Clinical Infectious Diseases

MAJOR ARTICLE

Breastfeeding among people with HIV in North America: a multisite study

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Background: In North American countries national guidelines have strongly recommended formula over breastmilk for people with HIV because of concern for HIV transmission. However, data from resource-limited settings suggest the risk is less than 1% among virally suppressed people. Information regarding breastfeeding experience in high resource settings is lacking.

Methods: A retrospective multi-site study was performed for individuals with HIV who breastfed from 2014-2022 in the United States (8 sites) and Canada (3 sites). Descriptive statistics were used for data analysis.

Results: Among the 72 cases reported, most had been diagnosed with HIV and were on antiretroviral therapy (ART) prior to the index pregnancy and had undetectable viral loads at delivery. Most commonly reported reasons for choosing to breastfeed were health benefits, community expectations, and parent-child bonding. Median duration of breastfeeding was 24 weeks (range 1 day to 72 weeks). Regimens for infant prophylaxis and protocols for testing of infants and birthing parents varied widely among institutions. No neonatal transmissions occurred among the 94% of infants for whom results were available >= 6 weeks after weaning.

Conclusions: This study describes the largest cohort to date of people with HIV who breastfed in North America. Findings demonstrate high variability among institutions in policies, infant prophylaxis, and infant and parental testing practices. The study describes challenges in weighing the potential risks of transmission with personal and community factors. Finally, this study highlights the relatively small numbers of patients living with HIV who chose to breastfeed at any one location, and the need for further multi-site studies to identify best care practices.

Keywords: HIV, breastfeeding, prenatal care, institutional practices

BACKGROUND

The majority of evidence regarding the risks of HIV transmission via breastfeeding* comes from resource-limited countries, where exclusive breastfeeding is recommended because of higher infant mortality rates due to diarrheal disease and malnutrition when formula is used[1]. Prior to the availability of antiretroviral therapy (ART), transmission risk via breastfeeding was estimated to be 16%[2]. With maternal ART, transmission risk decreased to 1-5%, though maternal viral loads during breastfeeding were often unknown[3]. In the Promoting Maternal and Infant Survival Everywhere (PROMISE) study, in which postpartum maternal ART was compared to

infant nevirapine [4, 5], 0.3% transmission via breastfeeding was documented in the first six months and 0.6% transmission at 12 months for women on ART. Two of the 8 transmissions in the maternal ART arm of the PROMISE study occurred in people with undetectable viral loads at the time of infant diagnosis, but these mothers had only become virally suppressed late in pregnancy. Partly in response to the evidence of a lower incidence in breastfeeding transmission than previously estimated, more people with HIV in resource-rich countries are expressing a desire to breastfeed, and discussing the risks and benefits with their healthcare provider.

In North American countries, national guidelines have historically recommended replacement feeding (with formula or pasteurized donor breastmilk), due to the concern for lactational transmission of HIV. The rationale was that in areas of the world such as the US, Canada, and Europe where formula feeding is available and is perceived as acceptable, feasible, affordable, sustainable, and safe, replacement feeding eliminates the risk of lactational HIV transmission[6]. While formula may be acceptable to many parents, others prefer breastmilk feeding due to concern about inadvertent disclosure of HIV status by going against community or family expectations, or due to perceived benefits for maternal and infant health, and desire to bond with their baby via breastfeeding. Some have had the opportunity to breastfeed children born prior to the current pregnancy, including in settings where breastfeeding is encouraged for all persons regardless of HIV status, and wish to continue this practice upon the birth of their current infant[7-9]. The affordability, sustainability and safety of formula has also been challenged recently with issues in the US due to lack of clean drinking water (for example in Flint, Michigan[10], Jackson, Mississippi[11]) and significant nationwide formula shortages that disproportionately affected low income families[12].

