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# “Discrimination is harder to live with than the disease”: an interview study of the perceptions and experiences of sexual and reproductive health and rights among women living with HIV in Sweden

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**Abstract:** Around 40% of people living with human immunodeficiency virus (HIV) in Sweden are women. However, little is known about their experiences, particularly those related to sexual and reproductive health and rights (SRHR). This study aims to explore perceptions and experiences of SRHR among women living with HIV (LWH). Twelve interviews were conducted with women LWH from September to October 2019 and analysed using thematic analysis. The central theme describing participants' experiences of social relationships, intimate encounters and reproductive life, “Discrimination is harder to live with than the disease itself”, is based on three themes that contain subthemes. Theme 1 describes how participants reconsider and reorient their sexual and reproductive life after diagnosis. Theme 2 highlights how (mis)perceptions of HIV affect sexual and reproductive life and lead to abusive treatment and internalisation. Theme 3 describes a paradoxical shift of responsibilities where participants experience being compelled to take greater responsibility in some situations and stripped of the right to decide in others. This study suggests that despite notable progress in HIV treatment, stigma and discrimination stemming from outdated beliefs and (mis)conceptions, ambiguous policies and guidelines, and unequal access to information affect SRHR experiences of women LWH more than the virus itself. The results emphasise the need to: update knowledge within healthcare settings and among the public; clarify ambiguous legislations and guidelines; ensure equal access to information to enable all women LWH to take informed decisions, make fully informed choices and realise their SRHR; and consider the diversity of women LWH and enable shared decision-making. DOI: 10.1080/26410397.2023.2245197

**Keywords:** HIV infection, women, sexual health, reproductive health, reproductive rights, access to information, disclosure, stigma, discrimination, Sweden

## Introduction

The number of people surviving with HIV has increased worldwide in recent decades due to effective antiretroviral (ARV) therapy. In 2021, there were around 38 million people living with HIV globally and more than half of them (54%) were women and girls.<sup>1</sup> In 2021, there were 8289 people living with HIV in Sweden and women represented around 40% of these, a higher proportion than the average in the European WHO region.<sup>2</sup> Up to 64% of people living with HIV were

born abroad and almost all (98.6%) of those living with HIV in Sweden were accessing treatment. On average, 94.9% of those who were on ARV treatment at different Swedish clinics were virally suppressed, suggesting that they had undetectable and untransmittable levels of HIV in their blood after at least six months of treatment, otherwise referred to as the “undetectable equals untransmittable” (U = U) message.<sup>2</sup>

The progress made in ARV therapy has transformed HIV from a fatal to a chronic disease.

As a result, the global and national responses have changed over time.<sup>3</sup> In Sweden, the guidelines have also altered over time from mandatory partner notification and tracing for all people diagnosed with HIV in the mid-1980s to the current guidelines where the obligation to tell is applied based on individual treatment status (U = U).<sup>4</sup> However, HIV is not only a medical condition but also a social disease with social, political, ethical and legal consequences. For instance, HIV-related stigma and discrimination are social consequences that negatively affect the social life and well-being of people living with HIV, including their sexual and reproductive life.<sup>5</sup>

A metasynthesis of 18 peer-reviewed qualitative studies on the experiences regarding sexuality and reproduction of women living with HIV (LWH) in high-income countries has revealed a wide variety of experiences in this respect.<sup>6</sup> HIV has been perceived as a burden that could be heavier or lighter depending on a person's actual life circumstances. Women who have experienced feelings of fear and loss had greater difficulty in living with HIV. On the other hand, motherhood, spiritual beliefs and supportive relationships made it easier to bear the burden of the disease.<sup>6</sup> A recent qualitative research synthesis has revealed that women LWH encounter reproductive decision-making without sufficient relevant knowledge and with limited social support.<sup>7</sup>

Existing literature on women LWH and breastfeeding in high-income settings shows that guidelines regarding the U = U message vary across countries due to a lack of evidence on the risk of transmission via breast milk.<sup>4,8,9</sup> Some countries advise women LWH against breastfeeding regardless of their treatment status<sup>4</sup> while others support shared decision-making about infant feeding with appropriate information and support from healthcare providers.<sup>8,9</sup> Some women LWH choose to breastfeed their infants after receiving counselling, while others opt not to breastfeed. The infant-feeding choices and practices of women LWH are determined by overarching sociocultural factors, including individual maternal factors, family and community influences and health system support, as well as socio-economic and socio-demographic factors.<sup>10,11</sup> Although four out of ten people living with HIV in Sweden are women,<sup>2</sup> none of the studies included in previous reviews were conducted in Sweden, suggesting a scarcity of studies in the Swedish context.

