Invited Review

2023 Updated Guidelines on Infant Feeding and HIV in the United States: What Are They and Why Have Recommendations Changed?

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The US Department of Health and Human Services guidelines on infant feeding among people with HIV have changed in response to (1) evidence of low risk of transmission via breast milk among individuals with consistent viral suppression, (2) considerations of equity and cultural norms, and (3) community desires. The 2023 guidelines recommend patient-centered shared decision-making. Individuals with HIV who are receiving antiretroviral therapy (ART) and have consistent viral suppression should be counseled on the options of formula feeding, feeding with banked donor milk, or breast (or chest) feeding, and nonjudgmentally supported in their decision. Individuals who choose to breastfeed should be counseled on and supported in adherence to ART, viral suppression, and engagement in postpartum care for themselves and their babies. Exclusive breastfeeding is recommended, with the understanding that brief periods of replacement feeding may be necessary. Data are lacking on ideal infant prophylaxis regimens.

Keywords: breastfeeding, infant, human milk, HIV, guidelines

Background

Counseling about infant feeding is an integral component of care for pregnant and postpartum people with HIV. The American Academy of Pediatrics recommends exclusive breastfeeding/chestfeeding (herein breastfeeding [see Authors' Note]) for 6 months for most babies. They cite the unique composition of human milk and numerous health benefits for the baby and the lactating parent.[1] For decades, women and other birthing people with HIV in the US and other high-income countries were told that formula feeding was the only safe option available to them. In recent years, this guidance has shifted as a result of advocacy from community members and people with lived experience, accumulating data showing that the risk of HIV transmission through breast milk among individuals with viral suppression is very low, and the recognition that restricting breastfeeding might increase the inequities that already exist for many birthing people with HIV. In January 2023, US guidelines were substantially revised, supporting shared decision-making for people with HIV who are receiving antiretroviral therapy (ART) and have consistent viral suppression. This article reviews the considerations that led to this change, infant feeding considerations for people with HIV, and best practices in counseling and treatment of people with HIV who choose to breastfeed their infants.

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History of Reproductive Coercion and HIV

People with HIV have long had to fight for reproductive freedom. Ronald Bayer wrote about this history in 1990.[2] In the setting of many unknowns, in 1985 the then Centers for Disease Control (now the Centers for Disease Control and Prevention [CDC]) published its first *Morbidity and Mortality Weekly Report* on the prevention of perinatal transmission of the virus that would come to be known as HIV. This report contains the statement that "infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus."[3] A CDC

Authors' Note
Breastfeeding and chestfeeding are both terms used to describe feeding a baby one's own human milk. Not everyone who gives birth or lactates identifies as a woman and some transgender men and gender-diverse individuals may prefer the terms "chestfeeding" or "bodyfeeding" over "breastfeeding."

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official wrote in 1987 that women and their sexual partners would have to "suppress often strong desires to bear children,"[4] acknowledging the coercion implied by this recommendation. Other agencies echoed the CDC guidance and at times went even further, from stating that women with HIV should be "advised to postpone pregnancy" to the overtly directive language that women with HIV should be "strongly encouraged not to become pregnant."[5,6] In his article, Bayer points out that the directive counseling adopted toward women with HIV was very different from the nondirective posture prioritized in genetic counseling for pregnant people and potential parents: "... the disquiet provoked by pediatric AIDS had elicited a willingness to embrace ... clinical practices that deviated from the conventions of nondirective counseling."[2]

Early policies designed to limit the birth of infants with HIV contributed to long-lasting stigma against women with HIV and a climate of intolerance for the reproductive freedom of people with HIV

There have always been vocal proponents of a nondirective, noncoercive approach to reproductive health and decision-making for people with HIV, including Janet Mitchell, a former chair of the obstetrics and gynecology department at Harlem Hospital, who was a forceful critic of the public health posture on HIV infection and pregnancy.[2] It was not lost on Dr Mitchell and many others that women with and at risk for HIV were disproportionately Black, Latinx, and poor, and were often injection drug users. Recommendations were not culturally responsive to the meaning of childbearing for these women: "we must ensure that counseling is as nonjudgmental, culturally sensitive, and ethnic specific as possible. Otherwise we run the risk of further alienating populations we have historically had little success in reaching."[7]

