


# The experience of pregnancy among women living with HIV in Nordic countries: A qualitative narrative enquiry

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## Abstract

**Objective:** The success of antiretroviral therapy has resulted in the normalization of pregnancy among women living with HIV and a very low risk of perinatal transmission of HIV. Despite these advances, women living with HIV still face complex medical and psychosocial issues during pregnancy. The purpose of this study is to describe experiences of pregnancy and the relevance of social support among women living with HIV in Nordic countries.

**Methods:** This qualitative study examined data from pregnant women living with HIV from sites in Denmark, Sweden and Finland from 2019 to 2020. Data were collected in the third trimester via individual interviews using a hybrid, narrative/semistructured format. The transcribed interviews were analyzed using narrative thematic analysis.

**Results:** In total, 31 women living with HIV were enrolled, of whom 61% originated from an African country and 29% from a Nordic country. The analysis generated four primary narrative themes: just a normal pregnancy, unique considerations and concerns, interactions with healthcare, and social support. Women living with HIV have a strong desire to have normal pregnancies and to be treated like any other pregnant woman. However, this normality is fragile, and being pregnant and living with HIV does come with unique considerations and concerns, such as fear of transmission, antiretroviral therapy, and the need for specialized care, which are fundamental to the women's experiences. Interactions with healthcare providers and social support influence their experiences in both positive and negative ways.

**Conclusion:** The findings emphasize a sense of normality in pregnancy among women living with HIV. However, pregnancy does come with unique considerations and concerns, which highly influence the women's experience of pregnancy. Healthcare providers should focus on person-centered care, ensuring continuity and that women living with HIV do not feel discriminated against throughout their pregnancy.

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## Introduction

Globally, women account for more than half (54%) of all adults living with HIV, with an estimated 19.3 million women living with HIV > 15 years of age in 2020. As a result of increased coverage and improved regimens, 85% of the estimated 1.3 million pregnant women living with HIV received antiretroviral therapy (ART) to prevent the transmission of HIV to their children.<sup>1</sup> The use of combination ART (cART) has normalized pregnancy, including the recommendation of vaginal delivery in well-treated women living with HIV. These interventions have led to a dramatic decrease in perinatal transmission worldwide.<sup>1-4</sup>

Women living with HIV have fertility desires similar to those of the general population.<sup>5,6</sup> Motherhood is often experienced as something positive,<sup>7</sup> and pregnancy is usually connected to a sense of normality and the experience of feeling whole.<sup>8</sup>

However, despite the normalization of pregnancy, becoming and being a mother with HIV is associated with unique pregnancy and postpartum considerations.<sup>9,10</sup> In addition to the usual adjustments to motherhood, pregnant women living with HIV must also cope with stressors that include their health, the unknown infectious status of their infants, and attending to their infants' unique needs, such as the administration of prophylactic medications.<sup>9</sup> Moreover, being pregnant may intensify concerns related to HIV disclosure, HIV stigma, and worrying about the negative impacts of maternal HIV on children.<sup>11</sup>

The broader social and environmental context may be important determinants for the experiences of pregnancy and the psychosocial well-being of women living with HIV. Findings from a recent Swedish qualitative study highlight that feeling safe with oneself and in one's relationships with others is essential to women living with HIV.<sup>12</sup> This includes the presence of supportive relationships, including those with healthcare providers.<sup>12</sup> How women living with HIV interact with healthcare providers may have a large impact on their pregnancy experience.<sup>9</sup>

The annual number of HIV pregnancies has increased, both in Nordic countries and internationally.<sup>13-16</sup> However, there is a gap in the literature on the experiences of pregnancy among women living with HIV in today's context. Psychosocial and emotional well-being is essential during pregnancy to facilitate attachment to one's newborn and to develop the capacity to parent effectively.<sup>17</sup> Thus, understanding and responding to the experiences of pregnant and postpartum women living with HIV are important so that goal-oriented interventions supporting these women

can be developed. The purpose of this study is to describe the experiences of pregnancy and the relevance of social support among women living with HIV in the Nordic countries of Denmark, Finland, and Sweden.