Data regarding breastfeeding experiences among people with HIV in high-resource settings is lacking. In response to feedback from clinicians across the US and Canada who work with individuals with HIV who choose to breastfeed, our objectives were to characterize people who breastfeed, including their motivations, challenges and facilitators, and duration of breastfeeding, and to describe institutional practices surrounding breastfeeding for patients with HIV, including counseling, infant prophylaxis, and infant and maternal monitoring.

*In this document, the term “breastfeeding” is used for simplicity to describe feeding a child parent’s own milk (either direct feeding or with expressed milk). We recognize that other terminology, such as chestfeeding, may be preferred by some individuals. Gender inclusive language is used throughout, except when reviewing data, when results are presented using the same terms used in the original publications, such as "pregnant women."

METHODS

After obtaining approval from the Baylor College of Medicine Institutional Review Board (H-43415), sites were recruited via announcements at HIV conferences, the ReproID listserve

sponsored by the University of California San Francisco (a multidisciplinary group of 600 individuals interested in the clinical management of HIV in pregnancy), and word of mouth. Investigators from participating sites in the US and Canada obtained approval from their respective IRBs. Any person with HIV, of any age, who breastfed between 2014 and 2022 in the US or Canada and received their care at a participating institution was eligible for inclusion in the study. People were excluded from the study if no maternal or infant data was available.

Institutional policies were reported for the site by the senior site investigator. Retrospective chart review was used to collect maternal and neonatal demographic and HIV information, peripartum viral suppression data, postpartum engagement and retention in care, and breastfeeding characteristics and challenges. Research teams were provided with predefined lists of motivations and challenges and given the opportunity to select one or more choices and also add free text to comment on motivations and challenges to breastfeeding. De-identified data were entered directly into a secure electronic Redcap database.

For this study, undetectable viral load is defined as either reported as "Undetectable" or $\leq$40 copies/ml. We recognize that specific lab cut-offs differed among locations and over time during the study interval. Index pregnancy refers to the most recent pregnancy reviewed for this study. Mixed feeding is defined as giving the infant any other liquid (including formula) or solids in addition to breastmilk.

De-identified data were exported from the database and all analyses were performed using Excel. Number and percentages were used to describe the cohort, mean (SD) and median (IQR) were used for normally and non-normally distributed data, respectively.

RESULTS

A total of 72 cases were collected from 11 sites in the United States (8 sites, 44 cases) and Canada (3 sites, 28 cases). The largest number of cases reported from one site was 26 (Canada) the fewest was one (US).

Sixty two percent (45 people) who breastfed were born in African countries, and all but two were planning on living in North America after delivery. Sixty six (92%) had been diagnosed with HIV prior to the index pregnancy, 52 (72%) had disclosed their HIV status to a partner, 62 (86%) were on ART prior to pregnancy, and 65 (90%) had an undetectable viral load at delivery (Table 1). Most were multiparous (n=58, 81%), had entered prenatal care in the first trimester (n=37, 51%), and attended at least one postpartum visit with both obstetrics (n=56, 78%) and an HIV primary care provider (n=35, 49%) in the first year postpartum (Table 2).

The most commonly reported reasons for choosing to breastfeed were health benefits to the baby, family/community expectations and fear of disclosure of HIV status, and parent-child bonding. Total duration of breastfeeding ranged from a 1 day to 72 weeks, with a median of 24

weeks. Most people stated they exclusively breastfed. Almost a third of the cohort reported breastfeeding challenges, the most common of which was inadequate breastmilk supply. Other reported difficulties included nipple pain/damage, mastitis, and difficulty with infant latching (Table 2). Providers reported concerns about how to manage these challenges, especially how to manage elevations in maternal viral load while breastfeeding, when and how to wean, and how to care for infants born prematurely or with other medical conditions that require care away from the birthparent.

A variety of neonatal antiretroviral regimens were used in this cohort. In order of simplest to most complex: Twelve infants received zidovudine alone for 4-6 weeks (similar to recommendations for non-breastfed infants); 7 received nevirapine monotherapy for 6 weeks or until weaning; 12 received zidovudine with or followed by nevirapine for 6 weeks, until weaning, or after weaning; 10 received full triple therapy for 6 weeks and then nevirapine monotherapy until full weaned, 22 received triple therapy until after cessation of breastfeeding.