Breastfeeding Guidelines in the US

Early policies designed to limit the birth of infants with HIV contributed to long-lasting stigma against women with HIV and a climate of intolerance for the reproductive freedom of people with HIV,[8,9] even with the availability of interventions to reduce or even eliminate the risk of perinatal transmission of HIV. However, the CDC and other federal agencies have moved away from official policies of discouraging pregnancy and have embraced the use of HIV preexposure prophylaxis, universal HIV testing, ART, and viral suppression for pregnant people with HIV, and antiretroviral prophylaxis for babies exposed to HIV, to reduce and eventually eliminate perinatal transmission of HIV.[10-13]

Until 2023, part of this package of preventive measures was a fairly absolute prohibition on breastfeeding for people with HIV. The Department of Health and Human Services (DHHS) Recommendations for the Use of Antiretroviral Drugs During Pregnancy and Interventions to Reduce Perinatal HIV Transmission in the United States (hereafter referred to as the "DHHS Perinatal HIV Guidelines") evolved over time to support counseling and harm-reduction measures for people with HIV "who choose to breastfeed despite intensive counseling," but maintained a stance that breastfeeding is not recommended for people with HIV.[10] The CDC consistent statement was that "in the United States, to prevent HIV transmission, it is recommended that mothers living with HIV not breastfeed their infants."[14] In 2023, the DHHS Perinatal HIV Guidelines were revised to include a greater focus on shared decision-making.

Change in Guidelines

On January 31, 2023, the DHHS Perinatal HIV Guidelines were updated with a greatly revised section on "Infant Feeding for People With HIV in the United States." This section states: "People with HIV should receive evidence-based, patient-centered counseling to support shared decision-making about infant feeding.... For people with HIV who are not on ART and/or do not have a suppressed viral load at delivery, replacement feeding with formula or banked pasteurized donor human milk is recommended to eliminate the risk of HIV transmission... Individuals with HIV on ART with a consistently suppressed viral load during pregnancy (at a minimum during the third trimester) and at the time of delivery should be counseled on the options of formula feeding, banked donor milk, or breastfeeding."[10] In another substantial change, the CDC archived its document on breastfeeding and HIV and chose to instead reference the DHHS Perinatal HIV Guidelines and the American Academy of Pediatrics' recommendations.[15]

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Table 1. Infant Feeding Considerations for People With HIV

Risk of HIV transmission	• Postexposure prophylaxis should be offered as soon as possible, within 72 hours, to all individuals who have sustained a mucosal or parenteral exposure to HIV. • Cases have been reported of HIV transmission when maternal HIV RNA level was less than 50 copies/mL leading up to and close to the time of transmission. • Fully suppressive antiretroviral therapy during pregnancy and breastfeeding decreases transmission risk to less than 1%, but not zero.
Bodily autonomy and reproductive justice	• Having support to choose how to feed one's baby is important for bodily autonomy and making decisions about what is best for oneself and one's family. • Directive counseling can feel degrading and harmful and strip an individual of agency.
Cultural considerations	• Sense that there are environmental, social, familial, and personal pressures to consider breastfeeding. • Fear that not breastfeeding would lead to disclosure of their HIV status.
Health benefits of breastfeeding	• Infant: lower risk of asthma, obesity, type 1 diabetes, severe lower respiratory disease, otitis media, sudden infant death syndrome, gastrointestinal infections, and necrotizing enterocolitis. • Lactating parent: lower risk of hypertension, type 2 diabetes, and breast and ovarian cancers.
Health equity	• Black women are disproportionately affected by HIV. • People of color experience a greater burden of many health conditions that may be alleviated by breastfeeding.

