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Infant feeding knowledge among women living with HIV and their interaction with healthcare providers in a high-income setting: a longitudinal mixed methods study

Ellen Moseholm^{1,2*}, Inka Aho³, Åsa Mellgren^{4,5}, Isik S Johansen⁶, Terese L Katzenstein⁷, Gitte Pedersen⁸, Merete Storgaard⁹ and Nina Weis^{1,10}

Abstract

Background Recent changes in the infant feeding guidelines for women living with HIV from high-income countries recommend a more supportive approach focusing on shared decision-making. Limited information is available on the infant feeding knowledge of women living with HIV and how healthcare providers engage with them in this context. This multicenter, longitudinal, mixed methods study aims to get a comprehensive and nuanced understanding of infant feeding knowledge among women living with HIV of Nordic and non-Nordic origin living in Nordic countries, and their interaction with healthcare providers regarding infant feeding planning.

Methods Pregnant women living with HIV in Denmark, Finland, and Sweden were recruited in 2019–2020. The Positive Attitudes Concerning Infant Feeding (PACIFY) questionnaire was completed in the 3rd trimester (T1), three (T2), and six (T3) months postpartum. Women who completed the quantitative survey were also invited to participate in qualitative semi-structured interviews at T1 and T3. Results from the survey and interviews were brought together through merging to assess for concordance, complementarity, expansion, or discordance between the datasets and to draw meta-inferences.

Results In total, 44 women living with HIV completed the survey, of whom 31 also participated in the interviews. The merged analyses identified two overarching domains: Knowledge about breastfeeding in the U=U era and Communications with healthcare providers. The women expressed confusion about breastfeeding in the context of undetectable equals untransmittable (U=U). Women of Nordic origin were more unsure about whether breastfeeding was possible in the context of U=U than women of non-Nordic origin. Increased postpartum monitoring with monthly testing of the mother was not seen as a barrier to breastfeeding, but concerns were found regarding infant testing and infant ART exposure. Infant feeding discussions with healthcare providers were welcome but could also question whether breastfeeding was feasible, and many participants highlighted a need for more information.

Conclusions Healthcare providers caring for women living with HIV must have up-to-date knowledge of HIV transmission risks during breastfeeding and engage in shared decision-making to optimally support infant feeding choices.

Presentations: An oral presentation of the preliminary results was presented at The AIDS Impact conference, June 12–14, 2023, Stockholm, Sweden.

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Keywords Women living with HIV, Infant feeding, Breastfeeding, Longitudinal-mixed methods study, Nordic setting, 2BMOM

Background

The success of combination antiretroviral therapy (ART) has reduced perinatal HIV transmission in many parts of the world, including the Nordic countries, to less than 1% [1–3]. Perinatal HIV transmission refers to the transmission of HIV from mother to child during pregnancy, delivery, or postpartum via breastfeeding. The estimated risk of HIV transmission through breastfeeding without maternal ART is 15–30% over a two-year period [4]. Results from the Promoting Maternal and Infant Survival Everywhere (PROMISE) trial showed that with successful maternal ART during pregnancy and postpartum the transmission risk during breastfeeding decreases to less than 1% [5, 6]. However, both the PROMISE trial [5, 6] and other transmission studies [7, 8] were conducted in low- and middle-income countries and most postnatal transmissions occurred in women who initiated ART late in pregnancy or among women with adherence challenges and/or detectable viremia. There is limited evidence on the transmission risk through breastfeeding in women who have been treated with ART throughout the whole pregnancy and postpartum period.

In most high-income countries (including the Nordic countries) where access to safe and accessible infant feeding options are readily accessible, exclusive formula feeding is recommended as the safest option for women living with HIV (WLWH) [9–12]. Qualitative studies have highlighted that some WLWH, especially those originating from low- and middle-income settings where breastfeeding is recommended irrespective of HIV status [13], may face personal, social, and familial pressures to breastfeed [14–16]. Fear of others finding out about HIV status has also been described as a concern [17]. Moreover, following the results of the PARTNER study, confirming that individuals with an undetectable viral load do not transmit HIV sexually [18], referred to as undetectable equals untransmittable (U=U), there has been much debate in the literature on whether this also applies to breastfeeding, particularly for women on ART throughout the pregnancy and the postpartum period [19–22].

Experts and patients have in the past decade called for a shared decision-making approach, where WLWH receive the information and support necessary to make informed infant feeding decisions [22–25]. This has led to recent updates in guidelines emphasizing that counseling on infant feeding is an integral component of care

for pregnant and postpartum WLWH and that WLWH should be supported in their choice of infant feeding, whether this is formula feeding or breastfeeding [11, 12].

Many factors influence infant feeding choices, including social and cultural factors, personal values, desire for infant bonding, and stigma [20, 26] and WLWH in high-income countries are increasingly choosing to breastfeed [26–28]. Healthcare providers (HCPs) play an important role in supporting safe infant feeding choices in the context of HIV. Recent studies from the US have documented that HCPs are being asked about breastfeeding in the context of HIV and that providers often have limited experience and knowledge when counseling WLWH on infant feeding choices [29, 30]. However, studies have also shown that many WLWH either do not receive counseling or are unsatisfied with the infant feeding counseling they do receive, and may not fully understand the scenarios where breastfeeding could be supported (e.g., in the context of fully suppressed HIV viral load) [31, 32]. Thus, guidance from HCPs and knowledge about infant feeding choices is an important component of care for pregnant and postpartum WLWH and the shared decision making process [33]. However, as highlighted in a recent meta-synthesis, there is a scarcity of research on infant feeding knowledge and counseling among WLWH living in high-income settings, especially in the context of U=U [14].

