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Financial and Food Insecurity are Primary Challenges to Breastfeeding for Women Living with HIV in Western Kenya: A Longitudinal Qualitative Investigation

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Abstract

Exclusive breastfeeding for the first 6 months and continued breastfeeding for 24 months or longer is recommended for all mothers world-wide, including women living with HIV (WLWH). Given evidence of suboptimal infant feeding and the need to understand context specific barriers, we explored experiences of perinatal WLWH in Kisumu, Kenya. We applied a longitudinal qualitative approach (4 in-depth interviews) with 30 women from pregnancy to 14–18 months postpartum. Cross-sectional profiling led to a narrative description of infant feeding across time. The majority of women breastfed exclusively for 6 months and weaned by 18 months. Severe financial and food insecurity were primary challenges as women worked through when/how to breastfeed or stop breastfeeding in the setting of multiple competing priorities/pressures across time. Financial

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and food support and increased support for breastfeeding beyond 18 months have the potential to reduce women's stress and uncertainty associated with infant feeding as well as optimize infant health and nutrition in this setting.

Resumen

Se recomienda la lactancia materna exclusiva durante los primeros 6 meses y la continuación de la lactancia durante 24 meses o más para todas las madres en todo el mundo, incluidas las mujeres que viven con el VIH (WLWH). Debido a la evidencia de alimentación infantil subóptima y la necesidad de comprender las barreras específicas del contexto, exploramos las experiencias de WLWH perinatal en Kisumu, Kenia. Aplicamos un enfoque cualitativo longitudinal (4 entrevistas en profundidad) con 30 mujeres desde el embarazo hasta los 14-18 meses posparto. El perfil transversal resultó en una descripción narrativa de la alimentación infantil a través del tiempo. La mayoría de las mujeres amamantaron exclusivamente durante 6 meses y dejó de amamantar a los 18 meses. La grave inseguridad financiera y alimentaria fueron los principales desafíos cuando las mujeres analizaban cuándo y cómo amamantar o dejar de amamantar en el contexto de múltiples prioridades y presiones en competencia a través del tiempo. El apoyo financiero y alimentario y un mayor apoyo para la lactancia más allá de los 18 meses tienen el potencial de reducir el estrés y la incertidumbre de las mujeres asociados con la alimentación infantil, así como optimizar la salud y la nutrición infantil en este entorno.

Keywords

WLWH; Breastfeeding; Exclusive breastfeeding; Infant feeding; Food Insecurity; Financial Insecurity; Kenya

Introduction

The World Health Organization (WHO) recommends the initiation of breastfeeding within an hour after birth, exclusive breastfeeding (EBF) for the first six months of life and continued breastfeeding while providing nutritionally adequate and safe complimentary food until two years postpartum or beyond for all women globally [1]. Optimal nutrition as outlined in these guidelines offers significant short and long-term protections and benefits to infants and young children. Specifically, for an infant's first six months, EBF significantly reduces all-cause and infection-related mortality when compared to mixed feeding or exclusive formula feeding [2]. Moreover, children six to 23 months of age who are not breastfed have approximately a two-fold higher risk of mortality when compared to breastfed children [2]. Breastfeeding undoubtedly reduces risk for infectious morbidity and mortality, while a longer duration of breastfeeding is also associated with reduced obesity and greater intelligence later in life [3]. After six months of age, when breastmilk alone is no longer enough, adequate complimentary feeding is critical to ensure infants have the nutrients needed to avoid nutritional deficiencies and stunting which hinder growth, development and long-term cognitive function [4].

Undernutrition, including that caused from sub-optimal breastfeeding and inadequate complimentary feeding, contributes to 3.1 million or 45% of under-five child deaths globally

each year [5]. Around half of under-five deaths occur in sub-Saharan Africa (SSA), which bears a disproportionate share of the global burden of sub-optimal nutrition [6, 7]. A variety of factors contribute to this disparity. Known barriers to breastfeeding in this setting include mothers returning to work or school [8], perceptions of insufficient breastmilk, as well as beliefs of infant thirst/need for water and cultural norms [9, 10]. Meanwhile, sub-optimal complimentary feeding in SSA has been associated with financial insecurity [11], lack of knowledge about infant nutritional requirements [12], and dimensions of women's empowerment [13].

For the estimated 1.3 million mothers living with HIV who give birth each year in SSA, there are additional challenges to providing optimal nutrition to infants and young children beyond those faced by HIV-uninfected mothers. [14]. For example, mothers' fears of transmitting HIV to their infants through breastmilk must compete against provider recommendations to breastfeed [15–17]. In addition, to effectively prevent mother to child transmission (MTCT), women must remain adherent to their HIV medications as well as administer HIV prophylaxis medications to their infants/children throughout the breastfeeding period. Despite challenges, evidence indicates optimal infant feeding is particularly important for HIV-exposed infants [18]. Moreover, in this setting, conditions for safe formula feeding such as clean water, sanitation and reliable access to sufficient infant formula are often inadequate. As such, when mothers are adherent to antiretroviral therapy, the WHO infant and young child feeding guidelines offer HIV exposed infants all of the above-mentioned protections/benefits and the best chance for HIV free survival [18].