Infant Feeding Considerations for People With HIV

Even before the change in federal guidelines, there were people with HIV in the US who expressed interest in breastfeeding and who successfully breastfed their babies, sometimes with the help and support of medical practitioners and sometimes surreptitiously. In a survey published in 2019, among 93 clinicians who provided specialty care to women with HIV, 29% were aware that women in their care had breastfed.[16] In a similar 2021 survey, 42% had cared for a person with HIV who breastfed.[17] If there is a risk of HIV transmission from breastfeeding and if formula feeding in the US is supposed to be acceptable, feasible, affordable, sustainable, and safe (AFASS, in the vernacular of the World Health Organization), why do so many parents choose to breastfeed? Beyond reducing the risk of HIV transmission to their baby, people with HIV may be thinking about the stigma and lack of privacy they face when they do not breastfeed, the health benefits of breastfeeding, and the goal of having the same choices and health outcomes as people without HIV. A summary of infant feeding considerations for people with HIV appears in Table 1.

Low Risk of Transmission

Without the use of ART, the estimated rate of breast milk transmission of HIV is about 16% over 2 years.[18] No systematic studies have been reported that indicate the risk of HIV transmission through human milk when the lactating person with HIV is started on ART before pregnancy or in the first trimester. The existing data come from studies in low- and middle-income countries, with ART started at varying time points during pregnancy. A systematic review and meta-analysis published in 2017 identified 6 studies with ART started at some point during pregnancy and continued for at least 6 months postpartum that provided estimates of postnatal transmission rates, excluding peripartum infections diagnosed before 6 weeks of age. The pooled postnatal transmission rate at 6 months was 1.1% (95% CI, 0.32%-1.85%), with substantial heterogeneity. Transmission rates in included studies ranged from 0.2% to 3.1%.[19]

The largest study to date on the use of antiretroviral medications to reduce the risk of lactational HIV transmission was the PROMISE (Promoting Maternal and Infant Survival Everywhere Study) trial, which included more than 2400 women with CD4+ counts 350 cells/μL and higher and compared the efficacy of prolonged infant nevirapine (NVP) prophylaxis with maternal ART. Both treatments continued through the cessation of breastfeeding or 18 months postpartum, whichever came first. This study showed estimated transmission rates of 0.3% at 6 months and 0.6% at 12 months in both arms.[20] Maternal plasma HIV RNA level and maternal HIV drug resistance were each independently associated with HIV transmission via breast milk.[21] Overall, out of 1220 mother-infant pairs in the maternal ART arm, there were 7 cases of HIV transmission. Two infants in the maternal ART arm acquired HIV despite a maternal plasma HIV RNA level

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measured as not detected or detected but less than 40 copies/mL on the date that the infants' first samples tested positive for HIV RNA. In both cases, maternal HIV RNA was detectable at delivery and in subsequent testing, which makes it challenging to extrapolate the findings to patients with longer and more consistent viral suppression.[22]

There have been at least 5 additional reported cases of HIV transmission in which the maternal viral load was less than 50 HIV RNA copies/mL close to the time of transmission.[23-25] Two cases were from an observational study in Malawi. In the first case, ART was started 8 weeks before delivery and maternal plasma HIV RNA level was less than 37 copies/mL at 1 month, 3 months, 6 months, and 12 months postpartum. The baby was breastfed until 9 months of age and tested positive for HIV at 12 months of age, after testing negative at months 1, 3, and 6. HIV RNA level measured in the breast milk was 293 copies/mL at 1 month postpartum and less than 37 copies/mL at months 3 and 6. In the second case, ART was started 14 weeks before delivery and maternal plasma HIV RNA level was less than 37 copies/mL at 1 month and 3 months postpartum. The baby tested positive for HIV at 3 months of age, after testing negative at 1 month. HIV RNA level measured in the breast milk was less than 37 copies/mL at 1 month postpartum and 90 copies/mL at 3 months.[24]