Using a mixed methods research design this study aimed to get a comprehensive and nuanced understanding of infant feeding knowledge among WLWH living in Nordic countries, their interaction with and support by HCPs regarding infant feeding choices, and to assess differences between WLWH of non-Nordic and Nordic origin.

Methods

Design

This study used data from the “Becoming and Being a Mother Living with HIV” (2BMOM) study, a multi-center, longitudinal, convergent mixed methods study among pregnant and postpartum WLWH in the Nordic countries Denmark, Finland, and Sweden [34]. The 2BMOM study, which is described in detail elsewhere [34], consisted of a survey study [35] and a qualitative interview study [36] (Fig. 1). Using multiple methods describing both general trends and detailed in-depth data on infant feeding knowledge and experiences with

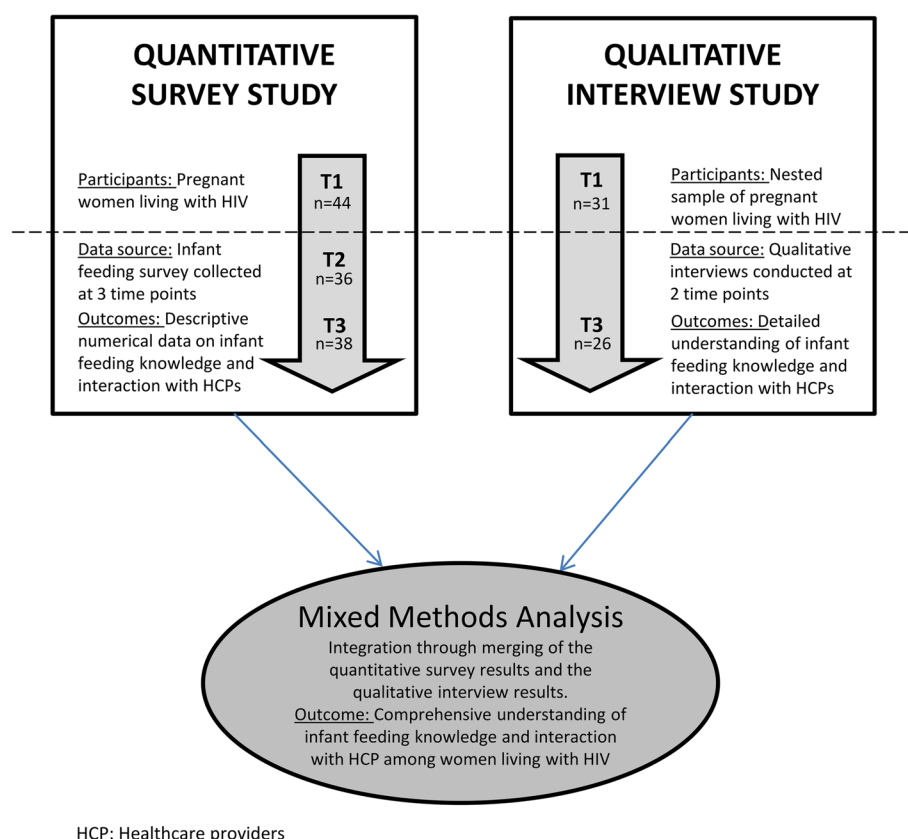


Fig. 1 Study diagram

HCPs can enhance understanding to guide support regarding infant feeding choices among WLWH [37].

Setting

There are approximately 5,400 WLWH living in Denmark, Finland, and Sweden [38–40]; the majority of whom have immigrated mainly from sub-Saharan Africa. The tax-based healthcare system in the Nordic countries ensures universal access to both medical healthcare and many social support services [41]. Thus, ART is provided free of charge, and people living with HIV are generally well-treated on ART with life expectancies approaching those of the general population [39, 40, 42]. Most pregnant WLWH in the Nordic countries have an undetectable viral load at the time of delivery resulting in a perinatal HIV transmission rate of < 1% [1, 2, 43]. Guidelines in the participating countries do not recommend breastfeeding for WLWH [9, 44, 45]. However, if a woman with an undetectable viral load decides to breastfeed, she should be supported in this choice and there should be increased monitoring of both mother and child throughout the breastfeeding period [9, 44].

Quantitative survey

Participants

Pregnant WLWH were consecutively recruited by the medical staff during routine clinical appointments between January 2019 and December 2020 from the participating sites: Departments of Infectious Diseases at Copenhagen University Hospitals, Hvidovre, and Rigshospitalet; Odense -, Aalborg – and Aarhus University Hospitals in Denmark, Helsinki University Hospital, Finland, and Sahlgrenska University Hospital, Sweden. Women were eligible for inclusion if they were ≥ 18 years of age, living with HIV, pregnant with a viable infant without life-threatening conditions or congenital anomalies, and able to speak and read English, Danish, Swedish, or Finnish.

Data collection

Quantitative data were collected using self-administered questionnaires via REDCap® in the 3rd trimester (T1), three and six months postpartum (T2 and T3, respectively). At each time point, a survey link was sent to the participants, who then completed the survey on their own time. Infant feeding knowledge was assessed using the Positive Attitudes Concerning Infant Feeding

(PACIFY) questionnaire, which contains 20 items assessing knowledge and different views and issues surrounding breastfeeding in WLWH [31]. The questionnaire was translated into Danish, Finnish, and Swedish using the forward-backward method [46]. Demographic variables were collected at baseline (T1). Information on clinical variables were obtained from the medical records.