In Kenya, where 1.4 million adults and children are living with HIV [19], the Ministry of Health's National Policy on Maternal, Infant and Young Child nutrition [20], and infant feeding guidelines for women living with HIV (WLWH) are in line with WHO recommendations [21, 22]. The Ministry of Health's strategies to improve infant and young child feeding and reduce mother to child transmission of HIV include the Baby Friendly Hospital and Community Initiatives to promote optimal infant feeding [23, 24], and expanded access to free HIV testing and antiretroviral therapy [22]. As a result, the rate of MTCT of HIV in Kenya decreased from 14.3% to 2013 to approximately 8% in 2021 [19, 25]. Yet, there is still progress to be made. According to Kenya's 2022 Demographic and Health Survey, only 60% of infants zero to five months old were exclusively breastfeeding (1% less than in 2014) and just 31% of infants six to 23 months old were fed the minimum acceptable diet [26]. Other recent estimates of the prevalence of EBF among WLWH in Kenya range widely from 43–71% [27, 28]. Meanwhile, several qualitative studies have highlighted barriers to optimal infant feeding among this population including perceived milk insufficiency, HIV related stigma, and a lack of maternal autonomy in decision-making [29–31]. Beyond breastfeeding, inadequate complimentary feeding in this setting has been attributed to poor sanitation, food insecurity and sociocultural factors [30, 32].

Given these challenges and complexities WLWH in Kenya face, and current evidence showing persistent sub-optimal infant and young child nutrition, there is a continued need to understand context specific barriers across the perinatal period. To fill this gap, we sought to explore the experiences of perinatal WLWH related to infant and young child feeding in Kisumu, Kenya. We conducted a longitudinal qualitative study where we enrolled 30

pregnant WLWH and conducted in-depth interviews at four timepoints from pregnancy to 18 months postpartum.

Methods

Setting/Sample

Our study took place in a prevention of mother to child transmission of HIV (PMTCT) clinic, supported by Family AIDS Care & Education Services and Centers for Disease Control/President's Plan for AIDS Relief, at one sub-county hospital in Kisumu County. The clinic provides comprehensive HIV services for pregnant and postpartum women and their infants. Kisumu, a port city on Lake Victoria, is located in a region of western Kenya where an estimated 17.4% of women (age 15–49) are living with HIV, compared to 5.2% of women nationally [33]. We recruited a convenience sample of 30 WLWH who were at least 18 years old and 28 to 38-weeks pregnant. Clinic staff assisted a research associate (RA) to identify women who were potentially eligible. In a private office, the RA then screened for eligibility and interest in participation. Women who were interested and eligible provided written informed consent to participate. We excluded women who had high risk pregnancies, were participating in other ongoing studies or who were planning on relocating within the timeframe of the study. Women were provided with refreshments and reimbursed for the cost of their transportation to the clinic.

Data Collection

From April 2019-March 2021 we conducted in-depth interviews at four time-points: (1) 28 to 38-weeks of gestation, (2) six weeks postpartum, (3) five to seven months postpartum and (4) 14 to 18 months postpartum. These timepoints were synchronized with the PMTCT clinic's schedule (see Fig. 1 for an overview of PMTCT services and infant feeding recommendations). Our interviews were conducted by our locally based RA who is fluent in Dholuo, Swahili and English and lasted approximately 60 to 90 min in length. Our interview guides were developed based on preliminary research and included questions and prompts to elicit narratives of women's experiences related to infant feeding and adherence to ART [34, 35]. We explicitly asked about barriers and facilitators related to infant and young child feeding in the context of living with HIV, and how plans and practices varied across time. In the ante-natal period, we asked about anticipated feeding practices and expected challenges, and in the post-partum period about both actual practices, challenges faced and continued plans. After the first two interviews, some questions in subsequent guides were tailored to individual participants allowing us to clarify and verify information previously provided as well as ask specific follow up questions about the progression of women's unique experiences. See Supplemental Table 1 for key questions from each timepoint. Our interviews were audio recorded, transcribed, translated into English and quality checked prior to analysis.

Ethical Approval was obtained from Kenya Medical Research Institute Scientific and Ethics Review Unit and the University of California San Francisco.

Data Analysis

We conducted a longitudinal qualitative analysis using the cross-sectional profiling method [36] while applying a deductive and synchronic approach [37]. Cross-sectional profiling is the development of narrative descriptions that fit into predetermined categories across time [36]. Specifically, we started with categories drawn from our interview guide. Using these categories as a framework, we read and discussed each transcript to collaboratively write a profile—descriptive narrative summary, for each participant at each timepoint [36]. Our analysis team, consisting of the principal investigator (ET) and two RAs (AM, BO), individually reviewed the profiles to for completeness and accuracy. Any discrepancies or necessary additions were discussed amongst our team and addressed. We then organized these narratives into a Table (30 participants x four timepoints), and reviewed the profiles to understand how infant feeding experiences changed or remained the same across time for each participant and how each participant’s experience related to that of the group. We focused on understanding the challenges women faced as well as what influenced women’s behaviors and decision making about infant feeding across time. We operationalized our primary constructs as follows: (1) EBF constitutes providing infants with breastmilk and their prescribed medications only (i.e., not providing any other foods, milk, infant formula, or water). (2) Mixed feeding constitutes providing breastmilk along with food and/or liquids including milk, formula and water during the first six months postpartum. (3) Complimentary feeding describes the period starting at six months postpartum during which women continue to breastfeed while introducing food and/or liquids including milk, formula and water (as recommended). The final result was an overall narrative description of the experience of infant feeding across time for the entire group highlighting both exemplar cases representing the majority of women’s experiences as well as outlying cases.