The Mma Bana study in Botswana compared triple nucleoside analogue reverse transcriptase inhibitor (nRTI) therapy with protease inhibitor-based therapy (lopinavir/ritonavir). Triple nRTI therapy is no longer recommended as a complete regimen for HIV treatment for pregnant or nonpregnant individuals, as these regimens are inferior to currently recommended combination antiretroviral regimens.[26] There were 2 cases of lactational transmission in which maternal plasma and breast milk HIV RNA levels were less than 50 copies/mL at 1 and 3 months postpartum, both in the nRTI arm. In one case, ART was started 4 weeks before delivery and viral load was elevated at delivery; the baby tested positive for HIV at 94 days of life after testing negative at 28 days. In the other case, ART was started 14 weeks before delivery and HIV RNA level was less than 50 copies/mL at delivery, although there were reported issues with adherence; the baby tested positive for HIV at 91 days of life after testing negative at 21 days.[25]

In DolPHIN-2 (Dolutegravir in Pregnant HIV Mothers and Their Neonates), which compared dolutegravir- versus efavirenz-based ART started in the third trimester, out of 268 mother-infant pairs, there was 1 case of breastfeeding-related HIV transmission. It was in the efavirenz group; the baby tested positive for HIV at 72 weeks of age (16 months), and maternal viral load was less than 50 copies/mL at 12 weeks, 24 weeks, 48 weeks, and 72 weeks postpartum.[23]

Where does this leave us in terms of the risk of HIV transmission through breastfeeding in the context of ART? The risk is less than 1%, but not zero, at least with ART started in the third trimester or at delivery. In high-income countries, case series have been reported in which ART was started before pregnancy or in the first trimester, with no cases of transmission.[27-34] However, the overall numbers were small. Thirteen women, described in a prospective study conducted in Italy, had no instances of transmission of HIV through breastfeeding.[31] In Germany, among 30 women with HIV who breastfed, there were no cases of transmission of HIV, although only 25 women had optimal viral suppression.[28,34] Four of the 5 women not considered to have optimal suppression had viral loads of 50 copies/mL to 70 copies/mL at some point postpartum, and 2 had had a detectable viral load early in pregnancy. A retrospective multisite study conducted in the US and Canada involved 72 cases of breastfeeding among people with HIV.[32] Of the 72 individuals, 86% were receiving ART before pregnancy, 85% had a viral load of less than 40 copies/mL at initiation of prenatal care, and 90% had a viral load of less than 40 copies/mL close to delivery (the viral load was >40 copies/mL in 1 case and unknown in 6 cases). There were no cases of HIV transmission, although 4 infants were lost to follow-up. Twenty-one of these cases had been reported previously in separate publications.[29,30,33]

The largest study to date on the use of ART to reduce the risk of lactational HIV transmission was the PROMISE trial, which showed estimated transmission rates via breastfeeding of 0.3% at 6 months and 0.6% at 12 months

Bodily Autonomy and Reproductive Justice

Many activists in the HIV community have framed the issue of choice in infant feeding within the concept of reproductive justice.[35] Reproductive justice is

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a movement started and led by Black women that focuses on reproductive liberty, which is understood to include but go beyond the right to choose abortion. Rather, the movement examines the structures and oppressive societal forces that affect all aspects of reproduction. SisterSong, a national membership organization devoted to improvement of the reproductive lives of marginalized communities, defines reproductive justice as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities."[36] For many people with HIV, receiving support to choose how they want to feed their baby is an important step in maintaining or regaining bodily autonomy and claiming their right to parent in safe and sustainable communities, "building upon a trust that they will make the best decisions for themselves and their families when equipped with comprehensive information and adequate resources and support," free from policing and undue surveillance.[35]

Qualitative research in the United Kingdom, Canada, and the US has elucidated the many considerations that people with HIV weigh when they choose an option for infant feeding or are told that formula feeding is the only option.[37-39] In the pre-2023 era when formula feeding was recommended for all people with HIV—without much consideration of the social, cultural, and emotional aspects of infant feeding—counseling was generally directive, sometimes to the point of being coercive.[39] Even for those who ultimately chose to feed their baby formula, this directive counseling could feel degrading and harmful and strip an individual of agency: "I was always told, since my first pregnancy, that I could ONLY formula feed ... when I continued to inquire about it my nurse said to me, 'Do you want to give your child HIV?? Then you can't breastfeed.' I was so hurt by this response I haven't inquired since. Even after multiple children."[39]

