematic search method, there may have been reports that were not identified. Finally, we use the terms LICs and HICs but we acknowledge the substantial variation within each. Many reports used the terms high resource settings and HICs interchangeably. It would be useful for the HIV research community to agree on how to use these terms for greater clarity.

Conclusion

Despite profound psychosocial burden reported by WLWHIV in these studies, there was a clear responsibility and commitment to protect their children from HIV transmission by not breastfeeding (Kapiriri et al., 2014; 2016). The decision to avoid breastfeeding was not a difficult one per se, but navigating the challenges associated with the decision were profound. HCPs are in a position to assuage some of the emotional burden experienced by WLWHIV in the context of infant feeding. This will require a substantial shift in cultural norms in HICs so that stigma is reduced.

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Supplemental Material

Supplementary Material may be found in the “Supplemental material” tab in the online version of this article.

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