Analysis

For comparison, descriptive data were stratified by migration status defined as non-Nordic origin (born outside a Nordic country) and Nordic origin (born in a Nordic country). Categorical variables were described as counts and calculated percentages, and continuous variables were described as means (95% confidence intervals (CI)). Analyses were performed using STATA 17 software.

Qualitative interviews

Participants

Eligible participants included pregnant WLWH who had completed the survey at T1 and who could speak Danish or English. Thus, a nested sample of WLWH were recruited for both the survey and the interviews at the time of recruitment into the study. Participants were consecutively sampled until reaching data saturation (i.e. the point when no substantially new information emerged from the interviews) [47, 48].

Data collection

Qualitative data were collected via individual interviews conducted by the first author (EM) in the third trimester (T1) and six months postpartum (T3). All interviews used a hybrid, narrative/semi-structured format [49]. This approach was chosen to ensure that the same concepts were explored in both the quantitative and qualitative phases of the 2BMOM study, while still allowing for new insights and perspectives to emerge [34]. The interviews were conducted in Danish or English in the home of the participant, at the relevant hospital, or online using a video meeting setup, based on the women's preference. The interviews lasted between 20 and 90 min (mean 51 min), were audio-recorded, and transcribed verbatim.

Analysis

The transcribed interviews were analyzed inductively using narrative thematic analysis as described by Riessman [50]. The analysis consisted of several consecutive steps: (1) Initial coding focusing on capturing the main ideas from the women's stories. (2) Emergent themes and patterns across a subset of transcripts were identified and discussed among the team members (EM, NW) while paying close attention to the whole story and the study aims. (3) The themes were then compared for similarities

and differences across participants and their narratives, focusing on women of non-Nordic and Nordic origin, respectively. (4) The themes were brought together to create and define the primary narrative themes [50]. (5) Consistency across the themes was discussed and a codebook was developed to document and organize the codes. In the final step, the codebook was used to code and analyze all the interview data using NVivo software, ©QSR International Pty Ltd.

Mixed methods integration and analysis

Integration in mixed methods research is defined as an intentional process by which the researcher brings qualitative and quantitative data together in one study [47]. The quantitative survey data and qualitative interview data in this study were brought together through merging using identified commonalities across the two datasets as the overarching domains [51]. Specifically, the results from the two datasets were merged in a joint display analysis using a side-by-side comparison to assess for complementarity, expansion, concordance, or discordance between the datasets and to draw meta-inferences (i.e., interpretations made based on both the qualitative and quantitative findings) [51–53] for WLWH of non-Nordic and Nordic origin. Complementarity occurred when the two datasets illustrated different but nonconflicting interpretations. Expansion occurred when the findings from the two datasets diverged and expanded insights by addressing different aspects of infant feeding knowledge and perceptions. Concordance occurred if the findings from both types of data led to the same interpretation, while discordance occurred if the survey and interview results were contradictory or disagreed with each other [52]. The results are presented in joint displays where the quantitative and qualitative results are visualized side-by-side in a table together with the meta-inferences [51, 53].

Results

Participant characteristics

Overall, 71 pregnant WLWH fulfilled the inclusion criteria during the study period of whom 57 agreed to participate in the quantitative survey and 47 pregnant women completed the baseline survey (T1). The main reasons for non-participation were language barriers and psychiatric or social complications. The PACIFY questionnaire was completed by 44 women at T1 and were thus included in this analysis (response rate 62%). A total of 36 and 38 women (82% and 86%) completed the survey at follow-up T2 and T3, respectively (Fig. 1). In total, 31 pregnant WLWH agreed to participate in the qualitative interviews including 24 from Denmark, five from Finland, and two from Sweden. Baseline characteristics are presented in Table 1. All participating women identified as cisgender.

Table 1 Baseline characteristics of women living with HIV included in the study

	Quantitative Survey (<i>n</i> = 44)	Qualitative Interviews (<i>n</i> = 31)
Age, mean (95% CI)	33.91 (32.4 : 35.5)	33.9 (29.5 : 36.6)
Relationship status, <i>n</i> (%)		
Married/living with a partner	35 (80)	25 (80)
Have a partner, but not living together	4 (9)	3 (10)
Do not have a current partner	5 (11)	3 (10)
Country of birth, <i>n</i> (%)		
Nordic country (Denmark, Finland or Sweden)	12 (27)	9 (29)
Africa	24 (55)	19 (61)
Other	8 (18)	3 (10)
Education, <i>n</i> (%)		
Primary/Secondary school	14 (32)	11 (35)
Higher education (college/university)	27 (61)	20 (65)
Unknown	3 (7)	0
Nulliparous, <i>n</i> (%)	15 (34)	14 (45)
Years since HIV diagnosis, mean (95% CI)	9.32 (7.0 ; 11.6)	9.55 (6.4 ; 12.7)
HIV diagnosis in pregnancy, <i>n</i> (%)		
Yes	3 (7)	3 (10)
Mode of HIV transmission, <i>n</i> (%)		
Sexual	39 (89)	27 (87)
Perinatal	5 (11)	4 (13)
HIV viral load*, <i>n</i> (%)		
< 50 copies/mL	36 (82)	24 (77)
≥ 50 copies/mL	8 (18)	7 (23)
Mode of delivery, <i>n</i> (%)		
Vaginal	31 (70)	22 (71)
Caesarean	13 (30)	9 (29)
Gestational age < 37 weeks, <i>n</i> (%)	4 (9)	< 3 (6)

* At baseline (T1). All participants had an HIV RNA viral load < 50 at the time of delivery.

Twelve women were born in a Nordic country, while 32 were born outside of the Nordic countries; 24 of whom were of African origin, while eight originated from South America, Southern or Eastern Europe, or the Middle East. All women were on ART at the time of delivery.

