Clinical Infectious Diseases

VIEWPOINTS

Providers Have a Responsibility to Discuss Options for Infant Feeding With Pregnant People With Human Immunodeficiency Virus in High-Income Countries

Jennifer McKinney,[1] Gayatri Mirani,[2] and Judy Levison[3]

[1]Department of Maternal Fetal Medicine, Baylor College of Medicine, Houston, Texas, USA; [2]Division of Allergy, Immunology, and Retrovirology, Texas Children's Hospital, Baylor College of Medicine, Houston, Texas, USA; and [3]Department of Obstetrics and Gynecology, Baylor College of Medicine, Houston, Texas, USA

Guidelines in high-income countries generally recommend against breastfeeding for a pregnant person with HIV due to the historical risk of transmission to the infant and generally acceptable, safe, and sustainable access to formula. Maternal antiretroviral therapy and infant prophylaxis have been shown to significantly decrease the risk of transmission during breastfeeding. In addition, formula may not be acceptable to patients for a variety of cultural, social, or personal reasons, and its sustainability is called into question in the setting of the current nationwide formula shortage. Providers caring for pregnant people with HIV have a responsibility to discuss infant feeding with their patients, and help them weigh the risks and benefits within the limits of the current body of evidence. We outline a process, including a written agreement, that can be used to discuss infant feeding with all patients and help them make the best decision for their family.

Keywords. HIV; breastfeeding; prenatal care; obstetrics; shared decision making.

In 2016, a Viewpoints article published in this journal examined the ethics of discussing breastfeeding for pregnant people with human immunodeficiency virus (HIV) [1]. The authors concluded that discussion of breastfeeding was ethically justifiable considering both provider duties of nonmaleficence and their obligation to respect patient autonomy. In 2017, the Centers for Disease Control and Prevention stated that individuals with a consistently undetectable viral load could not transmit HIV to a sexual partner, which has led to the acronym U = U (undetectable equals untransmissible) [2]. Both patients and providers are wondering whether U = U also applies to breastfeeding and what that would imply for infant-feeding practices [3]. In addition, parents in the United States are struggling with a new dilemma of how to feed their infant in the face of the current nationwide formula shortage [4, 5]. Further, as our country grapples with achieving reproductive justice ("the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities" [6, 7]), we must consider the integral right for all people to make an informed infant-feeding decision. Finally, the community is speaking out, and patients are pushing the field to reassess our counseling.

The purpose of this Viewpoint article is to briefly review the overall state of evidence on infant-feeding practices for patients with HIV, point out the gaps in the current infant-feeding guidelines in the United States, and describe 1 example of an approach to counseling and supporting pregnant people who choose to breastfeed their infant. Our intent is not to replace the national Perinatal Guidelines, which is an annually updated set of recommendations, but to describe how we have navigated questions not answered by the guidelines.

First, a note on language. The word "breastfeeding" will be used for simplicity's sake throughout this piece. However, we acknowledge that there are multiple terms, including "chestfeeding," used to describe this process, and we wish to be inclusive of any person with HIV, including trans men and nonbinary individuals, who wish to explore feeding a child from their body [8].

TRANSMISSION OF HIV VIA HUMAN MILK

Risk of HIV transmission via breast milk has been well documented, both in increased rates of transmission in infants who received breast milk versus other food sources, as well as cases where the patient becomes infected after pregnancy and transmits HIV to an infant during breastfeeding. Before antiretroviral therapy (ART), the risk of transmission via breastfeeding was estimated to be 16% [9]. Viral load appears to be one of the most important predictors of transmission, with studies demonstrating the highest levels of breast-milk HIV RNA in

Received 22 June 2022; editorial decision 05 September 2022; published online 13 September 2022

Correspondence: J. Levison, Department of Obstetrics and Gynecology, Ben Taub Hospital, 1504 Ben Taup Loop, Suite 3LD 62 001, Houston, TX 77030 (jlevison@bcm.edu).

Clinical Infectious Diseases® 2023;76(3):535–9

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https://doi.org/10.1093/cid/ciac761

colostrum compared with mature milk [10]. Increased transmission has also been linked to acute HIV infection [11], lower maternal CD4 count [12, 13], mastitis [14, 15], and mixed feeding where a combination of breast milk and other liquid and solid food sources are given, especially within the first 3–6 months [16–21]. Note that many of these studies were performed in the era prior to ART and therefore may not be applicable today.

