Breastfeeding and HIV-Infected Women in the United States: Harm Reduction Counseling Strategies

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Social and cultural forces have led some human immunodeficiency virus (HIV)–infected women to question the recommendation in the United States not to breastfeed. Without an open dialogue, women may choose to breastfeed exclusively or intermittently and not disclose this to their provider. We review the evidence from global studies of the risks of breastfeeding among HIV-infected mothers and propose a harm reduction model for women considering breastfeeding.

Keywords. breastfeeding; HIV; perinatal transmission; United States; harm reduction.

Several health interventions can be credited with the successful reduction in perinatal human immunodeficiency virus (HIV) transmission in the United States: routine prenatal HIV testing, rapid HIV testing on labor and delivery, maternal antiretroviral (ARV) therapy, infant ARV prophylaxis, and formula feeding. With optimal viral suppression at delivery, postnatal infant prophylaxis, and avoidance of breastfeeding, the risk of perinatal HIV transmission is 0.1% [1]. In the United States, infant formula is widely available and most water sources are safe; HIV-infected women are advised to avoid breastfeeding because of the increased risk of HIV transmission to their infants via breast milk [2–7]. Even though avoidance of breastfeeding has been a standard recommendation for HIV-infected women in the United States over the past 3 decades, some women are choosing to breastfeed.

LEARNING FROM RESOURCE-LIMITED SETTING STUDIES AND GUIDELINES

In resource-limited settings, morbidity and mortality are significantly higher among infants who are formula-fed compared with those who are breastfed, leading to recommendations for HIV-infected women to breastfeed when there is limited access to formula and clean drinking water [8–10]. Originally evaluated to minimize exposure to breast milk, mixed feeding (combined breast and formula feeding) was found to be associated with higher risk of HIV transmission compared with exclusive breastfeeding [11–15]. Kuhn et al demonstrated that HIV viral load in breast milk rises at the time of weaning or other disruptions in continuous breastfeeding [16]. Researchers have also identified an HIV-neutralizing protein in breast milk, tenascin C, which appears to inhibit binding of HIV virions to cells [17]. As a result, exclusive breastfeeding among HIV-infected women is recommended in low-resource areas.

Maternal and/or infant ARV use during breastfeeding dramatically reduces postnatal HIV transmission. In the absence of ARV use by either the breastfeeding woman or the infant, postnatal HIV transmission ranges from 1.6% in women with CD4 counts >350 cells/µL to 17% in women with CD4 counts <200 cells/µL [18]. In Kenya and Burkina Faso, the Kesho Bora study demonstrated that breastfeeding women maintained on triple...
ARV therapy (zidovudine, lamivudine, and lopinavir/ritonavir twice daily) until cessation of weaning at 20 weeks after birth had a lower risk of HIV transmission to their babies at 12-month follow-up (5.4%) than women whose babies received prophylactic ARVs (single-dose nevirapine at birth and lamivudine twice daily) only during the first week of life (9.5%) [19]. The Mma Bana Study in Botswana found that maternal ARV use (twice daily zidovudine/ lamivudine with a) abacavir OR b) lopinavir/ritonavir OR c) nevirapine) during pregnancy, and up to 6 months of breastfeeding was associated with a 1.1% cumulative risk of transmission [20]. However, 2 cases of late postnatal transmission (via breastfeeding) in women with undetectable viral loads did occur by 3 months of age; of note, both mothers were on triple nucleoside reverse transcriptase inhibitors, which may have been less potent than the more commonly used nonnucleoside reverse transcriptase inhibitor or protease inhibitor–based regimens. While postnatal maternal ARV adherence in these 2 cases may have been suboptimal, difficulties with ARV adherence are common, particularly postpartum, and may be more challenging in the nonclinical trial setting [21–23]. The Breastfeeding, Antiretrovirals, and Nutrition (BAN) trial compared infant ARV prophylaxis (daily nevirapine in increasing doses according to infant weight) vs maternal ARV therapy (the majority received zidovudine/lamivudine with lopinavir/ritonavir twice daily) for the duration of breastfeeding vs a control group of 1 week of neonatal ARV prophylaxis. At 6 months postpartum, the cumulative HIV incidence was 1.7%, 2.9%, and 5.7%, respectively [24].