Mixed methods analysis

The merged analyses identified two overarching domains: Knowledge about breastfeeding in the U=U era and Communications with healthcare providers.

Knowledge about breastfeeding in the U = U era

The results on knowledge about breastfeeding in the U=U era are presented in Table 2. In the survey, 75% of participants responded that it was not safe to breastfeed with a detectable HIV viral load, irrespective of maternal origin and with little change over time (non-Nordic origin *n* = 24/32 and Nordic origin *n* = 9/12 at T1). Half of the women of non-Nordic origin responded at T1 either

that it was safe to breastfeed with an undetectable HIV viral load (*n* = 7/32) or that they did not know (*n* = 8/32). Half of the women of Nordic origin responded at T1 that it was safe to breastfeed with an undetectable HIV viral load (*n* = 6/12), while one-third responded that they did not know (*n* = 4/12). At T2 and T3, 75% (*n* = 9/12) and 60% (*n* = 6/10) of the WLWH of Nordic origin responded that they did not know whether it was safe to breastfeed with an undetectable viral load.

The qualitative results complemented these findings showing that many of the women were confused about breastfeeding in a U=U context. Several of the women questioned why there was a risk of HIV transmission through breastfeeding when they could not transmit HIV through sex if they had an undetectable viral load. The women also noted that they could have a vaginal delivery, even though the risk of HIV transmission could not be completely ruled out, and wondered why this was not also the case with breastfeeding. Women who

Table 2 Knowledge about breastfeeding in the U=U era among women living with HIV of non-Nordic and Nordic origin depicted in a joint display of quantitative, qualitative, and mixed methods findings

DOMAIN: Knowledge about breastfeeding in the U=U era		
QUAN survey items	QUAL quotes	Meta-inferences
<p>Do you think it's safe for women in Nordic countries to breastfeed their babies?</p> <p>With a detectable VL With an undetectable VL</p> <p>Proportion (%)</p> <p>Non-Nordic Nordic origin Non-Nordic Nordic origin</p> <p>■ Yes ■ No ▨ Don't know</p>	<p>Non-Nordic origin</p> <p>"It is important for a mother to breastfeed her baby and they say no, they don't do that. I am confused. How is it that in Africa a mother with HIV can breastfeed the baby, but here they don't?" (ID 4, nulliparous, T1)</p> <p>They kept telling me that the load is so low, you know, it's undetectable....so there is this nagging contradiction. Why is it not safe to breastfeed, if it is undetectable? It must be some other mechanism" (ID 28, para 2, T3).</p> <p>"So, I ask, why can't I breastfeed? Then I am told that it is because I have HIV. But I am told all the time that it is undetectable. What does this mean? Can I or can I not breastfeed? They cannot recommend it, but some women choose to breastfeed, they say. So, yeah, it is confusing. (ID 17, para 4, T3).</p> <p>Nordic origin</p> <p>"In the birth they don't require caesarean anymore. You can give natural birth. There is blood and everything. But virus is low, so there is no risk. But then with the milk, there is still a risk." (ID 1, para 2, T1)</p> <p>"Will we ever get to a place where we can say that it is safe to breastfeed?" (ID 31, nulliparous, T3)</p> <p>"It seems to me that we are talking about so small risks. I know this may be provocative, that maybe this is the case with breastfeeding. Not that I would choose to breastfeed, because I did not want my baby to get all the medication" (ID 8, nulliparous, T3).</p> <p>"It was just not an option. However, the more I was asked if I wanted to breastfeed...there was a lot of focus on whether I was going to breastfeed or not, then suddenly it might be an option...So yes, it has been a bigger thing this time. Before I just thought that it wasn't an option (ID 19, para 2, T3).</p>	<p>Complementary</p> <p>Most women responded that it wasn't safe to BF with a detectable VL, but when asked whether it was safe to breastfeed with an undetectable VL, more than half of the women responded either that yes – it was safe, or that they did not know. Especially women of Nordic origin seemed unsure. These results are complimented by the qualitative findings showing that many of the women were confused about breastfeeding in the context of U=U, and among the women of African origin, there was confusion relating to the different recommendations in the Nordic and international (or African/WHO) guidelines.</p>
<p>If you were to breastfeed, would you be willing to have monthly blood tests to check your viral load or to make sure that your child has not become infected?*</p> <p>Proportion (%)</p> <p>Mother Child</p> <p>Non-Nordic origin Nordic origin Non-Nordic origin Nordic origin</p> <p>■ Yes ■ No ▨ Don't know</p>	<p>Non-Nordic</p> <p>"And checking the child also. So, it will be a lot of appointments for both the mother and child, if you breastfeed, I think." (ID 10, para 2, T1)</p> <p>"If you were allowed to breastfeed the baby, would you accept the baby to be tested? And I thought, that would actually work. I would say yes, I would accept that." (ID 22, nulliparous, T1)</p> <p>"Is it allowed for me and my baby, as long as we are under monthly testing... just to keep my baby safe from contracting the disease?" (ID 7, nulliparous, T1)</p> <p>"I asked if they wanted to follow me more closely if I were to breastfeed. If they wanted to take blood tests to make sure. I think that would be ideal" (ID 29, para 4, T1)</p> <p>"Has anyone tried to breastfeed and getting blood tests every month? It will be a lot of blood tests for both the child and mother if you choose to breastfeed" (ID 22, nulliparous, T1)</p> <p>"I'll not breastfeed because the milk will not be tested but if I had the chance that they will test my milk and I'm sure that nothing will happen, then I could do it." (ID 21, nulliparous, T1)</p> <p>"There was no clear guideline for me. I have chosen to breastfeed, and my child needs to have all these blood tests. This made me sad. Because it was my need to breastfeed. If I had known before that if I were to breastfeed then the child needed to be tested all the time, I might have made a different choice" (ID 17, para 4, T3)</p> <p>Nordic origin</p> <p>"I have asked like... but no studies have been made...maybe it can be a possibility in the future" (ID 1, para 2, T1).</p> <p>"I wish that, at least that... I could go and leave a test and they can see if it's something in the milk....Even if I cannot breastfeed, maybe somebody in the future can if they do tests like that." (ID 31, para 2, T1) "So, I think it is fine...that she is getting the bottle. It is actually really hard with all the blood tests and if there is a little chance...then I won't try it [breastfeeding]. (ID 2, para 2, T3)</p>	<p>Expansion</p> <p>80% of the women of non-Nordic origin and all of the women of Nordic origin would be willing to have monthly blood tests if they were to breastfeed, while only half and one-third of the women were willing to have monthly blood tests of the child. These findings are expanded by the qualitative findings highlighting that for some women having to undergo extra tests may be a sacrifice that they are willing to make to be able to breastfeed, while for others having the child undergo extra tests may both be a logistical and emotional challenge. Several women also find it logical to test the breast milk.</p>
<p>Do you have any concerns about breastfeeding while taking HIV medication?*</p> <p>Proportion (%)</p> <p>Non-Nordic origin Nordic origin</p> <p>■ Yes ■ No ▨ Don't know</p>	<p>Non-Nordic origin</p> <p>"Sometimes I feel sad about it, if you see, that all these things are going into my body." (ID 3, para 3, T1)</p> <p>"That the baby will be exposed to medication through the breast milk" (ID 5, para 3, T1)</p> <p>"The baby could become resistant to the medication...and will be exposed to all the chemicals in the medications and become ill because of it" (ID 6, para 2, T1)</p> <p>"I would like to know about the medications in the milk" (ID 7, nulliparous, T1)</p> <p>"I don't know much about it, because I was told not to breastfeed from the beginning". (ID 21, nulliparous, T1)</p> <p>Nordic origin</p> <p>"We don't know the long-term effects of the medication or how it would affect breastfeeding" (ID 19, para 1, T1)</p> <p>"What if the HIV medication has side-effects for the baby long term? The current knowledge is so limited". (ID 26, para 2, T1).</p> <p>"I would like to know more about the risk. I mean, it has been decided worldwide that women living with HIV can have children, even though there is a risk. So, it would be easier if the risk of transmitting HIV to the child through breastfeeding was known, so that you could decide based on that" (ID 8, nulliparous, T1).</p> <p>"I don't think I would have chosen to breastfeed, if it was possible, because I would not want my baby to get all that medication" (ID 24, nulliparous, T3)</p>	<p>Complementary</p> <p>More than half of the women – irrespective of origin responded that they were concerned or did not know about breastfeeding while taking anti-HIV medicine. The qualitative findings highlighted that exposing their child to potential medicine with unknown (long-term) effect was a real concern, which must be considered when thinking about breastfeeding in the context of HIV.</p>