Cultural Considerations

For some people, breastfeeding is part of the cultural expectation of motherhood, and not having this option is associated with a steep emotional cost. Participants in these studies described feelings of guilt and loss of an anticipated maternal experience. As one individual put it, "I just accept it but in my heart it pains me because as a woman you have to breastfeed your baby."[37]

Because breastfeeding is such a deeply ingrained expectation of new motherhood, people with HIV report having to explain themselves over and over again and make up excuses for not breastfeeding: "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."[38] Particular importance is placed on breastfeeding among many migrant women from countries in sub-Saharan Africa, where breastfeeding is the cultural norm and a decision to bottle-feed may signal a mother's HIV-positive status. One study participant said, "It's so sad because most people, like most Africans, they know that the moms who do not breastfeed are moms who has [sic] 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."[38]

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Health Benefits of Breastfeeding

The American Academy of Pediatrics recommends exclusive breastfeeding for approximately 6 months after birth and supports continued breastfeeding—along with appropriate complementary foods introduced at about 6 months—as long as mutually desired by parent and child, for up to 2 years or beyond. These recommendations are consistent with those of the World Health Organization.[1] Breastfeeding is associated with improved neonatal immune status and a lower risk of asthma, obesity, type 1 diabetes, severe lower respiratory disease, otitis media, sudden infant death syndrome, gastrointestinal infections, and necrotizing enterocolitis. In addition to bonding with their infant and avoiding the monetary costs of formula, benefits to the lactating parent include decreased risk of hypertension, type 2 diabetes, and breast and ovarian cancers.[1]

People with HIV are exposed to the same "breast is best" messaging as the general population. One study participant said they wanted to breastfeed because from what they read in all the books, breast milk was the best, so they wanted to give that to their baby.[37]

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Table 2. Components of Counseling on Infant Feeding Options for People With HIV

The infant feeding options that eliminate the risk of HIV transmission are formula and pasteurized donor human milk.
Fully suppressive antiretroviral therapy during pregnancy and breastfeeding decreases breastfeeding transmission risk to less than 1%, but not zero.
If breastfeeding is chosen, exclusive breastfeeding up to 6 months of age is recommended over mixed feeding (ie, breast milk and formula), with the understanding that intermittent formula feeding may be necessary, such as in cases of infant weight loss, a not-yet-established milk supply, or the mother not having enough stored milk. Solids should be introduced as recommended at 6 months of age, but not before.
The postpartum period, which can be difficult for all parents, can present several challenges to medication adherence and engagement in care. Ensuring that parents have access to both a supportive clinical team and peer support in the postpartum period is beneficial in promoting medication adherence and viral load monitoring.
Access to a lactation consultant or lactation support provider with expertise in supporting breastfeeding by individuals with HIV is beneficial.
As most studies of breastfeeding in people with HIV were conducted in resource-limited settings, more information is needed about the risk of HIV transmission through breastfeeding in high-resource settings and when individuals are adherent to antiretroviral therapy with sustained viral suppression starting early in pregnancy.
Breastfeeding provides numerous health benefits to both the infant (eg, reduction in risk of asthma, gastroenteritis, and otitis media) and the parent (eg, reduction in risk of hypertension, type 2 diabetes, and breast and ovarian cancers).