These findings shaped the current 2010 World Health Organization recommendations for low-resource settings: offer maternal ARV therapy throughout pregnancy and breastfeeding or maternal ARV therapy during pregnancy and infant ARV prophylaxis during breastfeeding until 1 week after complete weaning [25, 26].

Limited information is available as to outcomes of breastfeeding among HIV-infected women in the United States. Birkhead et al studied women in New York State 1988–2008 [27], and the Centers for Disease Control and Prevention’s Enhanced Perinatal Surveillance system [7] assessed outcomes among breastfeeding women in 15 US jurisdictions between 2005 and 2008; both found a 4.4–4.6 increase in HIV transmission among breastfed babies. However, many of their subjects were diagnosed late, were not on ARV therapy, and did not have optimal viral suppression before embarking on breastfeeding.

**HIV-INFECTED WOMEN IN THE UNITED STATES WHO DESIRE BREASTFEEDING: A WOMAN-CENTERED, HARM REDUCTION APPROACH TO COUNSELING**

Despite the clear US recommendation to avoid breastfeeding, some HIV-infected women are asking about the possibility of breastfeeding or choosing to breastfeed despite professional advice to the contrary. The National Perinatal HIV Hotline (2 of our authors staff this service) receives at least 2 calls per year from clinicians with questions about counseling HIV-infected pregnant women who are considering breastfeeding after delivery. A 2013 informal online survey of ReproIDHIV listserv subscribers of 280 clinicians, nurses, and epidemiologists involved in HIV care yielded a full spectrum of responses, ranging from “No one has asked if it was possible to breastfeed when HIV-infected (but I’ve never specifically explored it with women)” to “I have found that if we ask the question, then in fact a lot of these women struggle with this issue, and although they understand our recommendation not to breastfeed, they still have a lot of social, familial, and personal pressure to consider breastfeeding.” Some clinicians suspected that women had breastfed but not admitted it for fear of being criticized. In 2013, >200 individuals attended a regional perinatal forum in New York City and >50 women attended a community forum in Toronto to discuss the issue of HIV-infected women and breastfeeding.

**Case Study 1**

A 32-year-old woman, originally from Nigeria, was diagnosed with HIV during her current pregnancy. During prenatal care, she communicated to her obstetrician her desire to breastfeed. She feared that not breastfeeding would raise suspicion in her community about her HIV status. The patient was referred to the local pediatric HIV specialist, who explained the risks of HIV transmission via breastfeeding, as well as safety and efficacy data on breastfeeding with maternal ARV therapy and infant prophylactic ARVs until weaning. The patient expressed relief to discuss her concerns with a provider and continued to consider breastfeeding. Knowing she had options provided a space for her to contemplate the best decision for her situation. She opted to breastfeed for 6 weeks, both to “prove” to her community that she does not have HIV and in response to public messages that “breast is best.” Both she and her baby remained on ARVs while she breastfed.

**Case Study 2**

A 35-year-old woman in her second pregnancy with a known HIV-infected husband was diagnosed with HIV at the intake prenatal visit of her second pregnancy. She disclosed that the hardest part of adjusting to her diagnosis was the recommendation against breastfeeding. She had breastfed her first child for 2 years, had planned to do the same with this infant, and felt that breastfeeding provided optimal nutrition and immune support and was a critical component of mother–baby bonding. The obstetrician suggested she discuss her concerns with her infectious disease primary care clinician. After validating the desire to breastfeed, the infectious disease clinician reviewed the health
benefits of breastfeeding, the current data on HIV transmission risks with breastfeeding, the unknown safety of infant exposure to ARVs through breast milk, alternatives to breastfeeding, and additional methods to enhance bonding with her baby. The clinician also advised 1 session with the pediatric infectious disease physician who would be following her baby. Ultimately, the patient opted for banked human breast milk, which she fed her baby for 1 year.