## Methods

### Study design

This is a qualitative interview study conducted within the 2BMOM study, a multi-centre longitudinal mixed-methods study investigating psychosocial outcomes and experiences of women living with HIV in Nordic countries during pregnancy and early motherhood. Both quantitative and qualitative data were collected to enhance understanding not only of the psychosocial health of women living with HIV during pregnancy and postpartum but also to elucidate the nuances and details of their's experiences. Pregnant women living with HIV, non-pregnant women living with HIV, and pregnant women without HIV were recruited from seven sites in Denmark, Finland, and Sweden between January 2019 and December 2020. Quantitative data were collected via self-administered electronic questionnaires, with a subsample of pregnant women living with HIV taking part in semistructured qualitative interviews in the third trimester of pregnancy and 6 months post-partum (n=31). Methods are described in detail elsewhere.<sup>18</sup>

### Setting

There are approximately 1600, 1000 and 2800 women living with HIV in Denmark, Finland, and Sweden.<sup>16,19,20</sup> The majority of women living with HIV in these countries are immigrants, primarily from sub-Saharan Africa, and mostly became infected with HIV through sexual contact.<sup>13,16</sup> The healthcare system in Nordic countries is tax-based and ensures universal access to both medical healthcare and many social support services.<sup>22</sup> Hence, cART is provided free of charge, and people living with HIV in Nordic countries are generally well treated, with life expectancies approaching those of the general population.<sup>16,20,23</sup> Most pregnant women living with HIV have an undetectable viral load at the time of delivery, resulting in a perinatal transmission rate of <1%.<sup>4,16,21,24</sup>

### Ethics

All women gave voluntary, written informed consent to participate in the 2BMOM study, which included both the quantitative and qualitative phases of the study. All women

were informed that they could withdraw their consent at any time, without giving a reason and without it affecting current or future medical treatment. The study was approved by the Danish Data Protection Agency (VD-2018-253) and the Finnish and Swedish Ethics Committees (HUS/1330/2019 and Dnr: 2019-04451, respectively). Approval from the Danish National Ethics Committee was not required, as no biomedical intervention was performed.

### Participants

All women living with HIV enrolled in the 2BMOM survey study were asked to participate in a concurrent qualitative interview study. Hence, the participating women were recruited for both the survey and interviews within the same period from the participating sites (the Departments of Infectious Diseases at Copenhagen University Hospitals, Hvidovre and Rigshospitalet, Odense, Aalborg, and Aarhus University Hospitals in Denmark; the Department of Infectious Diseases, Helsinki University Hospital, Finland; and the Department of Infectious Diseases, Sahlgrenska University Hospital, Sweden) by medical staff during routine clinical appointments. Pregnant women living with HIV were asked to participate if they were 18 years or older, pregnant, expecting a viable infant without life-threatening conditions or congenital anomalies, and could speak and read Danish or English. The participants were consecutively sampled until reaching data saturation (i.e. the point when no substantially new information emerged from the interviews).<sup>25,26</sup> In total, 31 pregnant women living with HIV agreed to participate in the interview study: 24 women from Denmark, five women from Finland, and two women from Sweden. A summary of their characteristics is presented in Table 1.

### Data collection

The data were collected through individual interviews between January 2019 and December 2020 among women in the third trimester of pregnancy. All interviews were conducted by the first author (EM) using a hybrid, narrative/semistructured format.<sup>27,28</sup> The opening question was: ‘Can you tell us what your pregnancy experiences have been like for you as a woman living with HIV?’ This allowed each woman to share her story. Probes were used as clarifying and elaborating questions throughout the interviews, thus expanding the stories the women shared within the larger narrative.<sup>27</sup> Hence, the participants were initially asked to give a full narrative of their experiences. This was followed by a series of semi-structured questions and probes to elaborate on themes not brought up by the interviewees (see the Interview guide in Supplemental material 1). The interviews were conducted in Danish or English and in the participant’s home, at the relevant hospital, or online using a video meeting setup, whichever setting the woman preferred.

**Table 1.** Characteristics of participating women (n = 31).

Age, years	
Median (IQR)	33.9 (29.5: 36.6)
Range	23–45
Relationship status, n (%)	
Married/living with a partner	25 (80)
Have a partner, but not living together	3 (10)
Do not have a current partner	3 (10)
Country of birth, n (%)	
Nordic country (Denmark, Finland or Sweden)	9 (29)
Africa	19 (61)
Other	3 (10)
Education, n (%)	
Primary/secondary school	11 (35)
Higher education (college/university)	20 (65)
Employment, n (%)	
Yes, part or full time	18 (60)
Comorbidities*, n (%)	5 (16)
Nulliparous, n (%)	14 (45)
Years since HIV diagnosis, median [IQR]	8 [1 – 19]
HIV diagnosis during pregnancy, n (%)	
Yes	3 (10)
Mode of HIV transmission, n (%)	
Sexual	27 (87)
Perinatal transmission	4 (13)
ART treatment**, n (%)	
NRTIs + NNRTI	7 (23)
NRTIs + PI	12 (39)
NRTIs + InSTI	11 (35)
Other	< 3 (3)
CD4 count**, n (%)	
> 500 cells/mL	21 (68)
≤ 500 cells/mL	10 (32)
HIV viral load**, n (%)	
< 50 copies/mL	24 (77)
≥ 50 copies/mL	7 (23)