Maternal and infant monitoring also differed significantly by site. Institutions reported that maternal viral loads were generally tested every 1-2 months while breastfeeding; however, we lacked data to show how often testing was actually performed. For infants, some were tested at birth; most were tested at 2 weeks, 2 months, 4 months and then every 1-2 months while being breastfed; some were then tested 1, 4, and 6 months after weaning. Sixty eight infants (94%) had documented negative HIV PCR results greater than or equal to six weeks after complete cessation of breastfeeding; the remaining four neonates were lost to follow up.

Seven of 11 sites had breastfeeding policies in place for patients with HIV. Most had involved pediatric ID, obstetric providers and/or HIV infectious disease specialists in the development of the recommendations. Five sites also included the legal and/or ethics departments in their policy development. (Table 3).

DISCUSSION

This is the largest study to date of people with HIV in high resource countries who opted to breastfeed. Two reports of breastfeeding among women with HIV in European countries have been published: 13 cases from Italy[13] and 30 from Germany[14]. Of note, since the start of data collection for this work, three sites which submitted data to this study have published descriptive information from 3[15], 10[16], and 8[17] of included participants, respectively. Data collected for this cohort were more extensive than that collected for previous case series, so the decision was made to include all cases in final analyses. Fifty-one of the 72 cases have not been included in any previous publications. Country of origin, duration of known HIV diagnosis prior to pregnancy, partner disclosure, motivations to breastfeed, viral loads on entry in care and at delivery, presence/absence of institutional policies, and obstetric and HIV primary care follow-up in the year after delivery have not been included in most of the previous publications.

Motivations to breastfeed

In the current study, the most common reason for choosing to breastfeed was health benefits for the child, followed by family/community expectations and concern about HIV status disclosure, and parent bonding. More than half of people who chose to breastfeed came from African countries. Although almost all were living in the US or Canada during the index pregnancy, many lived within closely-knit ethnic communities where the expectation is that they will breastfeed. Not breastfeeding is frequently perceived by community members as a proxy for having HIV, which remains deeply stigmatizing—as has been documented in other countries[9, 18].

Besides individual motivations, the potential health benefits can also be considered. Breastfeeding reduces infants' risks of diabetes, asthma, and obesity and the mothers' risk of diabetes, obesity, hypertension, and breast/ovarian cancers—all of which are more prevalent in low-income communities that are disproportionately affected by HIV[19]. Discouraging breastfeeding in people with HIV may contribute to the inequities of health so common in resource-rich settings.

Challenges to breastfeeding counseling

Exclusive breastfeeding or not?

Twenty two percent (16 patients) reported mixed feeding to their providers. While we do not have specific information for the timing or quantity of mixed feeding during breastfeeding, we do know that nearly one fifth of reported breastfeeding difficulties were related to inadequate breastmilk supply. A study from the 1990s (prior to the availability of ART) demonstrated a higher incidence of transmission with mixed feeding[20]. As a result, clinicians have been hesitant to allow any formula supplementation if a person with HIV wants to breastfeed. However, there is no evidence that mixed feeding increases transmission risk when the lactating parent is virally suppressed on ART. At least one case in this cohort with inadequate milk supply had an infant who was given formula and subsequently told they should no longer breastfeed. Whether, and how, to include mixed feeding in infant feeding discussions has been the subject of ongoing debate among experts in both countries.

Expanded Infant prophylaxis or not?