Results

Participant Characteristics

Thirty women participated in 116 interviews at four time points from pregnancy to approximately 18 months postpartum (two women were lost to follow-up after the second interview). The median age was 28.8 years. Seven women were having their first baby and nine women tested positive for HIV for the first time during this pregnancy. The majority of women lived in informal settlements within Kisumu, while nine lived in rural Kisumu. Most women were moderately or severely food insecure across time according to the Individually-focused Food Insecurity Access Scale (see Table 1 for participant characteristics). Of the 28 women who participated in all four interviews, all remained engaged in care with no cases of MTCT among the group. The statuses of the two women lost to follow up and their infants are unknown.

Cross-sectional Profile Findings

Our analyses resulted in detailed narratives of women’s experiences related to infant and young child feeding in the context of HIV from pregnancy to 18 months postpartum. We have included the experience of the majority of our participants while also acknowledging exceptional cases and experiences shared only by a few (see Table 2 for an overview of key findings and exceptional cases).

Pregnancy (28 to 38 Weeks): Anticipating Challenges with EBF

During their third trimester, women were highly concerned with protecting their unborn infants from HIV. Women reported receiving information from providers on the importance of EBF for the first six months postpartum and being warned that the practice of mixed feeding prior to six months would increase the risk of transmitting HIV to their infants. Accordingly, all women planned to EBF to the extent they felt possible and the majority (80%) reported they planned to EBF for the first six months postpartum. Despite their desire to protect their infants, and having plans in place, many women expressed worry and anticipated challenges related to EBF, particularly women who were having their first baby while living with HIV and had not practiced EBF before. In addition to a lack of experience, severe levels of food insecurity exacerbated women's worries about their ability to sustain EBF. Nearly a third of women doubted they would have enough food to support the production of sufficient breastmilk to meet their babies' needs.

(030, 27-year-old, widow, mother of two) P: *I do not think that I will have enough food and I am worried about that. I wonder if I will be able to produce enough milk for the baby and I am not getting enough food. I need to breastfeed this child for six months and I am not good at breastfeeding babies, I started weaning my other children at three months, but with this one I cannot do that because if I do, I will make him/her susceptible to the virus.*

Pregnant women also worried about how they would return to work while practicing EBF. Most women stopped work during pregnancy and as a result were experiencing increased financial and food insecurity. Thus, returning to work to earn much needed income was at the forefront of most women's minds. However, women anticipated the return to work would be extremely challenging or impossible while EBF for six months. This is because women equated EBF with needing to have their babies with them at all times given that resources for pumping and storing breastmilk were unavailable to them and they could not trust caregivers to refrain from giving their baby other things to eat.

(026, 36-year-old, separated, mother of two) P: *I have plans to open a business when my baby is six months because we were told that we are not supposed to leave the baby with anyone even for one second because the person can give him/her water, tea or porridge and the baby should not be given anything until after six months.*

In sum, despite the majority of pregnant women feeling considerable worry about their ability to practice EBF, more than half reported they believed they would overcome challenges and exclusively breastfeed for six months.

Birth to Six Weeks Postpartum: Exclusive Breastfeeding Begins

All women interviewed during their sixth week postpartum reported initiating breastfeeding soon after birth and had sustained EBF up to this timepoint. However, the worries of many women about EBF had transitioned to concrete challenges during these first weeks postpartum. Perceived milk insufficiency and EBF's interference with income generating activities or daily chores were the primary challenges described during this time. Half of the women described symptoms of milk insufficiency such as babies crying from what

seemed to be hunger even after breastfeeding, the inability to express milk from their breasts even while infants continued to suckle, painful nipples from babies suckling when they had no milk, and babies not gaining weight as expected. Women primarily attributed their inadequate breastmilk production to inadequate access to food and experiences of severe food insecurity.

(020, 24-year-old, married, mother of one) P: *Sometimes I lack breastmilk, so you know that if you don't get enough food, you won't have breastmilk.*

Moreover, women's options to return to work (and improve their access to food) were limited given their commitment to EBF. Only a few women reported resuming work and bringing their babies along with them at this early postpartum time. One woman faced challenges balancing work and infant care. She described customers who complained when she breastfed before serving their food, saying it delayed their service and was distasteful. In addition, among the women able to return to work with their baby, only one described improved access to food.

Support (or lack thereof) from providers was also an important factor in women's EBF experience. Women described receiving varying levels of support in the form of information or instructions about EBF. In addition, a few women reported discussing or planning to discuss their concerns about milk insufficiency or their desire to introduce supplemental feeds with providers. However, the women who did consult with their provider reported receiving little help identifying practical strategies to overcome their specific breastfeeding challenges or options for alternative infant feeding practices.

(025, 37-year-old, single, mother of four) P: *I asked [the provider] and I was told that there was nothing else I could give him/her. But sometimes I experience a challenge because the baby breastfeeds and night comes before I even eat anything since morning. I sometimes have pity on the baby because there is no way he/she can even add weight.*

Although, most women still described good and supportive relationships with providers and a high level of trust in the recommendations received, some were uncertain about the rationale behind EBF. They explained their understanding to be that any mixed feeding increased the risk of MTCT regardless of ART adherence. As a result, around one-third of the women anticipated that they would stop breastfeeding completely after six months of EBF, believing complimentary feeding would increase the risk for MTCT and should therefore not be practiced at any time. As one woman explains,

(013, 19-year-old, single, first-time mother) P: *Okay, I won't breastfeed after six months, I will introduce him to other foods. Because if I do mixed feeding when he is HIV negative then it can affect him.*

A lack of understanding of the risks and benefits of each infant feeding option, changing guidelines over time, and the known possibility of HIV being transmitted through breastmilk fueled ongoing apprehensions about breastfeeding in general and consequently many women at this time point also voiced general questions about EBF and the risks posed to their infants.