Since prenatal and postpartum ART has become more widely implemented, transmission during breastfeeding has decreased, with estimates ranging from 1% to 5% with any ART use, although many of the studies did not include correlations to maternal viral load [22–27]. The PROMISE (*Promoting Maternal Infant Survival Everywhere*) study, a randomized open-label trial performed in 7 low-resource countries, directly compared transmission of HIV in the setting of either maternal ART or daily nevirapine infant prophylaxis, and included careful monitoring of maternal viral loads throughout the duration of breastfeeding [12, 28]. Transmission occurred in 0.57% in the maternal ART arm (7/1219) in the first 12 months, and transmission was directly related to maternal viral load. Notably, 2 transmissions in the maternal ART cohort occurred at a time that the maternal viral load was less than 40 copies/mL; however, the mothers had had previously detectable virus [12]. When this number of transmissions is compared with the total number of breastfeeding sessions, the risk seems extremely low [29]. Because no comparable studies have been performed in high-resource settings, we are forced to generalize from these data and counsel that the risk is likely low, but not zero.

CHANGING GUIDELINES

In low-resource countries, exclusive breastfeeding is recommended because formula may not always be acceptable, feasible, affordable, sustainable, and safe. Further, studies have demonstrated increased neonatal mortality when breast milk is not used in these settings [30]. In high-resource settings, formula has been generally thought to be safe and sustainable (a reality called into question with the current formula shortage), and therefore, the recommendation to avoid breastfeeding has been the cornerstone of guidelines for the prevention of perinatal HIV transmission. However, this recommendation skirts the many advantages of breastfeeding in high-resource settings for both infants (a reduction in allergies and asthma as well as fewer infections) and lactating parents (including a reduction in diabetes, cardiovascular disease, and breast cancer) [31].

Until 2015, the Department of Health and Human Services' national guidelines for the prevention of perinatal HIV transmission (https://clinicalinfo.hiv.gov/en/guidelines/perinatal) contained a single sentence regarding breastfeeding: "Breastfeeding is not recommended for HIV-infected women in the United States, including those receiving combined antiretroviral therapy." In 2015, the panel recognized that some pregnant individuals were expressing an interest in breastfeeding, and an additional comment was added: "However, clinicians should be aware that women may face social, familial, and personal pressures to consider breastfeeding despite this recommendation. It is important to address possible barriers to formula feeding beginning during the antenatal period." By 2018, in response to clinicians having small but increasing numbers of pregnant patients with HIV expressing interest in breastfeeding, the Perinatal Guidelines panel added a section on "Counseling and Managing Individuals with HIV Who Desire to Breastfeed." The current guidelines summarize the state of the evidence and suggest more open discussions about infant feeding.

BREASTFEEDING IN HIGH-INCOME SETTINGS

Prior to 2018 many clinicians feared being held legally liable for putting an infant at risk for HIV acquisition if one of their patients breastfed. Publication of the 2018 guidelines was followed by more discussion of breastfeeding in developed countries. After publication of the 2018 guidelines, clinicians who had previously been afraid of publicly acknowledging that they had patients who were breastfeeding began to speak up. Among 93 US clinicians who provide specialty care to pregnant patients with HIV, one-third of the providers were aware that women in their care breastfed their infants [32]. A survey of 15 treatment centers in Germany showed that the number of women with HIV who had opted to breastfeed increased from 1 to 13 between 2009 and 2018 [33]. And we now have published case reports from 3 high-resource sites: 3 patients in Toronto, Canada; 10 in Baltimore, Maryland; and 13 in Italy [3, 34, 35].

The reasons for interest in breastfeeding are many and personal. In our experience, originally, the largest number of women who chose to breastfeed were those of African descent, who feared that not breastfeeding would disclose their HIV status to their communities. Now we are seeing more patients responding to "breast is best" messaging, desiring to breastfeed their current children as they have breastfed their other children either pre-HIV or in a different country, fear of inadequate bonding without breastfeeding, and more recently, serious concerns about how to feed their infant in the setting of the ongoing formula shortage.

ANTENATAL COUNSELING APPROACH

The challenge in helping patients make an informed decision regarding infant feeding is that HIV providers in high-resource settings must give advice in the context of a distinct lack of evidence and many unanswered questions (see Table 1). Our clinic in Houston has developed a process where we use a written agreement (a nonbinding, nonlegal document; see Table 2) to

Table 1. Examples of Unanswered Questions Regarding Infant Feeding for People With HIV

Questions
–Do I really need to exclusively breastfeed if I am living with consistent viral suppression?
–What is the optimal duration of breastfeeding? If I have a consistently undetectable viral load, is it different than if I did not have HIV?
–If I run out of stored breast milk (as might happen if the electricity fails and frozen stores are lost), can I give occasional formula?
–If I have mastitis and I feed my infant from my healthy breast but do not initially have enough milk, can I give formula?
–What is the additive effect of infant prophylaxis or treatment in the setting of me taking my antiretroviral therapy?
–Is there an ideal weaning pattern? Does it matter once an infant reaches 6 months of age and has a more mature intestinal tract than a newborn?
–What if I have "blips" in my viral load while breastfeeding? How high a viral load is too high? When does my risk of transmission increase?
–What if I was diagnosed during pregnancy or it took some time to achieve adequate viral suppression? Is my risk of transmitting HIV to my child higher?
–What if I have a resistant virus but optimally suppressed, is there still a higher risk for my infant?