Another enigma for pediatricians has been what kind of prophylaxis (if any) beyond the standard two weeks of zidovudine should be administered to infants of breastfeeding parents and for how long. Based on studies from resource-limited settings, either maternal ART or infant prophylaxis with nevirapine has been recommended[4, 5, 21, 22]. Most global guidelines recommend maternal lifelong ART including periods during pregnancy and postpartum. However, in resource-rich countries pediatricians have been unsure whether and/or what kind of infant ARV prophylaxis to advise, and management differs by country and by institution. Because of

concerns about maternal adherence to ART postpartum[23, 24] some clinicians prefer to prescribe infant prophylaxis for the duration of breastfeeding. We saw similar variation in this North American cohort. No perinatal HIV transmissions have been reported in any currently published cohort in high resource settings, but the question about whether and what protection infant prophylaxis provides remains unanswered.

Maternal and infant follow up

Regarding maternal and infant follow-up after delivery, the majority of people in the study had at least one postpartum visit. Thirty-five (49%) were documented to have had at least one visit to an HIV primary care provider in the first year after delivery which was likely an underestimate if the individual sought primary care outside of the reporting healthcare system. However, lack of maternal follow up in the first year postpartum remains an issue [23, 25, 26] and strategies to encourage people to stay in care after delivery are especially important for those who choose to breastfeed. Enhanced parental and infant assessment, support, and counseling are crucial for maintaining safety during breastfeeding, and also for identifying issues that might increase transmission risk (for example, the development of cracked nipples or mastitis). The frequency of infant HIV testing and postpartum birthing parent viral load testing was variable. While the best model for follow up is unclear, coordination between the infant and the breastfeeding parent's healthcare providers is essential.

Need for guidance

The lack of evidence-based feeding recommendations results in many local programs developing individual approaches to support people with HIV who choose to breastfeed [27]. This is especially complicated because infant feeding requires collaboration among a large group of diverse specialties (prenatal care providers; pediatric care providers; adult and pediatric infectious disease specialists; labor and delivery, postpartum, and pediatric nurses; lactation consultants; doulas; social workers; and case management teams). Further, some institutions have concerns about liability and legal implications, which results in varied system support for such practices. Unfortunately, the lack of guidelines means that people with HIV are unlikely to receive standardized evidence-based support in achieving their infant feeding goals depending on where they receive care, and this can increase existing health disparities[19]. Our hope is that by collecting and presenting these data, and encouraging national and international discussion, standardized recommendations may help expand infant feeding options to all locations where parents living with HIV and their infants receive care.

Strengths/limitations

This is the largest observational study of breastfeeding among people with HIV in North America. It considers policies and practices from a wide variety of geographic locations in North America unlike previous case series that have reported experiences from a single institution. The main limitation of this study is that it is retrospective, and relies on information obtained from

record review. Consequently, this cohort is limited to individuals who disclosed their feeding status, and to the limited description of motivations, barriers and facilitators described in the medical record. The rate of retention in care of birthing parents and infants may have been underestimated since some obtained postpartum follow up outside of the participating institutions. There were, and continue to be, no known cases of lactational transmission in this cohort (personal communication with the study team). However, only 50% of the participants had a negative infant HIV PCR recorded six weeks or more after cessation of breastfeeding. Throughout the study, birthing people and their infants were closely monitored by their HIV healthcare provider and by pediatric HIV specialists. These circumstances are not possible in all clinical settings, reducing generalizability. Finally, some of these cases have been published as case series since the start of data collection. Data presented here is more extensive, but care should be taken not to consider information from all published reports in an aggregate manner since there are overlapping cases[15-17].

CONCLUSION

Advocacy to support the feeding choices of people with HIV, and the number of people with HIV in high resource countries who are choosing to breastfeed, are progressively increasing. People in care and their clinicians have started to rethink the risks of HIV transmission (low in virally suppressed people) and the benefits of breastfeeding (potentially high). We describe the current clinical practices surrounding breastfeeding and HIV in North America. At the institutional level, we found variability in breastfeeding policies, involved medical specialties, infant prophylaxis regimen and duration, and infant and maternal HIV testing schedules. For people with HIV, we highlight the challenges faced in weighing the potential risks of perinatal transmission with multiple family and community expectations, infant and maternal health concerns, and concerns about bonding with their children. Finally, this study highlights the relatively small numbers of patients living with HIV who chose to breastfeed at any one location, and the need for further multi-site studies to answer the many remaining questions regarding infant feeding choices among people with HIV.