With these scenarios in mind, we explore a model using a harm reduction approach to facilitate counseling and managing HIV-infected women in the United States who express a desire to breastfeed. The strategy includes validation of a woman’s desire to breastfeed, understanding her motivation to breastfeed, exploring alternatives, and offering harm reduction.

Validate Her Desire to Breastfeed
Engaging each HIV-infected pregnant woman about breastfeeding, and encouraging discussion about her feelings and thoughts about breastfeeding, provide an opportunity to explore her perspective and desires without endorsing breastfeeding. Validating her experience well ahead of delivery offers more time to support the woman through the HIV disclosure process and develop strategies to maximally reduce perinatal HIV transmission risk. The decision to breastfeed or formula feed can be a conflicted experience for some HIV-infected women, and engaging a woman in a discussion may enhance openness about her desires and, ultimately, her infant feeding practices.

Seek to Understand Her Motivation to Breastfeed
Social and cultural forces have led some HIV-infected women to question or ignore the US recommendation against breastfeeding [28]. Stigma, cultural pressure, and/or awareness of health benefits of breastfeeding may play a role in their decision-making process. The first case illustrates how formula feeding may be perceived as a surrogate for having HIV within some African and other immigrant communities in the United States. Stigma remains strong, and fears around disclosure or exposure of HIV status play a significant role in women’s decision making about infant feeding [28].

In the second case study, awareness of the nutritional benefits of breastfeeding, desire for bonding through breastfeeding, preference for “natural” processes, and avoidance of unnecessary medical interventions influenced the woman’s desire to breastfeed. Also, the Women, Infants, and Children (WIC) program provides additional food and financial benefits while breastfeeding; many women are hesitant to explain to the WIC personnel that they are not breastfeeding secondary to HIV. Any changes in policy will need to be made on a federal level. Knowing the motives and supporting women in navigating the varying messages about breastfeeding can guide the provider’s counseling.

Explore Alternatives
When faced with these scenarios, clinicians have both a responsibility and opportunity to educate women about HIV transmission risk associated with breastfeeding even with maternal ARV therapy and/or infant prophylaxis. Without an open and ongoing dialogue, women may choose to breastfeed and not disclose this to their provider or avoid treatment altogether. Providers might consider discussions about breastfeeding as part of the education process to support patients in making informed choices and as part of a risk reduction model of care. Similarly, clinicians should also review with women the risks of HIV transmission via premastication (prechewing) of infant food [29, 30]. The cornerstone of safer feeding counseling is an inclusive discussion about all options available to HIV-infected women. The conversation may include the following (Table 1):

1. Formula feeding: In high-resource settings where formula is affordable, feasible, accessible, safe, and sustainable, formula feeding is a method with zero risk of HIV transmission, assuming no breastfeeding or premastication of food occurs [29, 30].
2. Banked breast milk: Human milk banks have traditionally provided breast milk to premature babies whose mothers may not have adequate milk supply, with a goal of providing optimal nutrition as well as preventing necrotizing enterocolitis. Banked breast milk may also be used to feed babies whose mothers have multiple infants, are ill, are on medication incompatible with nursing, or have infections such as HIV that are transmissible via breastfeeding. There are 13 milk banks affiliated with the Human Milk Banking Association of North America (HMBANA), which as of 2010 served 39 states and 264 cities in the United States and 3 provinces and 7 cities in Canada [31, 32].

Milk banks pasteurize donated human breast milk and the donors are tested for HIV; use of milk pasteurized by the milk bank reduces the chance of microbial contamination found in tested samples obtained from online sellers [32]. Although the current out-of-pocket cost for banked breast milk processing and shipment is $3–$5 per ounce, some hospitals as well as private and public insurance companies cover these costs. The HMBANA guidelines stipulate that no one will be denied banked breast milk because of inability to pay. In the unregulated, online market, the cost of buying breast milk from women with surplus milk supply is in the range of $1–$3 per ounce [33].