(006, 35-year-old, married, mother of three) P: *Why must it be six months of exclusive breast feeding, since six months is a long time, at times the baby does not get satisfied with just breast milk, what can be done when the baby feels really hungry and is crying?*

Support and information (both for and against EBF) from friends, family and neighbors also influenced women's early infant feeding decisions and behaviors. Many women mentioned positive support for EBF from friends or family, such as food and financial support or advice. In contrast, the majority of women (including some of the same women who received support for EBF) reported advice or pressure from friends or family to stop breastfeeding or introduce complimentary feeds. There were even a few women who reported other people giving their babies things to eat/drink including traditional medicines when they were not around. The opposition to EBF was primarily related to perceptions that the babies were not thriving or not being satisfied by breastmilk alone. Though a few also faced pressure related to fears about HIV transmission through breastmilk.

(006) P: *Yes, people are saying that I should cook porridge for him because baby boys feed a lot; others say I give him milk.*

Relatedly, many women reported that "plastic teeth" removal (a traditional practice that involves cutting an infant's gums and/or the removal of an infant's incisor buds) was proposed by friends, family or neighbors as a remedy for any number of infant health problems including for infants who were frequently crying and perceived to not be feeding well early postpartum. "Plastic teeth" removal was strongly discouraged by providers as it is often conducted under unsanitary conditions and puts infants at risk for bleeding and infection. Even still, around one-third of the women reported taking their babies to traditional healers who carried out this practice, with no reports of complications beyond minor bleeding. Another third of women reported their babies did not have "plastic teeth" and therefore did not need to have them removed. Among the remaining women, a few reported using alternative treatments to address "plastic teeth" such as applying powders or herbs to their baby's gums and several women opted not to have plastic teeth removed after receiving instructions from providers. In sum, for many women, plastic teeth removal was a practice considered in the context of early infant feeding.

(010, 25-year-old, married, mother of two) P: *I kept wondering what was wrong with the baby then I took her to some elderly woman to ask if she had plastic teeth and to have it checked. When she checked she found out that she had them and she told me to take her to a place where they could be removed. Once they were removed, about four, that is how the fever sub-sided. The fever made her cry all the time.*

By and large, despite struggles with milk insufficiency, worries about HIV transmission to their infants and a myriad of pressures including the need to return to work or to introduce complimentary feeds, women continued to EBF their babies as recommended. There were only four women at six weeks postpartum who reported they planned to begin mixed feeding prior to the recommended six months, all four of these women were experiencing their first pregnancy while living with HIV.

Six Months Postpartum: Exclusive Breastfeeding Ends Weaning Begins

By six months postpartum, the majority of women reported having exclusively breastfed for the entire six months. For slightly more than half of the women, who persistently struggled with the aforementioned challenges, the end of EBF came with a great sense of relief both because they had managed to comply with the recommendation and because the end of EBF would allow them to return to work.

(007, 33-year-old, single, mother of four) P: *Right now, since he is ready to start weaning, I can look for a job and leave the baby behind for someone to take care of and I can cook porridge for the baby to take while I am away, that way I won't be worried about the baby but before leaving the baby was difficult because he was breastfeeding exclusively, so I wasn't confident back then.*

More than one-third of women had resumed work by six months with some bringing their babies along to facilitate continued breastfeeding and care. Of those who remained unemployed, the majority reported plans to resume work as soon as possible.

Four women confirmed they started mixed feeding prior to reaching six months postpartum. Only one of these women was from the group of four women who, at six weeks postpartum, reported plans to begin mixed feeding prior to six months (see above). Two others were women experiencing their first pregnancy while living with HIV. These four women cited a variety of reasons for mixed feeding including that their infants were underweight, breastfeeding too much or that their infant was not satisfied by breastmilk alone. Among women who started mixed feeding prior to six months, few sought guidance from their providers even when they were struggling to EBF. One woman, who was struggling with perceived milk insufficiency did discuss her concerns with her provider and was advised to start supplementing her underweight baby with cow's milk. However, she described being very reluctant to do so given the previous messaging from providers about the increased risk of HIV transmission with early mixed feeding. In addition, she lacked the financial resources to purchase cow's milk. In another example, two women reported choosing not to discuss their decision to practice mixed feeding with providers in order to avoid conflict/being scolded.

(006) P: *I did not inform them because I thought that they would scold me since I was supposed to start weaning at six months, but I felt the baby would have a hard time if I waited up to six months.*

At the six-month postpartum visit, providers instructed women to begin complimentary feeding by introducing milk, porridge and other foods while continuing to breastfeed. In as much as women welcomed the end of EBF, confronting the challenge of procuring foods created new worries about how to provide for their infant. Citing their own financial and food insecurity, many women noted feeling the new burden of trying to purchase enough nutritious food for their baby to eat with milk, porridge, and mashed fruits being the primary complimentary foods mentioned.