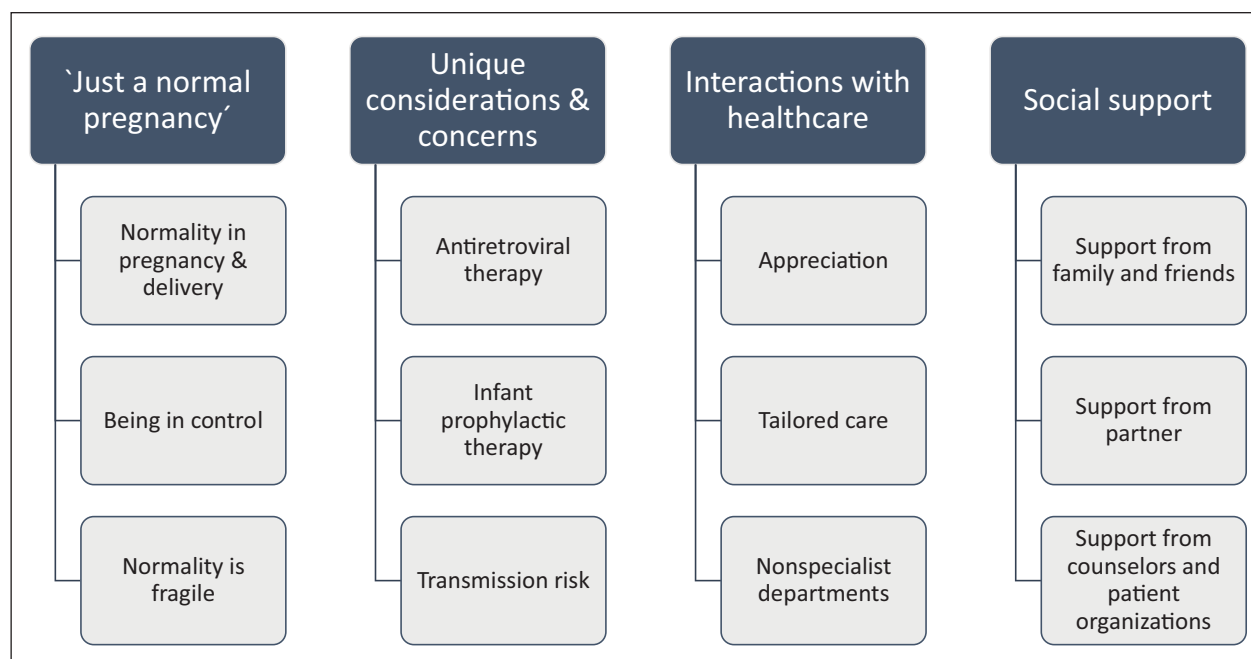
\*Diabetes, psychiatric illness, asthma and anaemia.

\*\*At enrolment.

The interviews lasted between 20 and 90 minutes (mean: 51 minutes), were audio-recorded, and were transcribed verbatim.

### Analysis

The transcribed interviews were examined using narrative thematic analysis as described by Riessman.<sup>29,30</sup> An inductive approach was used with an emphasis on the content of the text: ‘what’ is said more than ‘how’ it is said.<sup>29</sup> Hence, the data were analyzed textually. The analysis involved several steps. First, an initial coding focusing on capturing the main ideas from the women’s stories was conducted. Emergent themes and patterns across a subset of transcripts were identified and discussed among the team members (EM, NW, and DS) while paying close



**Figure 1.** Coding tree.

attention to the uniqueness of the entire story that was told and the study's aims. The themes were then compared for similarities and differences across participants and their narratives (EM, NW, and DS). Next, the themes were brought together to create and define the primary narrative themes,<sup>29</sup> and a codebook was developed to document and organize the codes (EM and DS). In the final step, the codebook was used to code and explore all interview data using NVivo software, QSR International Pty Ltd, to support data management (EM). Special attention was given to any new themes or perspectives emerging during this phase of analysis. The initial investigation was conducted by EM, NW, and DS. EM and DS worked together in the subsequent analysis to critically reflect on and review interpretations of the findings, and to ensure that the findings were based on the participating women's narratives.