Non-Nordic origin: T1 n=32, T2 n=24, T3 n=28; Nordic origin: T1 n=12, T2 n=12, T3 n=10

VL= HIV RNA viral load

*Only asked at T1

immigrated, especially women of African origin, found it confusing that the guidelines in their home country recommended breastfeeding in WLWH, while in the Nordic countries, breastfeeding was not recommended.

All of the women of Nordic origin ($n=12/12$) and most of the women of non-Nordic origin ($n=27/32$) would be willing to have monthly blood tests to check viral load if they were to breastfeed. However, participants were less likely to have additional blood tests taken on their child (non-Nordic origin $n=24/32$ and Nordic origin $n=7/12$). The qualitative findings revealed that women saw additional tests as a practical way to make breastfeeding with HIV safer, providing reassurance for some. However, the women were also concerned about the number of appointments this would require and putting their child through additional blood tests. One mother decided to breastfeed but was unprepared for the additional monthly tests her child required, leading her to stop breastfeeding after two months. 47% ($n=15/32$) of women of non-Nordic origin and 33% ($n=4/12$) of women of Nordic origin responded that they had concerns about breastfeeding while on ART, while one-third in both groups responded that they did not know. The qualitative findings highlighted that exposure to antiretroviral (ARV) drugs through breastfeeding was something the women considered when balancing between the risks and benefits of breastfeeding. A few women stated that this was not something they had thought about, because breastfeeding was not an option when living with HIV.

Communications with healthcare providers

The results on communications with HCPs are presented in Table 3. A majority of the women in both groups had discussed breastfeeding with their HCPs; 84% ($n=27/32$) at T1, 88% (21/24) at T2 and 89% ($n=25/28$) at T3 among women of non-Nordic origin and 83% ($n=10/12$) at T1, 75% ($n=9/12$) at T2, and 80% ($n=8/10$) at T3 among women of Nordic origin. The qualitative findings expanded this showing that discussions with HCPs ranged from hardline recommendation of breastfeeding avoidance to more open-ended questions about infant feeding/breastfeeding. These open-ended questions and discussions were welcome but could also add to the confusion about whether breastfeeding was possible. Some women brought up the subject of infant feeding themselves, seeking information, especially with what to say if asked about breastfeeding by others.