Offer Harm Reduction
An alternative to the unequivocal directive, “Do not breastfeed,” is a harm reduction model, which presents individuals with options that may reduce the risk of a negative outcome in the setting of potentially risky behaviors. The model suggests that “people will make more health-positive choices if they have access to adequate support, empowerment, and education” [34]. Harm reduction has been applied to several risky health behaviors, including illicit drug use. Whereas stopping drug use may
be the optimal outcome, needle exchange programs, which have been associated with decreased risk of HIV transmission, may be a more realistic intervention for someone who is not committed to stopping drug use [35]. Harm reduction is best offered as one part of a multifaceted prevention package in which the patient has access to the tools or methods that work best for them at that time.

Applying the harm reduction model to breastfeeding among HIV-infected women in the United States may include asking HIV-infected pregnant women, “What does the recommendation to avoid breastfeeding mean to you? How will this be perceived by your family and friends?” Providers may then offer a hierarchical message, strongly emphasizing bottle feeding (either formula or banked human milk) as optimal but offering alternatives to those women who decide to breastfeed despite being fully informed of the risks, including exclusive breastfeeding while receiving maternal and/or infant ARVs [19, 23], heat-treating breast milk [36], or using a lactational surrogate or “wet nurse.”

**Table 1. Potential Risks and Benefits of Different Feeding Options for HIV-Exposed Infants in the United States**

<table>
<thead>
<tr>
<th>Feeding Option</th>
<th>Risk of HIV Transmission</th>
<th>Cultural Acceptability</th>
<th>Feasibility</th>
<th>Affordability</th>
<th>Sustainability</th>
<th>Safety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formula feeding</td>
<td>None</td>
<td>+/-</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>+++</td>
</tr>
<tr>
<td>Milk bank</td>
<td>Nonea</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>+++</td>
</tr>
<tr>
<td>Exclusive breastfeeding while on maternal ARVs</td>
<td>1.1% (Mama Bana)</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>+</td>
</tr>
<tr>
<td>Exclusive breastfeeding and infant ARV prophylaxis</td>
<td>1.7% (BAN)</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>Unknown in the US; +++ outside of US</td>
<td>No US data</td>
</tr>
<tr>
<td>Flash-heat treatment</td>
<td>No efficacy data available</td>
<td>Unknown in the US, + outside of US</td>
<td>Unknown in the US, + outside of US</td>
<td>++</td>
<td>Unknown</td>
<td>++</td>
</tr>
<tr>
<td>Lactational surrogate (“wet nurse”)</td>
<td>None/minimalb</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>++</td>
</tr>
</tbody>
</table>

Abbreviations: +/-, potential for both risks and benefits; +, benefit; +++, great benefit; ARV, antiretroviral; BAN, Breastfeeding, Antiretrovirals, and Nutrition study; HIV, human immunodeficiency virus.

a Assuming adequate HIV testing of milk donor.
b Assuming adequate HIV testing of and no risk for incident HIV in wet nurse.

therapy and viral suppression is critical to minimize risk of lactational HIV transmission. The BAN study estimated a 1.7% risk of HIV acquisition among infants receiving ARV prophylaxis while breastfeeding [24]. Although the risk of transmission during breastfeeding is likely very low if a woman has an undetectable viral load and/or the infant receives ARV prophylaxis, transmissions may still occur. Additionally, much is still unknown about how to eliminate lactational transmission risk and any possible long-term risks of infant ARV exposure via breast milk.