Adapted from the Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission.[10]

Others felt that, although not breastfeeding made them feel "guilty" and "inadequate," the health risks of breastfeeding while infected with HIV outweighed the benefits: "I felt comfortable with the decision I made and felt I personally had no choice but to bottle feed if my babies' well-being was my greatest concern."[39] With the evidence supporting the low risk of HIV transmission in the setting of ART and consistent viral suppression starting before pregnancy or early in the pregnancy, and the different ways that each individual weighs the benefits of breastfeeding, experts have argued that breastfeeding by people with effectively treated HIV infection is an "equipoise option" and that it should be up to the patient, not the medical team, to decide which option is best.[40]

Health Equity

An additional important consideration in the discussion about infant feeding for people with HIV is that of health equity. Black women and birthing people in the US are disproportionately vulnerable to HIV and perinatal morbidity and mortality while simultaneously experiencing several barriers to successful breastfeeding, even when they do not have HIV.[41-44] People with limited access to social and health resources are the most affected by HIV, primarily owing to the effects of structural racism, and also experience a greater burden of health conditions that may be attenuated by breastfeeding. Prohibiting breastfeeding may inadvertently exacerbate these health inequities.[45]

Even in the US, some people have limited access to safe water or difficulty obtaining formula. In 2022, reports of contaminated formula, increasing costs of formula, and formula shortages revealed flaws in the formula production and distribution system, leaving many of the country's most vulnerable families struggling to feed their babies.[46] In addition to the widely publicized water crisis in Flint, Michigan, it is estimated that millions of Americans have incomplete indoor plumbing or poor water quality, making them reliant on expensive bottled water or forced to use potentially unsafe tap or well water to prepare formula.[47] Giving parents with HIV the option to breastfeed their babies does not fix these problems—all families deserve access to clean water and safe and affordable formula—but these inequities and health disparities should be considered as part of counseling and support for infant feeding decisions for people with HIV in the US.

Counseling and Management

The DHHS Perinatal HIV Guidelines state that individuals with HIV who are receiving ART and have consistent viral suppression during pregnancy (at least during the third trimester) and at the time of delivery should be counseled on the options of formula feeding, feeding with banked donor milk, or breastfeeding. This counseling should begin before conception or as early in pregnancy as possible, and plans for infant feeding

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Table 3. Components of Management for People With HIV Who Choose to Breastfeed

Support the parent's antiretroviral therapy adherence and engagement in care throughout pregnancy and infant feeding	• Provide case management and/or social work support from individual(s) with perinatal support experience. • Provide early active referral to a supportive lactation consultant knowledgeable about concerns regarding HIV transmission and situations in which to consider stopping or temporarily interrupting breastfeeding. • Screen and provide support for postpartum depression and other mental health conditions that are highly prevalent among new parents and may affect antiretroviral therapy adherence. Postpartum depression occurs more frequently in individuals with HIV than in those without HIV.
Document sustained viral suppression before delivery and throughout breastfeeding	• No data exist to inform the appropriate frequency of viral load testing for the breastfeeding parent. One approach is to monitor the plasma viral load of the parent every 1 to 2 months during breastfeeding. • Decide which clinician (eg, prenatal care clinician or primary care HIV clinician) is responsible for monitoring viral loads of the parent postpartum and continuing counseling/education around infant feeding. • If the parent's viral load becomes detectable, consult an expert in breastfeeding and HIV immediately and consider options for temporarily or permanently discontinuing breastfeeding. • Recommend exclusive breastfeeding in the first 6 months of life, followed by the introduction of complementary foods with continued breastfeeding, if desired. Some people may choose to breastfeed for less than 6 months. • In pre–antiretroviral therapy studies, exclusive breastfeeding was associated with lower rates of HIV transmission than mixed feeding (a term used to describe feeding of breast milk plus other liquid or solid foods, including formula). The highest risk in these studies was from very early introduction of solids (before 2 months of age). • In the context of parental antiretroviral therapy and viral suppression, it is not known whether formula supplementation increases the risk of HIV acquisition in the breastfed infant.
Administer appropriate antiretroviral prophylaxis starting at birth	Options include the following: • zidovudine for 2 weeks, if otherwise eligible • zidovudine for 4 to 6 weeks • nevirapine for 6 weeks • nevirapine continued throughout breastfeeding
Provide guidance on good breast care	• Include strategies to avoid and promptly resolve overproduction of breast milk, milk stasis, and breast engorgement, which can lead to sore nipples, mastitis, or abscess. • Promptly identify and treat mastitis, thrush, and cracked or bleeding nipples. These conditions may increase the risk of HIV transmission through breastfeeding, although the impact of these conditions in the context of antiretroviral therapy and viral suppression is unknown.
Develop a joint plan for weaning with family and clinicians	• Because very rapid weaning was associated with increased risk of HIV shedding into breast milk and risk of transmission in the pre–antiretroviral therapy era, weaning over a 2- to 4-week period might be safer, with special attention paid to good breast care and avoidance of breast engorgement and milk stasis.
Monitor for infant HIV acquisition with periodic virologic diagnostic testing	For infants with perinatal HIV exposure who are being breastfed, virologic diagnostic testing is recommended at the following times: • birth • 14 to 21 days • 1 to 2 months • 4 to 6 months An additional test should be performed between the 1- to 2-month and 4- to 6-month time points if the gap between tests is greater than 3 months. Testing should continue every 3 months for the duration of breastfeeding. Testing should also be performed at 4 to 6 weeks, 3 months, and 6 months after cessation of breastfeeding.