### Trustworthiness

Several procedures were employed to enhance trustworthiness and credibility throughout the study (see Supplemental material 2 for a completed COREQ checklist). First, several authors were involved in the analysis, documenting every step of the analytical procedures and holding consensus meetings to establish agreement on thematic categories.<sup>31,32</sup> Second, a detailed description of the context and research process is provided to enhance the transparency of the results. Finally, the identified themes are described in detail, including quotes from the women to show confirmability between the data and findings.<sup>32</sup> In cases where the original quotes were in Danish, they were

translated by bilingual researchers using the forward-backward translation method.

### Results

The analysis generated four primary narrative themes, highlighting the ways that women living with HIV narrate their pregnancy experiences: (1) just a normal pregnancy; (2) unique considerations and concerns; (3) interactions with healthcare and (4) social support (Figure 1). These four themes are connected throughout the narratives and to the women's history and previous experiences.

#### *Just a normal pregnancy*

Emerging from the women's narratives were multiple stories about the concept of normality.

The feeling of *normality was related to both pregnancy and delivery*: being pregnant brought a sense of normality to the women, which increased acceptance of being able to live a good life with HIV:

'I'm like a normal person even with the infection. In addition, that was like, that's cool . . . and happy sometimes that . . . I can be normal . . . [laughing] . . . Without being . . . totally healthy, like I can be a mother, and sometimes I have my infection and accept it the way it is, and my baby will be fine. To think about that is a very big relief for me.' (ID 22, age 20–24, immigrant)

Having a normal pregnancy was important to many of the women; they did not want to be treated differently than other pregnant women. The participants knew about the

precautions needed throughout the pregnancy but felt that as long as they were compliant with their medicine, the focus should be on the pregnancy and less on their HIV. ‘I take my medicine every day, right? So I am just as normal as people not living with HIV’ (ID 9, age 25–30, born in a Nordic country).

Planning for and having a vaginal delivery was important, as this increased the feeling of normality. However, some women had doubts about the risks and lack of control associated with a vaginal delivery:

‘And that is why I am asking now, what kind of birth should I be doing . . . a natural birth or caesarean? The caesarean, they can control it more. The professionals. The natural birth can go wrong, that they can’t control . . . maybe they can’t control.’ (ID 28, age 35–40, immigrant)

For many participants, *being in control* was important, and pregnancy changed this in several ways. Pregnancy was associated with social expectations, and the women often had to explain why they were having extra scans or planning to deliver at a specific hospital. This was especially prevalent among women who had not disclosed their HIV status:

‘Sometimes it is hard to explain at work or with relatives because I, I have to, the scans are made by doctors at the hospitals, while normally it would be done by midwives at the local health care centre so it’s always with this HIV you have to have this explanation ready.’ (ID 29, age 30–35, born in a Nordic country)

Being a mother already brought a different perspective because the women knew what to expect both with pregnancy and their HIV, which made them experience less anxiety:

‘I think it is because I have my daughter. I am not concerned because I have done it before, so to speak.’ (ID 3, age 35–40, born in a Nordic country)

The feeling of *normality was fragile* and often interrupted by encounters of medical surveillance or complications. For example, if the women experienced complications or concerns during their pregnancy, they often found it difficult to distinguish if this could be due to their pregnancy, HIV, or medication. ‘I am pregnant and I’m taking the medicine, so is it the side effects from the medicine or the pregnancy?’ (ID 16, age 30–35, immigrant). Narratives from women who were pregnant during the COVID-19 pandemic revealed that for some this was associated with increased anxiety concerning both pregnancy and HIV infection. ‘I should be careful of Corona, I should be careful of HIV [short laugh], I should be careful of everything’ (ID 23, age 35–40, immigrant).