(030) P: *I have been worried about that because I do not know where I am going to get the food for the baby because I am not even able to get food that I can eat so where would I get the one for the baby, I even joked with the doctor that should I*

cut my thigh so that I can give the baby. I really do not know where I am going to get the food, if I had money then I would have gone and bought flour for the baby. Where am I going to get flour and milk?

By six months postpartum, women had also received their infants HIV test results, all of which were negative. This news was extremely rewarding, a relief, and motivating for women who worried deeply about their baby's HIV status during pregnancy and early postpartum.

(021, 24-year-old, single, first-time mother) P: *Okay, I felt good and that really made me to feel so much proud taking my medicine and with confidence because at least I have made a step of saving her the first test...*

Reassurance from the infant's first HIV test along with new information, recommendations and support from providers led to a change in many women's previous plans to stop breastfeeding at six months and instead women continued to breastfeed while introducing complimentary foods. In fact, all women continued to breastfeed and began complimentary feeding, including those who previously equated any mixed feeding with an increased risk for HIV transmission and most women reported intentions to continue breastfeeding for one year postpartum or longer.

14 to 18 Months Postpartum: Weaning Continues, Breastfeeding Ends for Some

From six months postpartum until the final interview at around 18 months postpartum, women described facing a variety of challenges with regards to introducing their babies to food and the process of weaning them from breastmilk/breastfeeding. Women primarily started complimentary feeding by giving their babies porridge and cow's milk. About a quarter of the women reported an ongoing lack of finances which made accessing these foods for their babies very difficult. For some, this was a main motivation to continue breastfeeding.

(023, 34-year-old, separated, mother of four) P: *It wasn't easy. You know when I went to work, I used to ask that woman (employer) to give me some little money because the baby was not well and that I wanted to buy him food. Sometimes I could be given and sometimes she could say that she didn't have and that I should wait.*

Many women also reported that weaning was challenging because their babies preferred breastmilk or "lacked an appetite" for any of the available complimentary foods.

(004, 23-year-old, single, first-time mother) P: *She had refused to eat anything a baby was supposed to eat, never letting it near her mouth for a bit, she was just breastfeeding and she is now grown, she could breastfeed and I could not even sleep because she was not getting satisfied with breast milk and she still wanted to breastfeed.*

Thus, during the time between the third and fourth interviews, women continued breastfeeding to various extents with many eventually stopping. Several women reported stopping breastfeeding between seven to 12 months postpartum; one woman stopped at seven months after her baby fell ill, another woman described her baby stopping on his own

at around 10 months because of her low milk supply and a third woman reported stopping at around seven months postpartum after being advised to stop by providers. At around one year postpartum, several more women reported stopping breastfeeding for a variety of other reasons, including their baby getting teeth or their baby stopping on their own. Most often it was because women felt ready to stop breastfeeding and believed stopping breastfeeding was necessary to encourage/force their baby to consume other foods in order to thrive.

(009, 34-year-old, married, mother of four) P: *She was breastfeeding until I could feel tired and I felt that she had ‘outgrown’ breastmilk, and I thought that I should just stop her even if she cried. Her father also told me to stop her as she was ready to and she should eat, even if she cries, I should not give her, she will cry for only two days and get used to it, she will feel hungry and eat eventually.*

Meanwhile, two-thirds of the women continued to breastfeed beyond 12 months. Notably, these women reported that the principal message delivered by providers during this period was that they should continue to wean and ultimately stop breastfeeding completely by 18 months postpartum. The rationale being that at 18 months the infant’s last HIV test is performed, and if no longer breastfeeding, the baby would no longer be exposed to HIV infection after that test. Thus, the infant would definitively be declared HIV negative with no possibility of MTCT beyond that point. There would be no need for further infant HIV testing or prophylaxis medications and, above all, no further worry about HIV transmission to the infant.

(001, 28-year-old, married, first-time mother) P: *I was told that she should have stopped breastfeeding by the time she was a year and six months old, so that she is tested [HIV test] after she has stopped breastfeeding.*

Some women accepted the providers’ recommendation and were able to stop breastfeeding with ease by this 18-month timepoint. However, around a quarter of the women struggled in their attempt to stop breastfeeding and resorted to a variety of methods such as applying bitter products on their nipples or sleeping separately from their baby.

(006) P: *I put pepper and other bitter things but that does not stop him, when the taste subsides, he continues to breastfeed. I do not know what to do because I am trying to stop him from breastfeeding, and he does not want to stop because he loves breast milk.*

Six women continued to breastfeed beyond 18 months postpartum and a few of those women planned to breastfeed for up to two years. Women reported their decision to continue breastfeeding, despite their provider’s recommendation to stop, was either because their attempts to stop were unsuccessful, they did not feel ready to stop, or they worried about having access to enough food for their babies after stopping.

(030) P: *I have not stopped her and since I am having trouble accessing food, I feel that I should just breastfeed her, and the doctor also advised me that if I am taking my medication even when I am breastfeeding her until she is three years old, she cannot contract HIV if I am taking my medication well and giving her Septrin well.*

Women who breastfed for longer than 18 months were not offered alternative treatment plans for their infants. Two women reported providers supporting their decision to continue

breastfeeding while emphasizing the importance of the women's adherence to ART, but none were offered additional prophylaxis medications or HIV testing for their infants beyond 18 months postpartum. In a few cases it was unclear if providers knew that women were continuing to breastfeed or if they believed women had stopped at 18 months as they had been advised to do. Regardless, women who chose to continue to breastfeed beyond 18 months felt reassured by the results of at least the first four of their infant's HIV tests (taken at six weeks, six months, 12 months and 18 months), with zero cases of MTCT among the group. Moreover, the majority of women, and all of the women who continued to breastfeed, also had less than detectable viral loads (taken at 12-months postpartum). With this in mind, those who continued to breastfeed did so with greater confidence and few worries about MTCT.