Abbreviation: HIV, human immunodeficiency virus.

Table 2. Patient-Provider Agreement for Patients With HIV Who Desire to Breastfeed Their Infant

		Initials
I understand that if I breastfeed, there is a small risk of transmitting HIV to my baby through breast milk.		
I need to have a consistently undetectable viral load prior to delivery. I understand we do not know the optimal duration of undetectable viral loads to minimize risk.		
Even if I maintain an undetectable viral load, there is still a risk of transmitting HIV to my baby through breast milk.		
I have decided to breastfeed my baby.		
I will try to exclusively breastfeed, meaning that I will not intermittently give my baby any formula or other food (cereal, baby food, pre-chewed food). If I am in a situation where formula may need to be used, I will speak to my provider or my baby's HIV specialist first. I understand that alternating formula and breast milk is a higher risk for HIV transmission to my baby than exclusively breastfeeding. I may pump milk from my breast and give it to my baby in a bottle.		
I will continue to take my medications every day.		
I will have a viral load checked as recommended at least every 2 months.		
If I develop a breast infection (mastitis), I will not breastfeed from that breast. I may pump milk from that breast and discard it until the breast has healed.		
I will have a consultation with the pediatric HIV specialist prior to my delivery.		
I will give my baby their medications as recommended by their pediatric HIV specialist, continuing prescribed medication until 1 month after my baby has been fully weaned.		
I will bring my baby in for HIV testing at the times recommended by the pediatric HIV specialist.		
When I am ready to wean my baby, I will work with the pediatric HIV specialist to develop a plan for weaning so that risk of transmission of HIV at the time of weaning is minimized.		
I will openly communicate problems in keeping this agreement with my provider.		
I will bring this agreement to the hospital where I plan to deliver my baby and give it to the doctors and nurses taking care of me.		
Printed name of patient	Signature of patient	Date
Printed name of obstetrician	Signature of obstetrician	Date
Printed name of pediatrician	Signature of pediatrician	Date

Abbreviation: HIV, human immunodeficiency virus.

standardize and guide counseling for all patients and facilitate communication with all maternal and pediatric team members.

We believe clinicians should be asking about infant-feeding plans with all pregnant patients starting early in pregnancy. It is our practice to discuss this topic during the initial visit, in the second trimester, and again in the third trimester for all patients. During the initial visit, we address what patients have heard about HIV in pregnancy, including perceived "rules' about mode of delivery and breastfeeding. This is not a time to expect a decision from a patient but rather to introduce options in infant-feeding that we will discuss more later in pregnancy.

In the second trimester we follow up with an in-depth discussion of potential risks and benefits of breastfeeding. For those who express possible interest in breastfeeding we use the agreement shown in Table 2 as a template for our counseling, to ensure that all patients are given the same information. We discuss the risk of transmission of HIV in breast milk, including those factors and practices that may increase that risk, such as mixed feeding or "viral blips" and episodes of suboptimal viral suppression. We are frank about the lack of evidence in many areas, and let our patients know that the best way to eliminate risk completely is to choose to formula feed. For those who are interested in breastfeeding, or would like more information to make a decision, we offer a consultation with a pediatric HIV specialist who will be caring for the infant after delivery.

Our antenatal consults with a pediatric HIV specialist occur as telemedicine visits. The pediatrician reviews the risks and benefits of breastfeeding in the context of that patient's clinical course; most consults occur for patients who have been optimally virally suppressed throughout pregnancy, but we have also had consults in the setting of history of resistant virus, or new diagnoses during pregnancy. Consults last approximately 45 minutes, and topics are covered as summarized in Table 3. Of note, many of these discussion points are evidence-informed, but are specific to practices in our institution (for example, our practice to continue antiretroviral prophylaxis for all infants while breastfeeding). We recognize that there are many different approaches and hope that, in the future, formal guidance in the national guidelines for such topics can help standardize care.

We revisit the topic during the third trimester, again reviewing risks, and ensuring that patients understand what will happen after delivery. We document their decision in the chart,

Table 3. Topics Covered in Antenatal Pediatric HIV Consultation

• Length of breastfeeding with recommendation for exclusive breastfeeding for 6 months, followed by addition of complementary foods after 6 months if the patient desires to breastfeed longer. We do note that data for mixed feeding are mainly from an era where ART was not available, so there may not be an increased risk if supplementation with formula is required in certain situations.
• Importance of pumping to achieve and maintain supply and bottle feeding with breast milk when feasible
• Antiretroviral prophylaxis for the infant during breastfeeding and post-weaning
• Risks to infant for exposure to medications (both maternal medications and potential development of resistance due to exposure to extended monotherapy while breastfeeding)
• Expected lab work and in-person visits
• Weaning process
• Need for strict adherence to ART during breastfeeding
• Need for the patient to have their viral load checked every 2 months
• Situations where urgent additional consultations will be needed with the pediatric and/or obstetric providers: changes in patient's health, increase in viral load, breast health such as bleeding or infection, infants having thrush, vomiting, or diarrhea leading to gut inflammation.
• The patient's support system
• Support services available at the clinic, including social work and case management

Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus.

and the agreement is scanned into the electronic medical record. Patients understand this is not a legal document but instead a reflection of the support of their care team for this health decision. The third trimester is also an ideal time to make sure the entire multidisciplinary care team is on-board to support the patient's desired feeding plan. If a pregnant person with HIV is not delivering at one of our affiliated hospitals, a multidisciplinary discussion with staff at their hospital of choice to address any concerns or questions ahead of time will be helpful. Team members involved in the discussion may differ by hospital, but in general, should include obstetric providers; neonatal and pediatric care providers, including specialists in pediatric infectious disease; nursing staff from labor and delivery, postpartum, and newborn nursery/neonatal intensive care unit (NICU); lactation staff; patient education staff; and anyone else who may be involved during the patient's delivery admission.

DELIVERY AND EARLY POSTPARTUM CONSIDERATIONS

After delivery, routine postpartum lactation support should be available to all patients, whether choosing to breastfeed or not. Especially important for those choosing to breastfeed is early support to achieve adequate supply, minimize breast trauma, and reduce the need for formula supplementation. A back-up plan should be made—for example, pumping intermittently from the beginning to build a small freezer store or human donor milk if available. Breast pumping will be necessary for most patients, so help should be given to obtain an electric breast pump. Note that any person who interacts with the postpartum breastfeeding patient with HIV may be operating under preconceived notions of not allowing people with HIV to breastfeed. We have found that the patient having the written agreement showing provider support to be helpful in navigating these situations (for example, to show to the USDA Special Supplemental Nutrition Program for Women, Infants and Children [WIC] when requesting a breast pump). Close monitoring in the early postpartum period is also needed to detect and address any issues that may affect medication adherence, including postpartum depression or unpredictable schedules.

The pediatric HIV specialists meet with the patient and neonate in person in the postpartum unit. During this visit, the medications for prophylaxis are reviewed, and contact information for the clinic is given to the parent. Neonatal prophylactic medications are provided in the hospital so that the parent has them in hand before discharge.

MONITORING DURING BREASTFEEDING

No guidelines currently exist regarding how to monitor a postpartum patient with HIV who is breastfeeding. We currently are scheduling obstetric follow-up appointments for patients at 2 weeks and 6 weeks postpartum, and then every 2 months to allow breastfeeding troubleshooting and allow frequent viral load monitoring. The infant is seen for the first time in the pediatric HIV clinic at 2 weeks and HIV-1 RNA qualitative polymerase chain reaction (PCR) results are checked at that time and monthly while breastfeeding, and at 1 month, 3 months, and 6 months after weaning. Blood work to check liver enzymes and a complete blood count are also done every 2 months. Last, there is a follow-up at 18 months of age for antibody testing.

There are various challenging circumstances that will arise during any person's breastfeeding journey, including low supply, difficult or painful latch, mastitis, and infant gastrointestinal problems. The patient must be comfortable with the lack of solid evidence guiding management in these situations. Defaulting to a multidisciplinary discussion with obstetric, pediatric, and lactation specialists to come to a consensus on a plan is our general approach to these situations.

CONCLUSIONS

Many providers are not comfortable with the degree of uncertainty involved in infant-feeding decisions for their patients with HIV. However, this is not a reason to avoid the conversation. People with HIV choose to breastfeed and it is our belief that open and honest discussions lead to the best potential outcomes for patients and their children. The purpose of this viewpoint is not to encourage or recommend breastfeeding for our patients but instead to make sure we engage in a patient-

centered approach where we listen more than talk, and help guide the patient to develop the safest plan for their family. Consolidating individual strategies into concrete guidelines to successfully guide people with HIV who desire to breastfeed will be a necessary first step. We then have a responsibility as clinicians to improve our own and our patients' understanding of the risks by collecting data to start answering all of the unanswered questions regarding breastfeeding in the patient with HIV.

Note

Potential conflicts of interest. J. L. reports work as a consultant to the National Clinician Consultation Center (University of California San Francisco). J. M. reports grants from Texas Department of State Health Services Perinatal HIV Grant and Center for Medicaid/Medicare Services Opioid Misuse Model Grant, and support for attending meetings and/or travel from Baylor College of Medicine. All other authors report no potential conflicts.

All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Conflicts that the editors consider relevant to the content of the manuscript have been disclosed.

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