The women had mainly discussed breastfeeding with their HIV doctor and their midwife; 89% ($n=24/27$) and 78% ($n=21/20$) of women of non-Nordic origin and 90% ($n=9/10$) and 70% ($n=7/10$) of women of Nordic origin, respectively. However, the quantitative results also

highlight that the women discussed breastfeeding with a wide range of HCPs across the pregnancy-postpartum trajectory. These discussions were often initiated by the HCPs. The qualitative results complimented these findings showing that these discussions were experienced as reassuring by many of the women, helping them reflect and deal with the emotional strain related to their choice of not breastfeeding. However, the qualitative findings also revealed that the women often felt healthcare providers lacked up-to-date knowledge about HIV, particularly in the context of infant feeding, leading them to feel they had to educate the providers.

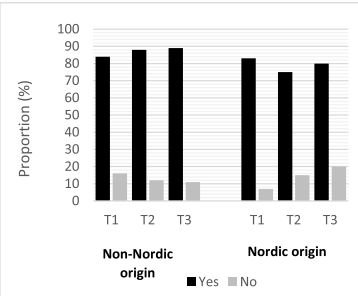
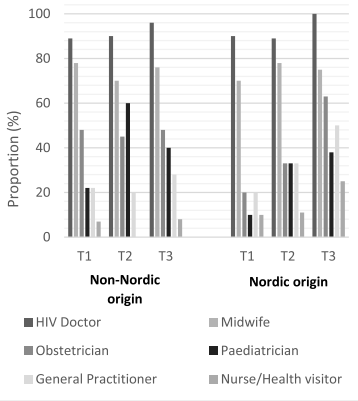
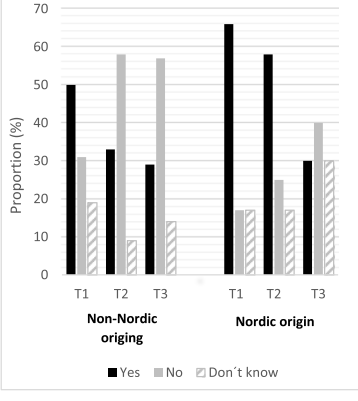
Half of the women of non-Nordic origin ($n=16/32$) and 66% ($n=8/12$) of the women of Nordic origin would like more information on the risks and benefits of breastfeeding for WLWH in pregnancy. The need for information was less in the postpartum period, especially among the women of non-Nordic origin. The qualitative data expanded on these findings highlighting that the women were interested in knowing whether breastfeeding was possible, whether it was safe to breastfeed while living with HIV, and knowledge about what research was being done in the area.

Discussion

The findings from this mixed methods study on infant feeding knowledge among WLWH in Nordic countries and their interaction with HCPs found that there was confusion about breastfeeding in the context of U=U, that the women did discuss infant feeding with HCPs across the pregnancy and postpartum trajectory, and that these discussions were welcome, but could also add to the confusion about whether breastfeeding was feasible.

Several of the previous studies exploring infant feeding knowledge have been conducted prior to the introduction of U=U with a focus on WLWH who have migrated to either the UK or the USA [16, 54, 55]. More recent qualitative studies conducted among WLWH in Canada and the USA [56, 57] support our finding that the recommendation of breastfeeding avoidance in a U=U context is difficult to understand for many WLWH. Our finding about confusion related to the difference in infant feeding guidelines, especially among women who have migrated from low- and middle-income countries where breastfeeding is recommended irrespective of HIV status, have been reported in previous studies [16, 54, 57]. However, the quantitative findings from our study show that women of Nordic origin seem to be more unsure about the safety of breastfeeding with an undetectable viral load compared to women of non-Nordic origin. In the PACIFY study, one-third of 94 WLWH in the UK responded that they did not know if it was safe to breastfeed with

Table 3 Communications with healthcare providers among women living with HIV of non-Nordic and Nordic origin depicted in a joint display of quantitative, qualitative, and mixed methods findings