For the women who were diagnosed with HIV during pregnancy, the focus was less on normality and more on

coping and managing both their HIV diagnosis and pregnancy. They described feelings of ambivalence, as they were happy about the pregnancy, but also concerned and confused about their HIV diagnosis and what it meant for their baby:

‘I was happy and sad about this pregnancy. You know, to be pregnant, and you don’t know you are pregnant, and you have this virus, and you don’t know that you are HIV-positive. I mean, I can’t bear it.’ (ID 27, age 37, immigrant)

### Unique considerations and concerns

Being pregnant and living with HIV comes with unique considerations and concerns, which very much affected how the women experienced their pregnancies. Many participants changed their *antiretroviral therapy* regimens either because they were planning to become pregnant, or early in pregnancy due to the risk of teratogenicity. This often resulted in having to take more tablets and increased side effects. Nausea was common among the participants, and the women found it difficult to determine whether it was caused by pregnancy, antiretroviral medicine, or a combination of both:

‘I think it is double up. I think they enhance each other because I can take the medicine and be nauseous, but not throw up. I am just nauseous. But add the pregnancy, and there can be some very interesting nights and mornings.’ (ID 3, age 35–40, born in a Nordic country)

Although many of the women were very grateful for their antiretroviral therapy, taking the pills every day was also a reminder of their HIV. However, being pregnant enhanced the significance of taking the medicine, and the women were highly aware that this was important not only for their health but also for the health of their babies.

Thoughts about *infant prophylactic therapy* provided after delivery were also prevalent during pregnancy. Some women just accepted it, thinking the medicine helped protect their babies, while others were concerned and felt guilty about it:

‘I feel bad for her. It is not her fault, and yet she still has to suffer in a way, right? I’m thinking that if I’m feeling this bad, then how will a baby react to the medicine? I don’t know, but I just think it is bad for her, giving her the medicine . . . I know she must have it, but I just feel guilty, that she needs to have it when it is not her fault.’ (ID 13, age 20–25, born in a Nordic country)

Throughout their pregnancies, most of the women worried about *transmitting HIV* to their children, despite being well informed about the low risk of perinatal transmission. The women, who were already mothers, found reassurance in the fact that they had had children before who were healthy and not infected. Many of the women knew the

science and were aware that this fear of transmission was not rational, but it was still a very real concern during pregnancy:

'I know the risk is minimal, but all this talk about HIV not being transmittable and all that, has meant that it is not something I think about for myself. But now it is something else, with my child, because I fear that she might get it.' (ID 9, age 25–30, born in a Nordic country)

Many women felt reassured after they talked to health-care providers. However, some women felt that perhaps the risk of transmission was downplayed and expressed doubts about whether they could trust healthcare providers:

'Being pregnant and sitting across from all these doctors, nurses, and therapists saying you don't need to worry about that. We would rather have HIV than diabetes, I mean come on. I just reached a point where I became irritated, thinking that there may be something negative, some risk still exists; tell me about it.' (ID 8, age 40–45, born in a Nordic country)

### Interactions with healthcare

Women's close contact with the healthcare system and their interactions with healthcare providers were essential to their pregnancy experience. This was associated with their previous experiences, their expectations, and their cultural background. The narratives revealed that the participants' experiences with healthcare providers were mostly positive. The women also expressed great *appreciation* for the care providers and were very grateful to live in a country with a good healthcare system. This was especially prevalent among the women originating from Africa, who compared the care they were receiving to the healthcare systems in their home country:

'My worry was that if I was in Africa, maybe I would have been dead by now. Because maybe the medicine you have to buy, you don't have a good job, you don't eat good food and you worry all the time. So I am happy to be here.' (ID 4, age 25–30, immigrant)

The women received *tailored care* throughout the pregnancy, which included extra clinical appointments and scans; for some women, this was reassuring. They often saw the same providers, who specialized in HIV, at each clinical appointment, and this was a positive experience that made them feel normal, encouraged, and supported:

'They take the time to talk and listen, to understand, and to use the extra time. You know, like they truly care. I am happy about that. In addition, I don't feel abnormal when I see the doctor. They make sure of that. If I feel different than others, they tell me I am not, and it is important that I know that.' (ID 16, age 30–35, immigrant)

However, the narratives also highlighted that for some women, the need for specialized care was a burden, making them feel different from other pregnant women:

'It has been too much. I have talked to other pregnant ladies, and they have not had half the scans that I have. In addition, I cannot understand that just because you have the illness I have, that the baby shouldn't grow normally. In addition, that is why I need to go, so they can check if the baby is growing normally.' (ID 3, age 35–40, born in a Nordic country)

Some women also felt that the extra check-ups and tests were associated with increased anxiety because the chance of finding something that needed additional monitoring increased:

'It sometimes feels like full-time work to be pregnant and keeping track of all the appointments . . . I am just thinking that sometimes because there is an extra focus on you, you are put through things that might not be necessary . . . because as an expecting mother, I think your feelings are slightly sensitive, and mentioning alarming words has a big effect. I think this could be avoided in many situations.' (ID 30, age 30–35, born in a Nordic country)

Some of the women had other complications such as bleeding, abnormal growth, or the risk of pre-eclampsia, which needed closer follow-ups; this was often more easily accepted, as the need for close monitoring was not associated with their HIV. The many clinical appointments during pregnancy could be challenging to manage along with work and other commitments. However, the providers tried to align appointments on the same day to minimize the number of hospital visits; this was much appreciated by the women.