Adapted from the Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission.[10]

should be nonjudgmentally reviewed throughout pregnancy and again after delivery.[10] A summary of the components of counseling can be found in Table 2. If a parent decides to breastfeed, counseling should include the importance of adherence to ART, viral suppression during pregnancy and breastfeeding, and engagement in postpartum care for both the lactating parent and the infant.[10] A summary of the components of management can be found in Table 3.

The DHHS Perinatal HIV Guidelines explicitly state

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that referral to child protective services (CPS) or similar family welfare agencies is not an appropriate response to someone's asking about breastfeeding or choosing to breastfeed. There are many heartbreaking stories of health care practitioners threatening to call or calling CPS and refusing to provide care to people with HIV who choose to breastfeed, often in an attempt to intimidate and coerce them into not breastfeeding.[17,48] Calling CPS or refusing to provide care shuts down conversation, furthers HIV stigma, pushes people out of care, harms families, and fits into a pattern of biased policing and application of policies that lead to the most marginalized people—particularly Black and Indigenous communities—being unjustly surveilled and punished for reproduction-related health decisions.[49]

Infant Prophylaxis

There is no consensus on the appropriate management of antiretroviral prophylaxis for infants of individuals with sustained viral suppression who are breastfed. The DHHS Perinatal HIV Guidelines give several options: most panel members agree that low-risk infants who otherwise qualify for only 2 weeks of infant zidovudine (ZDV) do not need any additional prophylaxis; several panel members prefer to extend the duration of ZDV prophylaxis to 4 to 6 weeks; some panel members recommend 6 weeks of NVP; and others opt to continue NVP throughout breastfeeding. Daily lamivudine and daily lopinavir/ritonavir are alternatives for infants who cannot tolerate ZDV or NVP.

It is important to note that no trials have been conducted to evaluate or compare different agents for postnatal prophylaxis among breastfeeding infants of people receiving ART. In a post hoc analysis of the HPTN (HIV Prevention Trials Network) 046 study, which showed a less than 1% risk of postnatal HIV transmission in the extended NVP and the placebo arms, the addition of infant prophylaxis did not further reduce breastfeeding transmission in mothers who were receiving ART.[50] In the absence of data or consensus, practitioners may choose to include parents or caregivers in the decision about how long to continue infant prophylaxis. The primary focus should be on ART adherence and support for the lactating person with HIV.