DOMAIN: Communications with healthcare providers		
QUAN survey items	QUAL quotes	Meta-inferences
<p>Have any healthcare workers discussed breastfeeding with you?</p>  <p>Non-Nordic origin Nordic origin</p> <p>■ Yes ■ No</p>	<p>Non-Nordic origin</p> <p>"I have been asked a lot of questions about breastfeeding. If I wanted to do it, and then...oh no, that is not recommended...it has been really different what people have said. And then some people ask me what I want. So, I don't really understand" (ID 21, nulliparous, T3)</p> <p>"He just said it is not recommended. And I was like, ah, okay. We didn't talk about it more...I thought that it was more open now. But apparently not...." (ID 22, nulliparous, T1)</p> <p>"This time around they didn't tell me much...I think, they know I can't breastfeed." (ID 29, para 4, T1)</p> <p>Nordic origin</p> <p>"I've been trying to ask at every opportunity I can get from different doctors or nurses or anyone who might have some tips" (ID 19, nulliparous, T1)</p> <p>"It is not something I have discussed with my doctor, not yet. I want to, because I want to know what to say if somebody asks me about breastfeeding" (ID 23, nulliparous, T1).</p>	<p>Expansion</p> <p>Most women had experienced healthcare workers discussing breastfeeding with them. The qualitative findings showed that these discussions were very welcome but could also add to the confusion about whether breastfeeding was possible – especially among women of non-Nordic origin. Some women had not discussed infant feeding with a healthcare provider, but they wanted to – especially regarding what to say when being asked by others about why they weren't breastfeeding – preparing themselves for this situation.</p>
<p>Who has discussed breastfeeding with you?*</p>  <p>Non-Nordic origin Nordic origin</p> <p>■ HIV Doctor ■ Midwife ■ Obstetrician ■ Paediatrician ■ General Practitioner ■ Nurse/Health visitor</p>	<p>Non-Nordic origin</p> <p>"The midwife asked me 'do you want to breastfeed'. Breastfeed? I have not done that with the others. Can I do that? It's against the recommendations." (ID 17, para 4, T1)</p> <p>"The last time I met [HIV doctor] she was asking me, what I will say. And she asked me what I said the last time" (ID 3, para 3, T1)</p> <p>"The HIV doctor only asked me: Do you want to do it or not, because some women they like to do it, and... they... choose the risk, and my birth doctor recommended me...don't do that". (ID 16, nulliparous, T3)</p> <p>Nordic origin</p> <p>"Last time at the infectious disease department I talked to my doctor, and she said 'Well, if you are thinking about breastfeeding, you need to tell us, so we know where we stand. I was like, is that an option?' (ID 19, para 2, T1).</p> <p>"My midwife told me that motherhood was not in the breasts and I think that was very nice..that breastfeeding was not the only way to create a close bond" (ID 26, para 2, T3)</p> <p>"When I went to a check-up with my HIV doctor, she might have brought it up at an early stage. I think I wouldn't have realized it myself when I was just few weeks pregnant. Since then, I have been asking every doctor and nurse I see" (ID 31, nulliparous, T1)</p> <p>"I have had many long talks with both doctors and nurses. Many of them are not updated and I have to tell them everything. (ID 8, nulliparous, T1).</p>	<p>Complimentary</p> <p>The women experienced being asked about breastfeeding, mainly by their HIV-doctor and midwife. This finding was supported by the qualitative results, which also highlighted that talking with their healthcare provider was reassuring and helped them reflect and deal with the emotional strain related to their choice of not breastfeeding.</p>
<p>Would you like more information on the risks and benefits of breastfeeding for women living with HIV?</p>  <p>Non-Nordic origin Nordic origin</p> <p>■ Yes ■ No ■ Don't know</p>	<p>Non-Nordic origin</p> <p>"I would like to know if breastfeeding could be possible for me and my baby" (ID 21, nulliparous, T1)</p> <p>"Are there any studies on this? What was the outcome of the babies that were breastfed? Did any babies get infected?" (ID 30, para 2, T3)</p> <p>"How big is the risk when breastfeeding with HIV?" (ID 5, para 3, T1)</p> <p>"There should be more research...you will never get the data if we are not allowed [to breastfeed]. (ID 17, para 4, T1).</p> <p>"I am just hoping that one day they will have the treatment. So that my baby number two can breastfeed". (ID 20, para 2, T1)</p> <p>"I would like to know how far they are with research in HIV and breastfeeding. Is there anything new?". (ID 29, para 4, T3).</p> <p>Nordic origin</p> <p>"I have been wondering if I can breastfeed my baby. If that is possible" (ID 31, nulliparous, T1)</p> <p>"Is it medically safe. What are the benefits versus the risk?" (ID 19, para 2, T3)</p> <p>"What research is being done?" (ID 24, nulliparous, T1)</p> <p>"I have asked...are there not any studies that have been done so that maybe it can be a possibility in the future or something like that" (ID 2, para 2, T1)</p> <p>"I wish that, at least that... that I could go and leave some test and they can see if it's something in the milk, even if I cannot breastfeed but maybe somebody in the future can if do tests like that." (ID 26, para 2, T1)</p>	<p>Expansion</p> <p>Most of the women would like more information about the risks and benefits of breastfeeding in the context of HIV – especially during pregnancy. The qualitative data highlighted that the women were interested in knowing whether breastfeeding was possible, if it was safe to breastfeed when living with HIV, and knowledge about ongoing research on the topic.</p>

T1=3rd trimester, T2=3 months postpartum, T3=6 months postpartum

Non-Nordic origin T1 n=32, T2 n=24, T3 n=28; Nordic origin T1=12, T2 n=12, T3 n=10

*Only women who responded that they had discussed breastfeeding with healthcare providers. Non-Nordic origin: T1 n=27, T2 n=20, T3 n=25; Nordic origin: T1 n=10, T2 n=9, T3 n=8. Multiple responses possible.

an undetectable viral load [31]. Knowledge regarding HIV transmission has been shown to provide confidence in infant feeding choices in WLWH while varying advice from HCPs and difference in guidelines can create ambiguity and insecurity about HIV transmission risks [58].

Although women in both groups would like more information about the risks and benefits of breastfeeding when living with HIV, especially during pregnancy, the need for more information was highest among women of Nordic origin.

International guidelines for pregnant and postpartum women with HIV recommend increased monitoring of both mother and child throughout the breastfeeding period [11, 12]. Almost all WLWH in our study would agree to have additional blood tests drawn for themselves in case of breastfeeding. However, approximately a quarter of WLWH of non-Nordic origin and one-third of WLWH of Nordic origin did not want or were unsure about additional testing of their child. Infant HIV testing has been described as emotionally difficult and associated with feelings of guilt and sadness by other studies [15–17, 54]. Our results highlight that preparing WLWH who choose to breastfeed about the additional testing of the child is important, as this may influence their infant feeding choice. Another important aspect is infant ARV exposure through breast milk. ARVs are passed through breast milk, although the clinical relevance of ARV concentrations in breast milk is not fully understood [59]. Serious adverse events in infants, due to maternal ART, appear to be uncommon [20]. However, our results show that ARV exposure through breast milk is relevant to WLWH when considering their infant feeding choices.

The majority of WLWH had discussed infant feeding with their HCP, a finding that is supported by the PACIFY study [31]. What this study adds is knowledge about the quality and debts of these conversations.