In *nonspecialist departments*, some providers seemed to lack knowledge of HIV. This was related to both past experiences and experiences during pregnancy, which created feelings of mistrust and insecurity. The women felt they were put in situations where they had to update the healthcare providers on HIV or to answer questions about their HIV that were not relevant to the situation. These experiences added an extra layer of anxiety and a fear of stigma linked to the delivery:

'My biggest fear of giving birth is to have a midwife that is afraid of me. When you are going to deliver a baby, it is one of the biggest things in your . . . in a person's life. Everybody deserves to feel like . . . they should not have to deal with other people's fear on that specific day.' (ID 31, age 30–35, born in a Nordic country)

### Social support

Support from others, or lack thereof, had a large influence on the women's experiences throughout pregnancy. *Support from family and friends* was experienced as both positive and challenging. Many of the participants were

immigrants originating from Africa. They often had poor support networks, and some had an unresolved immigration status. This affected their pregnancy experience in many ways, including increased anxiety, isolation, and feelings of loneliness:

‘No, I am alone here. I am alone here. That is why I don’t have any connections, truly. Even my husband’s family they are . . . they are his family. In addition, it is a different culture than ours.’ (ID 14 age 40–45, immigrant)

Many of the women had close contact with their family living in their home country, and several of the women were planning to have family members visiting closer to the birth. This was often a great source of support but also brought about much anxiety if they had not disclosed their HIV status. These women had many thoughts about how to hide their own medicine, the baby’s medicine, and the fact that they were not breastfeeding:

‘My mom is coming here . . . she doesn’t know anything about my infection. So I have to make a special effort to keep it secret because she will be living with us.’ (ID 28, age 40–45, immigrant)

Women originating from Nordic countries expressed having more social support and were also more likely to be open about their HIV status, which meant they were more relaxed in their relationships with others. A few of the participants had close friends who were also pregnant or new mothers, while others had friends living with HIV while being parents, which was a great source of support for them:

‘I have some friends who are HIV-infected and have kids. I think, especially one friend, we support each other a lot because our lives are very similar in many ways. We are the same age, well-treated, and so on.’ (ID 3, age 35–40, born in a Nordic country)

The women who were perinatally infected with HIV often found support within their own families, especially their mothers, because they felt their mothers could relate to some of the unique concerns and worries related to both HIV and pregnancy:

‘With my mother it is slightly more . . . also with the infection. She understands slightly more about how I feel. I truly rely on her. She is a great source of support.’ (ID 5, age 20–25, born in a Nordic country)

Most of the women were in stable relationships, where they had disclosed their HIV status and experienced good support from their partners. Some women, however, had not told their partners about their HIV status, which caused much anxiety. These women had often had bad experiences disclosing their HIV status in the past and were afraid of rejection:

‘I didn’t tell my partner about my problem, because I truly had a bad experience, and I . . . I know maybe it is not good but I . . . I was concerned also. I was sure there was no risk for him, so I didn’t tell him and I want to keep my secret.’ (ID 23, age 35–40, immigrant)

In addition, some of the participants were still trying to determine the relationship with the expectant father of their child, not knowing if he would be involved or whether they would be single mothers. This caused much anguish and concern, but also many thoughts about their ability to become mothers:

‘I am just afraid that my children will not have a father. That they will only have a mother. So I need to be strong for them.’ (ID 4, age 25–30, immigrant)

Other women found support from counselors and patient organizations for people living with HIV because they felt this was a place where they could be open, honest, and understood. Several of the narratives revealed that many of the women wanted to talk to other women living with HIV but had concerns about disclosure:

‘Because I still have that thing that I need to talk about with somebody who’s going through the same thing as me. In addition, I’ve never talked to somebody. But I don’t want to talk to somebody who knows me, because then they will judge me; maybe they will talk about me with my family and my friends.’ (ID 21, age 35–40, immigrant)

## Discussion

This study showed that women living with HIV have a strong desire to have a normal pregnancy and to be treated as any other pregnant women. However, this normality is fragile, and being pregnant and living with HIV does come with unique considerations and concerns that are fundamental to the women’s experiences. Moreover, the narratives highlight that interactions with healthcare providers and women’s social support networks influence their pregnancy experience in both positive and negative ways.