Discussion

Our findings provide a longitudinal qualitative perspective of current infant and young child feeding experiences among WLWH engaged in comprehensive HIV care, in western Kenya. The majority of women breastfed exclusively for the first six months, and there were no cases of MTCT as assessed by PCR tests at 18-months postpartum. We found that food insecurity was a central challenge across time in this setting during both the breastfeeding period and the introduction of complimentary foods. In addition, we found that women faced constant worries and uncertainties throughout the perinatal period as they worked through when and how to breastfeed or stop breastfeeding in the setting of multiple competing priorities/pressures across time. Women prioritized EBF, but faced perceived milk insufficiency, social pressures to mixed feed before six months and the need to resume work to improve access to food. Later, women weighed provider recommendations to stop breastfeeding by 18 months and the desire to eliminate the ongoing possibility of MTCT against the benefits of continued breastfeeding and their infants' preference to continue. Ultimately, we reveal a missed opportunity to promote and support breastfeeding beyond 18 months postpartum as recommended by the WHO's 2016 evidence-based guidelines.

While persevering to maintain their commitment to EBF, mothers reported limited access to food, which they believed contributed to insufficient breastmilk production and necessitated their prompt return to work to earn income to meet basic needs. Previous studies have identified returning to the workforce [16, 29, 38, 39] and perceived milk insufficiency [16, 17, 40, 41] as reported barriers to EBF. In addition, studies have linked reported milk insufficiency and reduced EBF to food insecurity in Kenya [10, 29, 39, 41, 42], and Miller (2019) confirmed (using objective measures) that women's reported levels of food insecurity were inversely related to breastmilk intake (greater food insecurity scores were associated with decreased breastmilk intake) [43]. We connect these important findings and expand this knowledge by showing that food insecurity, in addition to being associated with perceived milk insufficiency, increased pressure on women to return to gainful employment as soon as possible postpartum—further challenging women's commitment to EBF. We are also the first study to our knowledge that shows how food insecurity impacts feeding decisions and behaviors for WLWH across time and beyond the period of EBF. We show that food insecurity contributed to increased worries about infant feeding during pregnancy, perceived milk insufficiency and pressure to return to work early postpartum, and limited access to

food during complimentary feeding, motivating some women to continue breastfeeding for longer periods.

Information and support from healthcare workers also influenced women's infant feeding practices. Our findings are in line with other studies that found education and support from professional and lay health workers increased EBF intention and practice among WLWH [17, 28, 39, 44, 45]. However, similar to Hazemba's (2016) findings from Zambia, we found there was little room for women to collaborate with their providers to make decisions about infant feeding [40]. Women were simply (re)instructed to practice EBF for the first six months postpartum, without support for overcoming challenges or the option of contributing to shared decision-making with their provider based on their individual circumstances. This approach, while seemingly effective in providing a clear message for women to EBF, likely increased worry for women who practiced (or desired to practice) early mixed feeding. Moreover, it created an environment where some women were reluctant to report their struggles with EBF or their decision to mix-feed. This effectively closed the door to further information or support that could have optimized women's infant feeding experiences. These findings corroborate findings of Østergaard (2010) who noted the tendency for WLWH in Malawi to report EBF to providers while actually providing their infants with water, porridge or other supplemental feeds and Oiye et al. (2017) who found that the subjectively reported rate of EBF was far higher than the objectively measured rate of EBF (using the deuterium oxide dilution technique) for a group of WLWH in Kenya [17, 27].

Beyond the period of EBF, providers also influenced women's decisions about when to stop breastfeeding, with the majority of women stopping prior to 18 months as instructed. Although nurses and lay health workers acknowledged the WHO guidelines promoting continued breastfeeding for 24 months postpartum and beyond, 18 months was clearly promoted to the women as the time to stop breastfeeding. The exact reason for this discrepancy is not evident from our data, and to our knowledge no previous studies have identified this barrier to continued breastfeeding. However, we can speculate that providers were doing their best to support the practical implementation of these guidelines, given the resources at hand. Medication stockouts and limited resources to support further infant testing are real challenges in this setting. Indeed, providers deserve much credit for disseminating complex guidelines which have rapidly changed in response to growing evidence over the last several decades [18]. Nevertheless, given that women were highly food insecure, with good adherence, and no cases of MTCT among the group, the lost nutritional benefits of continued breastfeeding warrants examining.

In addition to providers and lay healthcare workers, partners, family, friends and neighbors have also been shown to impact infant feeding, particularly by impeding EBF [17]. Yet women in our study were largely able to resist social pressures that went against the recommendations of providers. They also did not report stigma as a significant barrier to EBF as other studies have described [30]. This is perhaps because we interviewed women who were at least 18 years old and excluded younger mothers who are particularly susceptible to pressure from their parents or mothers-in-law [28, 31]. It could also be because nearly all the women in our study had disclosed their HIV status to their partners or the people they live with and were thus more easily able to rationalize EBF to their

partners or close family. Disclosure of HIV status has been recognized as a factor positively impacting EBF and non-disclosure has been found to reduce EBF[31, 39, 44, 46]. Finally, EBF has recently been more widely promoted as an important practice for all new mothers regardless of their HIV status. Thus, there could be reduced stigma as EBF is no longer strictly associated with being HIV positive and a broader understanding of breastmilk as complete nutrition for the first six months is more established.