Our findings highlight that the women want to engage in discussions about infant feeding. This is supported by a recent US study [15]. Our results also highlight that the discussions about infant feeding may add to the confusion about whether breastfeeding is possible in a U=U context. Several women experienced that the discussions with HCPs were limited to a recommendation of breastfeeding avoidance. Rather than focusing on breastfeeding or not, WLWH emphasizes a more comprehensive perspective of choice in relation to infant feeding [17, 57]. Infant feeding discussions among women who chose not to breastfeed were experienced as supportive and reassuring, especially with concerns about bonding. Moreover, receiving help with developing strategies on what to say when asked about breastfeeding was also important for many participants, a finding supported by others [29, 56].

Clinical implications

Implementing a shared decision-making approach to support infant feeding choices can help WLWH to understand the risk of transmission with breastfeeding and why U=U does not, with the current knowledge, apply to breastfeeding, and also accept global differences in guidelines [57, 60]. This requires that the risks and benefits of breastfeeding in the context of HIV are discussed, in addition to frequent follow-up visits for

both the mother and infant if the mother decides to breastfeed [60].

Advising in the context of many unanswered questions and distinct lack of evidence may be challenging for many HCPs [30, 61]. Findings from a recent US study show that HCPs struggle with the tension between responding to patients' choices, while simultaneously protecting infants from risk of infection and following official guideline recommendations [30]. Examples of how to discuss infant feeding with WLWH have been published [61, 62]. What these have in common is that counseling should be ongoing throughout the pregnancy and postpartum period, that HCPs should be honest about the lack of evidence, and informing the women that the best way to eliminate risk is to abstain from breastfeeding [61, 62].

Infant feeding is a social, cultural, and emotional issue that is best understood in relationship to the women's cultural and social background, and as WLWH [15, 17]. Thus, it is important that HCPs actively listen and answer questions without judgment [56] and takes into account how culture and HIV-related stigma intersect with infant feeding knowledge and experiences when engaging in shared decision-making [17]. Initiating an open and honest conversation about infant feeding options based on current evidence and guidelines is crucial and resources from national HIV organizations and local NGO's are available to support HCP during this process [63–66].

Strengths and limitations

To our knowledge, this is the first study focusing specifically on infant feeding knowledge and experiences in WLWH living in Nordic countries. Using multiple methods provided a more comprehensive and nuanced understanding of infant feeding knowledge and experience with HCP. The small sample size and the risk of selection bias is a limitation, reducing generalizability. The number of pregnant WLWH in the Nordic countries are small (<70/year at the participating sites) and although >60% of eligible women were included, this study does not reflect the perspective of WLWH who do not speak a native Nordic language or English.

The term "breastfeeding" was used in the survey. Although we acknowledge that there are multiple terms, including chestfeeding used to describe this process, the results cannot necessarily be extrapolated to apply to chestfeeding. Moreover, we used a hybrid, narrative/semi-structured format in the interviews to ensure that overarching themes were explored in both the quantitative and qualitative strands. Although in conformity with the aim of the overall study, this approach may have limited the elaboration of the women's experiences. Finally, the study was completed during the COVID-19 pandemic, which could have had an impact on the results.

The participants may have had less contact with HCPs and other support systems during this time, potentially impacting the amount of information they received about infant feeding.

Conclusion

This mixed methods study among WLWH with different backgrounds living in a high-income setting highlights that WLWH are confused about breastfeeding choices and transmission risk. Women of Nordic origin were more unsure about whether breastfeeding was possible in the context of U=U than women of non-Nordic origin. The study also found that increased postpartum monitoring with monthly testing of the mother was not seen as a barrier to breastfeeding, but concerns were found regarding infant testing and infant ART exposure. Infant feeding discussions with HCPs across the pregnancy and postpartum trajectory were welcome, irrespective of origin. Thus, HCPs caring for WLWH must have updated knowledge about HIV transmission risk during breastfeeding and initiate a shared decision-making process to provide optimal support for infant feeding choices in WLWH.

Abbreviations

ART	Antiretroviral Therapy
ARV	Antiretroviral
HCP	Healthcare providers
PACIFY	Positive Attitudes Concerning Infant Feeding
The 2BMOM study	The Becoming and Being a Mother living with HIV study
WLWH	Women Living with HIV
U = U	Undetectable equals untransmittable

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Authors' contributions

EM and NW had the original concept for the study. All authors contributed to study design, data interpretation, writing the report, and approved the final version. EM, IA, ÅM, ISJ, TLK, GP, MS and NW contributed to the data collection. EM had full access to the data and completed the analysis together with NW.

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Availability of data and materials

The data that support the findings of this study are available from the corresponding author, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly

available. Data are however available from the authors upon reasonable request and with permission of relevant regulatory agencies.

Declarations

Ethics approval and consent to participate

The 2BMOM study was approved by the Danish Data Protection Agency (VD-2018-253), the Finnish Ethics Committee (HUS/1330/2019), and the Swedish Ethics Committee (Dnr: 2019-04451). Approval from the Danish National Ethics Committee was not required as no biomedical intervention was performed. All women gave informed consent to participate. The participants did not receive any reimbursements.

Competing interests

EM reports grants from Gilead and the Novo Nordisk Foundation; honorarium paid to her institution from GSK, Gilead and Merck Sharp Dohme, outside the submitted work. IA reports personal fees from Merck Sharp Dohme, Gilead, and Glaxo Smith Kline, and a grant from Gilead, outside the submitted work. ÅM reports personal fees from Gilead and Viiv/GSK, outside the submitted work. TLK reports personal fees and grants from Viiv/Glaxo Smith Kline, Gilead, CLS Behring, and Baxalta, outside of the submitted work. NW reports honorarium paid to her institution from Merck Sharp Dohme, outside the submitted work. The remaining authors (GP, ISJ, DB, and MS) declare no competing interests.

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