### ‘Just a normal pregnancy’

Our finding that being pregnant brought a sense of normality to women living with HIV and the importance of being treated as ‘normal’ is supported by other studies.<sup>7,8,33–35</sup> The results from several meta-syntheses indicate that the burden of HIV is often associated with feelings of loss of normality, while pregnancy is perceived to be a route to being normal, making the burden of HIV easier to bear.<sup>7,8</sup> Normality in pregnancy is defined by social and cultural expectations about pregnancy; the context, and women’s feminine identity<sup>7</sup>, and a sense of normality seems to have a supportive, strengthening function for

women living with HIV.<sup>35</sup> Hence, healthcare professionals should, regardless of their level of previous experience with HIV, focus on the ordinary aspects of pregnancy and not allow the presence of HIV to overshadow the care provided.<sup>35</sup>

Vaginal delivery was associated with a feeling of normality and social expectations of 'good mothering'. However, our findings also revealed that vaginal delivery may be associated with a lack of control and fear of complications and an increased concern about perinatal transmission risk. Vaginal birth is recommended in participating countries if the viral load is suppressed and there are no obstetric contraindications. Thus, comprehensive, repeated assurances from healthcare providers are important throughout pregnancy to alleviate any fear and anxiety that women might be experiencing.<sup>34</sup>

### *Unique considerations and concerns*

Pregnancy can be a complex experience for many women and is composed of ambivalent experiences such as safety/insecurity and happiness/sadness.<sup>34</sup> For pregnant women living with HIV, ambivalence is accompanied by anxiety, worry, and guilt due to the unique considerations and concerns related to their HIV. The fear of perinatal transmission of HIV was highly prevalent in the women's narratives, despite them knowing that the risk of transmission of HIV to their babies has been almost eliminated, especially in high-income settings.<sup>4,16,24,36</sup> Similar results have been found in other studies.<sup>12,34</sup> Hence, it is important to acknowledge that in many cases, this fear of transmission is prevalent until it is confirmed that the baby is not infected and healthcare providers should not neglect or underplay a woman's anxiety and concerns, as this may create mistrust and misunderstanding.

Our findings also showed concern related to any adverse effects associated with antiretroviral therapy, in addition to the prophylactic treatment provided to the baby after birth. This concern was often connected to feelings of guilt. For many women, antiretroviral therapy was a reminder of their HIV status. In addition, many of the women were very grateful for having treatment options. This ambivalence, which has been reported by others,<sup>37,38</sup> seems to be intensified during pregnancy because protecting and caring for their babies implied caring for themselves, pregnancy, and HIV infection.<sup>34,37</sup>

### *Interactions with healthcare*

Unlike previous findings, where women living with HIV have been questioned about why they were pregnant,<sup>10,39</sup> we found that this concern mainly came from the women themselves. The narratives highlighted that the women were supported in their choice to become pregnant, both by healthcare providers and their families, and although some of them had initial concerns about pregnancy because

of their HIV, meetings with healthcare providers made them feel less concerned and more empowered to go through with the pregnancy. These findings suggest a positive advancement in the stigma related to becoming pregnant when living with HIV.

Our results underscore the need for person-centered care with a focus on the individual woman's experience and context. An important element of this is for healthcare providers to consciously ensure that women living with HIV do not feel labeled or judged in interactions.<sup>39</sup> Healthcare providers can have a large impact on a woman's feeling of acceptance, and having access to non-judgemental and compassionate care can make a woman feel a sense of belonging, not only as a woman living with HIV but also as a pregnant woman.<sup>10,39</sup>

Similar to other studies,<sup>9,12,40,41</sup> the narratives underline that many of the women still experience – and in many cases expect to experience – stigma and ignorance towards HIV outside of specialized clinics. This was irrespective of the woman's cultural background. Women living with HIV, especially pregnant women living with HIV, are especially susceptible to the harmful effects of discrimination in healthcare.<sup>41,42</sup> Thus, ongoing educational interventions targeting healthcare providers working in non-HIV specialties caring for pregnant women are essential to reduce discrimination against women living with HIV.