Despite women being largely empowered to resist social pressures and deviate from cultural norms related to infant feeding, many women subjected their infants to the dangerous practice of having “plastic teeth” removed—a traditional practice that involves cutting an infant’s gums and/or the removal of an infant’s incisor buds. Although none of the infants in our study experienced significant adverse outcomes from the procedure, the relationship between infant feeding, MTCT and plastic teeth removal in this community is not well described in the literature and a deeper exploration could lend important insight.

Public Health Implications

Given the impact of food and financial insecurity on women’s experiences across time, food and financial support along with expanded formal employment and career opportunities for women are needed to optimize infant and young child nutrition in this setting. In addition, there is a need for improved communication between mothers and their providers. Current messaging delivered to WLWH about EBF could be softened to encourage women to report their actual infant feeding experiences/practices in order to gain practical support for overcoming specific infant feeding challenges (such as perceived milk insufficiency). Given that any breastfeeding is recommended over none, it is also important to acknowledge that EBF may not be feasible for some women, and provide adequate support for safe supplemental feeding (mixed feeding) when appropriate [18].

Our current findings and previous research applying Transitions Theory, have informed the development of a multi-level intervention to reduce financial and food insecurity and provide practically applicable knowledge and skills to optimize infant and young child nutrition [47]. The intervention currently being piloted consists of two components: monthly unconditional cash transfers to reduce financial insecurity from late pregnancy through 6 months postpartum, and personalized support for infant and young child feeding provided by a professional lactation specialist at regular intervals from late pregnancy through 3 months postpartum. By reducing upstream barriers and assisting mother to identify and address problems/challenges that lead to suboptimal infant feeding, our intervention aims to reduce the burden on mothers and optimize maternal and infant health and well-being in this context.

Limitations

All of our participants were 18 years of age or older, thus we do not incorporate the perspectives or specific challenges of younger mothers (under 18), whose infant and young child feeding experiences may be influenced to a greater extent (positively or negatively) by the adults they live with. We also did not collect data on infant/child growth or the adequacy of complimentary feeding which may give additional insight into how women’s feeding

decisions and behaviors impact the nutritional status of their infants/children. Finally, it must also be recognized that optimal nutrition is just one element of a broader PMTCT strategy. Perinatal WLWH must also adhere to ART and administer daily prophylactic medications to their infants, both noteworthy undertakings with associated challenges not discussed here. Thus, there is a need to incorporate the other elements of the PMTCT strategy to fully understand the challenges WLWH face.

Conclusions

Women engaged in comprehensive HIV care services in western Kenya reported high levels of adherence to the WHO's infant feeding guidelines, with the majority of women reporting EBF until six months postpartum, and zero cases of MTCT at 18 months postpartum. However, across time, women's experiences related to infant feeding were threaded with notable worry and uncertainty as women struggled to overcome challenges, including food insecurity and competing demands between EBF and work. Our findings underscore a need to optimize infant and young child feeding through theory-based interventions that improve access to financial and food support during the perinatal period and provide individualized support for overcoming specific barriers to EBF and continued support for complimentary feeding as well as longer durations of breastfeeding.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability

The qualitative data is not available for distribution.

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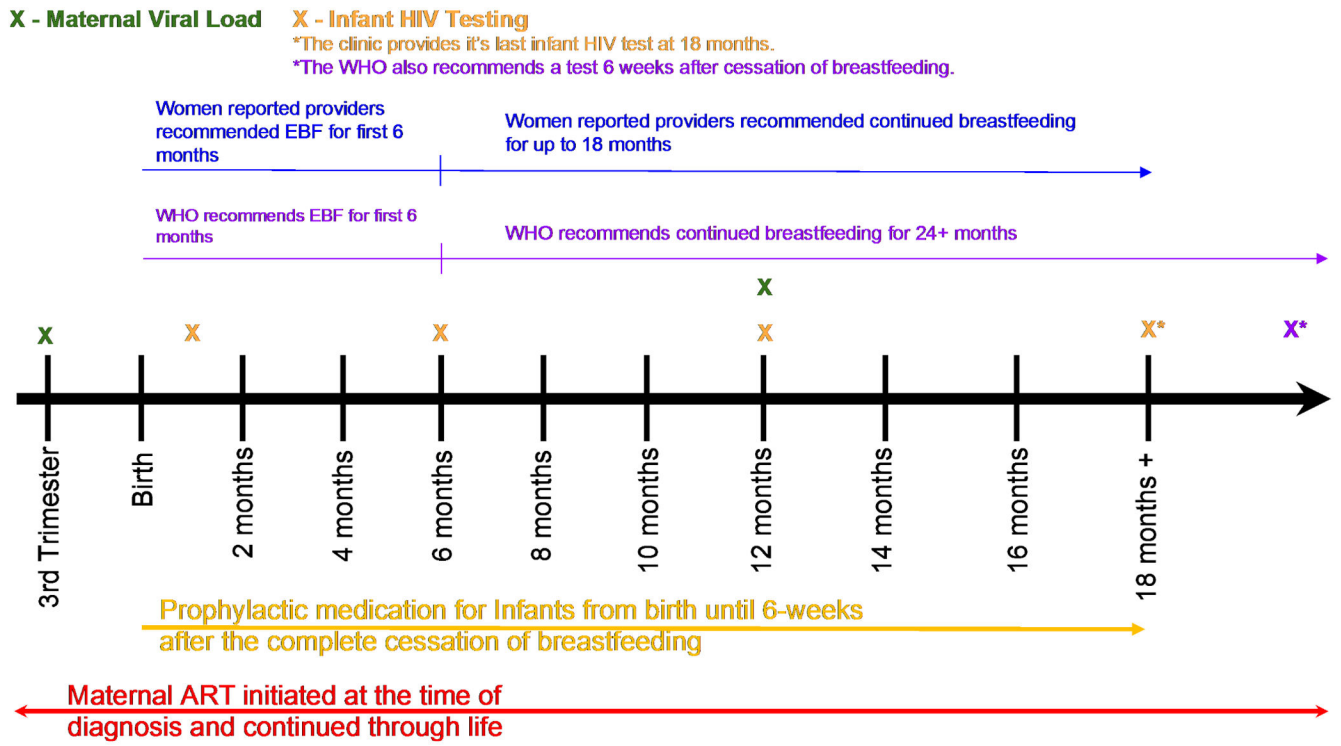