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TABLES

Table 1: Maternal demographic and HIV characteristics

	N=72
Age (years), median (IQR)	34 (29-37)
Maternal region of birth, n(%)	
North America	14 (19.4)
Central America/Caribbean	2 (2.8)
Europe	2 (2.8)
Africa	45 (62.5)
Asia	2 (2.8)
Unknown	7 (9.7)
Country of current residence, n(%)	
US	43 (59.7)
Canada	28 (38.9)
Nigeria (in US at time of delivery)	1 (1.4)

Length of stay in current country of residence, n(%)	
Less than 1 year	6 (8.3)
1-4 years	18 (25.0)
Greater than or equal to 5 years	39 (54.2)
Unknown	9 (12.5)
Preferred language, n(%)	
English	62 (86.1)
French	2 (2.8)
English and French	1 (1.4
Spanish	1 (1.4)
Other	6 (8.3)
Relationship status, n(%)	
Single or divorced	11 (15.3)
In a relationship or married	50 (69.4)
Unknown	11 (15.3)
Highest level of education, n(%)	
Less than high school equivalent	6 (8.3)

High school equivalent	15 (20.8)
College or advanced degree	17 (23.6)
Unknown	34 (47.2)
Employed during pregnancy, n(%)	
Yes	28 (38.9)
No	30 (41.7)
Unknown	14 (19.4)
Year of HIV diagnosis, n(%)	
1994-2004	17 (23.6)
2005-2014	31 (43.0)
2015-present	22 (30.6)
Unknown	2 (2.8)
Duration between HIV diagnosis and pregnancy, n(%)	
During index pregnancy	5 (6.9)
<12 months before index pregnancy	2 (2.8)
1- 5 years before index pregnancy	19 (26.4)
>5 years before index pregnancy	45 (62.5)

Unknown	1 (1.4)
Partner during index pregnancy, n(%)	
Yes	59 (81.9)
No	5 (6.9)
Unknown	8 (11.1)
Partner is living with HIV, n(%)	
Yes	10 (13.9)
No	27 (37.5)
Unknown	35 (48.6)
Disclosure of HIV status*, n(%)	
To partner	52 (72.2)
To other family	17 (23.6)
To friends	7 (9.7)
On ART prior to pregnancy, n(%)	
Yes	62 (86.1)
No	10 (13.9)
ART during pregnancy (initial regimen), n(%)	38 (52.8)

INSTI-based regimen	21 (29.2)
NNRTI-based regimen	7 (9.7)
PI-based regimen	6 (8.3)
Unknown	
Changed ART regimen postpartum, n(%)	16 (22.2)
NNRTI to NNRTI-based regimen	1
NNRTI to INSTI-based regimen	2
PI to INSTI-based regimen	3
PI to NNRTI-based regimen	1
INSTI to INSTI-based regimen	6
Changed but postpartum regimen not specified	3
Viral load at initiation of prenatal care, n(%)	
<40	61 (84.7)
>40	11 (15.3)
Viral load nearest delivery, n(%)	
<40	65 (90.3)
>40	1 (1.4)

Unknown	6 (8.3)
Viral load closest to 12 months postpartum, n(%)	
<40	29 (31.9)
>40	5 (8.3)
Last viral load within 12 months postpartum	
0-3 months	14 (19.4)
>3-6 months	4 (55.6)
>6-9 months	7 (9.7)
>9-12 months	9 (12.5)
No maternal labs after delivery	38 (58.3)
CD4 at initiation of prenatal care (median (IQR))	600 (492-761)

ART= antiretroviral therapy; INSTI: Integrase Strand Transfer Inhibitor; NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitor; PI: Protease Inhibitor