### *Social support*

Many of the women included in this study had limited social support and used distancing as a method to protect themselves against unwanted disclosure. These findings are similar to those of Greene et al.,<sup>33</sup> who, in their study on pregnant women living with HIV in Canada, found that some women started distancing themselves from social support networks early in their pregnancy, both figuratively and literally. Our findings emphasize that disclosure of HIV status is closely tied to social support, as women who had not disclosed their HIV status struggled with receiving help from their family and friends due to the risk of unintended disclosure. For many of the women, their primary source of support came from their partner; being in a relationship wherein women can be open and protected from the negative feelings related to an HIV diagnosis is particularly supportive.<sup>8</sup> Fear of rejection and being alone kept some women from disclosing their HIV status to their partners; furthermore, similar to findings from other studies,<sup>8,43,44</sup> this was an emotional burden, causing distress and creating restrictive relational boundaries.

Women originating from Nordic countries expressed having more support from both family and friends. This may be related to disclosure, as many of them were more open about their HIV status. However, it may also be related to immigration status, as women who were born abroad may experience limited social support due to



immigration and language barriers. Living with HIV adds another layer, especially if the women have not disclosed their HIV status, which may intensify feelings of isolation.<sup>45</sup> Isolation may also be salient because of pregnancy due to cultural and social norms associated with pregnancy, which may be different compared to those in the women's home countries.<sup>45</sup>

Peer support from others living with HIV has a positive effect on women living with HIV during pregnancy.<sup>12,46</sup> This was desired by several of the women in this study; however, the fear of disclosure prohibited them from acting on it. In addition, several women noted they felt alone with their HIV diagnosis because public opinion and most HIV support networks target men who have sex with men. Thus, HIV clinics and patient organizations should be encouraged to use peer-to-peer counseling without compromising disclosure as an additional supportive action offered to women living with HIV.<sup>12</sup>

### **Strengths and limitations**

To our knowledge, these results are the first to capture pregnancy experiences among women living with HIV in Nordic countries, where free access to healthcare should ensure appropriate medical treatment and support throughout pregnancy. Moreover, the interviews were conducted in a time period when the U equals U message (i.e. undetectable=not transmittable) has become known to women and more people in the society<sup>47</sup>; this may have impacted the finding that women felt more supported. A key limitation is that the study only reflects those who were willing to take part in the overall mixed-methods study,<sup>18</sup> raising the possibility that there could be some important differences between those who agreed to take part and those who chose not to do so. Country of residence and country of birth varied between the women, which could have influenced the generalizability of the results. Furthermore, the interviews were conducted in English or Danish only, thus excluding women who speak other languages. However, the participants were sampled consecutively and had diverse backgrounds and experiences, thus representing the broad characteristics of women living with HIV in Nordic countries. The interviews were carried out by one author, thereby increasing consistency throughout the data collection phase. Ten of the interviews were held by video conference due to the COVID-19 epidemic, and although an effort was made to ensure in-depth follow-up questions and probes, non-verbal communication may have been restricted. The women were encouraged to tell their stories; however, due to the general mixed-methods project, specific follow-up questions were asked if the women had not talked about these aspects in the initial part of the interview. This may have limited the elaboration of the women's narratives. Nevertheless, many of the predefined themes were brought up by the women themselves, and follow-up questions were often used to confirm or refute the relevance of those

themes in the overall mixed-methods project. Several authors participated in the analysis, and quotations from the interviews were added to further establish credibility. The different analysis procedures were transparent, thereby increasing replicability and validity.

### **Conclusion**

In sum, the findings emphasize a feeling of normality in pregnancy among women living with HIV. However, pregnancy does come with unique considerations and concerns, such as fear of transmission, the use of antiretroviral therapy in pregnancy, and the need for specialized care, which highly influence the pregnancy experience. Healthcare providers should focus on person-centered care, ensuring continuity and emotional support as well as ensuring that women living with HIV do not feel discriminated against throughout their pregnancies.

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### **Contributorship**

All authors contributed to the conceptualization of the study. The analysis was completed by EM, DS, and NW, who also developed the final coding tree. All authors participated in the study investigation, that is, enrolling participants and data collection. The interviews were conducted by E.M., who also wrote the initial manuscript draft, which was critically reviewed and commented on by I.A., I.S.J., M.S., G.P., D.S., T.L.K., and N.W. The final version is approved by all authors.

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## Supplemental material

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