Fig. 1.
 An overview of PMTCT services and infant feeding recommendations

Table 1

Sociodemographic characteristics

	Before pregnancy	Pregnancy (n = 30)	6 weeks (n = 30)	5–7 months (n = 28)	14–18 months (n = 28)
Employment					
Employed	25 (83%)	6 (20%)	4 (13%)	12 (43%)	20(71%)
Unemployed	5 (17%)	24 (80%)	26 (87%)	16 (57%)	8(29%)
Employment Type					
None/housewife	5 (17%)				8(29%)
Office work	3 (10%)				3(11%)
Trader	13 (43%)				5(17%)
Day Laborer	9 (30%)				12(43%)
Ethnic group					
Luo		29 (97%)			27(96%)
Kisii		1 (3%)			1(4%)
Education					
None		17 (57%)			
Primary		5 (17%)			
Secondary		5 (17%)			
College		3 (9%)			
Time engaged in HIV care					
2 years		9 (30%)			
> 2 years		21 (70%)			
Children living at home					
None		7 (23%)			
1–3		18 (60%)			
> 3		5 (17%)			
Relationship status					
Living w/ partner		17 (57%)*	16 (53%)	14 (50%)	17(61%)
Not living w/ partner		13 (43%)	14 (47%)	14 (50%)	11(39%)

* Four women reported polygamous relationships at pregnancy timepoint

Table 2

Key Findings from Cross-sectional profiling

<p>Pregnancy (28–38 Weeks): Anticipating Challenges with EBF</p> <p>Key findings:</p> <ul style="list-style-type: none"> • All planned to EBF for as long as possible, up to 6-months postpartum • Many worried about MTCT and challenges /barriers to EBF including EBF interfering with their return to work—leading to greater financial and food insecurity • More than half believed they could overcome challenges/barriers to EBF 	<p>Exceptional cases:</p> <ul style="list-style-type: none"> • Few had no worries, and were not anticipating challenges
<p>Birth to 6-Weeks Postpartum: Exclusive Breastfeeding Begins</p> <p>Key findings:</p> <ul style="list-style-type: none"> • All reported EBF • Commonly reported challenges: perceived milk insufficiency and EBF interfering with income generating activities. • Providers supportive, but offered few practical solutions for overcoming challenges • Family and friends influenced infant feeding decisions and behavior (for better or worse) 	<p>Exceptional cases:</p> <ul style="list-style-type: none"> • 4 planned to introduce foods or liquids other than breastmilk prior to 6 months postpartum
<p>6 Months Postpartum: Exclusive Breastfeeding Ends Weaning Begins</p> <p>Key findings:</p> <ul style="list-style-type: none"> • Most reported EBF for the first 6 months • All continued to breastfeed while starting complementary foods • Most planned to continue breastfeeding for one year or more • 1/3 returned to work, with the majority of the rest planning to resume work ASAP • Many reported challenges accessing complimentary foods due to financial insecurity • All babies tested HIV negative easing worries about MTCT 	<p>Exceptional cases:</p> <ul style="list-style-type: none"> • 4 reported mixed feeding before 6 months with reasons including perceived milk insufficiency and infants being underweight • Only 1 of these 4 was among the 4 who reported plans to mixed feed at 6 weeks
<p>14–18 Months Postpartum: Weaning Continues, Breastfeeding Ends for Some</p> <p>Key findings:</p> <ul style="list-style-type: none"> • Many reported challenges with complimentary feeding: lack of money to buy food and babies preferring breastmilk over new foods/porridge • 2/3 reported breastfeeding beyond 12 months • Providers encouraged women to stop breastfeeding by 18 months (the time of the child's last HIV test) and most followed this guidance • All babies tested HIV negative (again) which minimized remaining concerns about MTCT 	<p>Exceptional cases:</p> <ul style="list-style-type: none"> • 2 stopped breastfeeding at 7 months and 1 stopped at 10 months • Several stopped breastfeeding at 12 months • 6 continued breastfeeding beyond 18 months with futile attempts to stop or worries about food insecurity keeping some going. • Few planned to breastfeed for up to 2 years and beyond