*More than one answer allowed per patient

Table 2: Pregnancy and breastfeeding characteristics

	N=72
Parity, n(%)	
Nulliparous	13 (18.1)
Multiparous	58 (80.6)
Unknown	1 (1.4)
Gestational age at entry to prenatal care, n(%)	
<14 weeks	37 (51.4)
14-27 weeks	17 (23.6)
>27 weeks	7 (9.7)
Unknown	11 (15.3)
Number of prenatal visits, median (IQR)	7 (4-10)
Number of visits in 12 months postpartum, Obstetrics, n(%)	
None	16 (22.2)
One	36 (50.0)
Two or more	20 (27.8)
Number of visits in 12 months postpartum, HIV primary care, n(%)	

None	36 (50.0)
One	7 (9.7)
Two or more	28 (38.9)
Unknown	1 (1.4)
Number of visits to infant's infectious disease pediatrician in first 12 months of life, median (IQR)	6 (4-8)
Year of pregnancy, n(%)	
2014	1 (1.4)
2015	4 (5.6)
2016	4 (5.6)
2017	3 (4.2)
2018	10 (13.9)
2019	15 (20.8)
2020	21 (29.2)
2021	13 (18.1)
2022	1 (1.4)
Counseled on infant feeding by*, n(%):	

Obstetrician	52 (72.2)
Pediatrician	25 (34.7)
Adult HIV specialist	16 (22.2)
Lactation specialist	6 (8.3)
Social work	6 (8.3)
Ethics	7 (9.7)
Primary reason for breastfeeding, n(%)	
Community expectations/Fear of disclosure	13 (18.1)
Health benefits for the child	16 (22.2)
Bonding with the child	17 (23.6)
Breastfed prior children	6 (8.2)
Personal choice	3 (4.2)
Religious reasons	1 (1.4)
Unknown	16 (22.2)
Duration of breastfeeding, n%	
0-7 days	10 (13.9)
8 days-5 weeks	13 (18.1)

6-12 weeks	8 (11.1)
13-26 weeks	20 (27.8)
27-52 weeks	13 (18.1)
> 52 weeks	5 (6.9)
Unknown	3 (4.2)
Breastfeeding challenges, n(%)	
Low breastmilk supply	15 (20.8)
Pain	4 (5.6)
Mastitis	3 (4.2)
Difficulty with latching	4 (5.6)
Cracked nipples	3 (4.2)
Breastfeeding stopped due to maternal or neonatal hospitalization	2 (2.8)
None	6 (8.3)
Unknown	35 (48.6)
Mixed feeding reported to provider, n(%)	
Yes	16 (22.2)
No	54 (75.0)

Unknown	2 (2.8)
Introduction of solid foods, n(%)	
4-5 months	8 (11.1)
6-7 months	34 (47.2)
>8 months	3 (4.2)
Unknown	27 (37.5)
Weaning style, n(%)	
Rapid	36 (50.0)
Gradual	25 (34.7)
Unknown	11 (15.3)

*More than one answer allowed per patient

Table 3: Institutional characteristics and infant feeding policies

	N=11
Institution location, n(%)	
US	8 (72.7)
Canada	3 (27.2)
Number of deliveries at site for people with HIV per year, n(%)	
10-20 patients	3 (36.3)

21-30 patients	3 (9.0)
31-40 patients	1 (18.1)
>40 patients	4 (27.2)
Written policy regarding breastfeeding for people with HIV, n(%)	
Yes	7 (63.6)
No	4 (36.3)
Policy developed in coordination with*, n(%)	
Pediatrics	4 (36.3)
Pediatric infectious disease	8 (72.7)
Obstetrics	8 (72.7)
Labor and Delivery	3 (27.2)
Adult infectious disease	3 (27.2)
Lactation	6 (54.5)
Legal/Ethics	4 (36.3)

Note: intermittent item missingness leads to some column sums adding up to less than total.
US= United States
*More than one answer allowed per site