Formula

In pre–ART studies, exclusive breastfeeding was associated with lower rates of HIV transmission than mixed feeding (ie, feeding of infants with breast milk plus other liquid or solid foods, including formula).[51,52] The highest risk in these studies was from the very early introduction of solids (before 2 months of age).[53,54] In the context of parental ART and viral suppression, it is not known whether formula supplementation increases the risk of HIV acquisition in breastfed infants. As is the case with all individuals who choose to breastfeed, exclusive human milk feeding is recommended for the first 6 months of life, followed by the introduction of complementary foods with continued breastfeeding, if desired, with the understanding that intermittent formula feeding may be necessary, such as in cases of infant weight loss, a not-yet-established milk supply, mastitis, or bleeding nipples.[1]

Detectable Viral Load

In the case of a detectable viral load in a lactating parent, the DHHS Perinatal HIV Guidelines recommend that breastfeeding be temporarily stopped while viral load testing is repeated.[10] The following options may be considered in the interim: (1) giving previously expressed and stored milk from a date when the person had viral suppression, (2) pumping and flash heating expressed milk before feeding it to the baby, or (3) providing replacement feeding with formula or pasteurized donor human milk. If repeated testing shows a viral load below the level of detection, breastfeeding may resume.

Exclusive breastfeeding is recommended for the first 6 months of life, with the understanding that intermittent formula feeding may be necessary, such as in cases of infant weight loss, a not-yet-established milk supply, mastitis, or bleeding nipples

This situation also presents an opportunity to provide positive feedback and review the risks and benefits of continued breastfeeding, adherence strategies, and other considerations. If the repeated testing shows a detectable viral load, the guidelines advise immediate cessation of breastfeeding; this guidance is more directive than counseling for individuals receiving suppressive ART because of the increased risk of

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HIV transmission.[10] Given the sensitivity of HIV RNA assays, the level of detectable viral load above which breastfeeding should be stopped and additional infant antiretroviral prophylaxis should be started is a matter of clinical judgment and review of viral load trends. Consultation with an expert or the national perinatal HIV/AIDS hotline (888-448-8765) is recommended.

Conclusion

Women and other birthing people with HIV want to have happy, healthy, thriving children and families. HIV transmission is not the only factor parents might be weighing when they think about how best to support the health and well-being of their baby and their family. Support for informed choice of infant feeding options for people with HIV is a major shift in the care of women and other birthing people with HIV toward bodily autonomy and reproductive justice. This shift is due in large part to the advocacy of community members and organizations that have been pushing for years for parents with HIV to have access to the information, support, and tools necessary to make informed decisions about infant feeding.[35]

More data are needed on the risk of HIV transmission from a lactating parent with HIV who is receiving ART and has achieved and maintained viral suppression starting before pregnancy or early in pregnancy. Future work may lead to the ability to equate "undetectable" with "untransmittable," but, unfortunately, we are not there yet in this setting. Also needed is more research on the optimal antiretroviral prophylaxis regimen for breastfed infants and the impact of mixed feeding on HIV transmission risk in the context of viral suppression. Several institutions have published information on protocols for managing breastfeeding in people with HIV and their babies.[29,55,56] As more institutions and practitioners develop and refine protocols, materials, and best practices related to HIV and infant feeding, ideally in collaboration with patients and others with expertise that comes from lived experience, we hope these can be shared and disseminated.

Not everyone with HIV who is receiving ART with a viral load below the level of detection and gives birth is going to choose to feed their baby their own milk. Many, when given information about the nonzero risk of HIV transmission, will choose formula. Some may have access to banked human milk and will choose that for a certain period before switching to formula. Some may start off breastfeeding and then decide that it is not the right decision and switch to formula. In addition to providing supportive wraparound care for those who choose to breastfeed, we need to continue to push for universal access to high-quality, safe, and affordable formula as well as better lactation support and accommodation. Parents with HIV deserve our respect, not our suspicion, and have a right to make informed, supported, uncoerced decisions about infant feeding. And when they choose to breastfeed, support from their health care team is essential to their success.

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Reviewer 1 reported consultant or received advisor fees from Antiva, Assembly Biosciences, Generate Biomedicines, and IGM Biosciences, and fees for participation in review activities, eg, data monitoring boards, statistical analysis, or endpoint adjudication committees for Gilead Sciences, Inc. (Updated November 22, 2023) Reviewers 2 and 3 reported no relevant financial relationships with ineligible companies. (Updated November 22, 2023)

All relevant financial relationships with ineligible companies have been mitigated.

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