The few available Swedish studies have also shown that HIV affects the experiences and decision-making among people living with HIV in relation to sexuality and reproduction. An interview study with adolescents and young adults living with innate or early-acquired HIV suggested that some chose not to talk about HIV in connection with sexual encounters while others chose not to have sex.<sup>12</sup> Ljungcrantz's<sup>13</sup> thesis on the imaginaries and experiences of HIV as a chronic illness in Sweden has also revealed experiences of refraining from or stopping all sexual activities after an HIV diagnosis. Another interview study with women LWH has suggested that they experienced a great and constant fear of transmitting HIV to partners, which affected their sexual practices. Fear of rejection and negative reactions in case they shared their HIV status also affected how they experienced existing relationships and the possibility of establishing new ones.<sup>14</sup> A quantitative study among people living with HIV also found that about 44% of women LWH were dissatisfied with their sex lives. Sexual dissatisfaction was associated with distress, difficulty in achieving orgasm and perceptions that HIV had negatively changed their sex life.<sup>15</sup> Carlsson-Lalloo et al.<sup>16</sup> found in their interview study that perceptions about HIV and its contagiousness among women LWH, their friends and relatives deeply affected sexual habits and choices in relation to pregnancy and childbearing. Participants felt that HIV limited sexuality and childbearing but adequate knowledge contributed to making safer choices and decisions.<sup>16</sup> However, none of these previous studies adopted a rights perspective. Thus, there is a significant knowledge gap concerning women LWH in Sweden with regard to sexual and reproductive health and rights (SRHR). Against this background, the Public Health Agency of Sweden commissioned our department in 2019 to conduct research on SRHR among women LWH. The aim of this study is to explore the perceptions and experiences of SRHR among women LWH in Sweden.

### Conceptual framework

To assist in understanding women's experiences of sexual and reproductive health, we use the concept of SRHR, which is an umbrella term for four key concepts that are interconnected, but often treated as distinct. Therefore, a comprehensive and integrated definition of SRHR has been recommended in the Gutmacher–Lancet Commission report, based on various international and

regional agreements, technical reports and guidelines.<sup>17</sup> The integrated and comprehensive definition of SRHR defined sexual and reproductive health as “a state of physical, emotional, mental, and social well-being in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction, or infirmity”.<sup>17</sup> This definition requires a positive approach to sexuality and reproduction that recognises the role of pleasurable sexual relationships, trust and communication in the promotion of self-esteem and overall well-being. The definition further recognises the equal right of all individuals to make free decisions and choices concerning their bodies and to access services that support that right. To achieve and maintain sexual and reproductive health, the sexual and reproductive rights of all individuals, including people living with HIV, must be respected, protected and fulfilled.<sup>17</sup>

Sexual and reproductive rights are human rights and an integral part of the right to health that encompasses the rights of all individuals, including people living with HIV. These include the right to have their bodily integrity, privacy and personal autonomy respected and to freely define their own sexuality, including sexual orientation and gender identity and expression. It also includes the right to: decide whether and when to be sexually active; choose their sexual partners; have safe and pleasurable sexual experiences; and decide whether, when and whom to marry. It further includes the right to decide whether, when and by what means to have a child or children, and how many children to have, and to have access over their lifetimes to the information, resources, services and support necessary to achieve all of the above, free from discrimination, coercion, exploitation and violence.<sup>17</sup> In this study, the SRHR framework influenced the interview guide, sensitised us to aspects in the analysis process (see Data analysis section) and facilitated an interpretation of the aspects that are crucial for SRHR among women LWH.