**Heat Treatment of Breast Milk**

Flash heat treatment involves heating a glass container of expressed breast milk in a water bath until the water boils (which raises the milk temperature to approximately 73°C) and then allowing the milk temperature to drop to 37°C [37]. Flash heating of breast milk has been demonstrated to inactivate the infectivity of HIV in vitro and has been found to be feasible and acceptable among some HIV-infected women living in resource-limited settings [37, 38]. Flash heating does not appear to compromise the nutritional benefits of breast milk. In one study, flash heating increased folic and vitamins A, B12, and C to nontoxic levels, presumably secondary to the release of vitamins from binding proteins in the breast milk, and slightly decreased B2 and B6 [37]. However, flash heating is time consuming and may not alleviate the pressure to breastfeed among women who have not disclosed their HIV status. Moreover, this strategy has not been evaluated in large observational studies or clinical trials, so its effectiveness in eliminating breast milk...
transmission and the feasibility in nonresearch, resource-rich settings are not well established.

Lactational Surrogate
A lactational surrogate is a lactating woman other than the baby’s mother who breastfeeds the infant. Before choosing such a surrogate, establishing her HIV-negative status is critical. Similarly, as there are >50 cases of HIV transmission from a child to a nursing woman [39], ruling out HIV in the HIV-exposed infant is necessary. It is also crucial to assess the risk of incident HIV infection among lactational surrogates, including the option of serial HIV testing for those who are sexually active or potentially exposed to HIV in other settings.

NEXT STEPS FOR THE CLINICIAN

Initiating an infant feeding conversation using principles of harm reduction, clinicians would first ask open-ended, non-judgmental questions. Unless we inquire, even well-intentioned providers may miss an opportunity to identify women who may be considering breastfeeding. Validate a woman’s desire to breastfeed, seek to understand why, then approach the conversations from a risk reduction model.

Based on HIV-exposed infant feeding recommendations published by the British HIV Association in 2012 [40] and the American Academy of Pediatrics [3], the management of an HIV-infected woman who opts to breastfeed might include the following steps:

1. Discuss timing of and methods of weaning and the option to switch to formula or banked human milk at any time.
2. Discuss what is known and not known about reduction in lactational HIV transmission with the use of maternal ARVs, maternal ARV penetration into breast milk [41], and infant safety with ARV exposure via breast milk.
3. Explain that exclusive breastfeeding appears safer than mixed formula/breastfeeding. Provide resources, including a lactation consultant as needed, to support successful exclusive breastfeeding.
4. Ensure the woman is receiving a suppressive ARV regimen.
5. Discuss the option of infant ARV prophylaxis beyond the standard 6 weeks of zidovudine syrup, particularly if mother’s viral load is not suppressed or if there is concern for suboptimal maternal ARV adherence postpartum. This may include daily nevirapine until 1 week after weaning [25]. Also, lopinavir/ritonavir has been shown to be noninferior to lamivudine for infant prophylaxis until after cessation of breastfeeding with transmission rates of 1.4% and 1.5%, respectively [42].
6. Monitor maternal viral load monthly throughout the duration of breastfeeding.
7. Conduct HIV polymerase chain reaction testing for the infant monthly while breastfeeding and at 1, 3, and 6 months after weaning.
8. Monitor the infant for evidence of hematologic toxicity depending on ARV regimen and pediatric recommendations.
9. Educate the woman about presenting for care immediately for signs of mastitis and the importance of treating mastitis promptly to minimize HIV shedding in the breast milk compartment.

CONCLUSIONS

In resource-rich settings where formula feeding is acceptable, feasible, affordable, sustainable, and safe, feeding an HIV-exposed infant formula or breast milk from a licensed milk bank can eliminate the risk of lactational HIV transmission. Regardless of the recommendation to formula-feed HIV-exposed infants, there are circumstances in which women may consider or choose to breastfeed. Obstetric and pediatric HIV specialists can help women reduce the risk of HIV transmission to their infants, promote a patient–provider relationship built upon honesty and trust, and maximize retention in care by collaborating to ensure that women understand the HIV transmission risk even if they are on suppressive ARV therapy, offer safe alternatives to breastfeeding, and provide a harm reduction approach for women who make the choice to breastfeed.

Notes

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