## Methods

### Study design and setting

The study includes qualitative interviews with women LWH in Sweden focusing on their experiences of SRHR. According to the Swedish Communicable Disease Act (SFS 2004:168), HIV infection

is classified as a notifiable disease, dangerous to public health and subject to mandatory contact tracing. This act is aimed at preventing the spread of certain communicable diseases and providing support and treatment to those affected by such diseases. The latter are also subject to certain rules of conduct, including the obligation to protect and share their status with sexual partners or anyone who might be exposed to the risk of acquiring the virus, such as healthcare professionals.<sup>18</sup> However, since 2013, people living with HIV on effective ARV therapy who achieve and maintain an undetectable level of HIV in their blood, also known as U = U, can be exempt from the legal obligation to share their HIV status.<sup>4</sup> In addition, vaginal delivery is recommended for pregnant women LWH on effective ART if there are no obstetric reasons for a caesarean section. However, regardless of treatment status, women LWH have an obligation to abstain from breastfeeding their children to avoid exposing them to the risk of transmission.<sup>4</sup>

### Recruitment

Participants were recruited purposively through networks and non-governmental organisations supporting people living with HIV and HIV patient association groups run by people living with HIV, particularly a peer support association for women LWH and through an infectious disease clinic. The recruitment took place from September to October 2019. Representatives from these support and patient organisations and networks, as well as the HIV nurse and counsellor at the infectious disease clinic at a referral university hospital, were asked if they could distribute flyers or inform potential participants about the study. The flyers were disseminated among groups through social media, mailing lists or social events, or pinned up in physical premises. The flyers were available in English and Swedish and contained contact information for the research group to enable interested participants to get in touch by phone or via email. Upon making contact, they received more information about the study, and if they agreed to participate, an appointment was booked for the interview. The inclusion criteria for the study were: people who identified themselves as women LWH; being aged 25 or older; and residing in Sweden. Language was not an inclusion criterion as interpreters were made available for those with limited English or Swedish

proficiency. During the recruitment, we aimed for maximum variation regarding age, country of birth, place of residence, marital status, socio-economic status and sexual orientation.

### Participants

A total of 12 women aged 25–61 were included in the study. The participants came from a total of six countries (Sweden, Congo, Cameroon, Uganda, Eritrea and Zimbabwe) and lived in six different regions in Sweden. Some participants asked to remain anonymous with regard to the interview, and they were assured of this by the research group, who conducted the interview over the phone and did not ask for any personal data such as their exact place of residence or employment status. However, all participants provided information about their county or region of residence and country/region of birth.

### Data collection

The interviews were individual and were conducted by FKNK and IL. Of the 12 interviews, eight were conducted in Swedish, two in English and the other two in Tigrinya and Amharic with the assistance of telephone interpreters. Each participant was asked to choose between a telephone or face-to-face interview. Almost all participants chose telephone interviews except one, who preferred a face-to-face interview.

The interview guide was semi-structured and based on open-ended questions. It was developed in collaboration with scientists at the Public Health Agency and a female representative from a national patient organisation for people living with HIV. Each interview began with background questions, such as age, migrant status and time since diagnosis (see Table 1). The semi-structured part of the interview included the following overarching topics: sexual health and relationships; reproductive health; experiences of support; challenges; and needs. The interview questions were adapted to suit the participants' life situation, and follow-up questions were asked based on the participants' answers. The interviews lasted between 30 and 65 minutes (45 minutes on average). Data collection was completed when themes in relation to the purpose of the study recurred in the interviews and new interviews were not deemed to add unequivocally different themes.<sup>19</sup> In addition, the material was judged by the research team to be rich and wide-ranging.

### Data analysis

Reflexive thematic analysis was applied to the interviews in order to identify key themes.<sup>20</sup> The interviews were audio-recorded and transcribed verbatim by a professional third party (external transcriber), and transcripts were checked for accuracy by the interviewers (FKNK, IL). For the two interviews conducted in languages other than Swedish or English, only the Swedish translations of the audio-recorded interviews were transcribed. Thereafter, the transcriptions were checked against the audio by a different interpreter from the one who interpreted during

**Table 1. Socio-demographic characteristics of participants**

Characteristic	Categories	Number (Total = 12)
Age (years)	25–30 (Young adult)	3
	31–45 (Middle-aged adult)	4
	45–65 (Older adult)	5
Employment status	Working	4
	Studying	7
	Other (disability pension)	1
Time since HIV diagnosis (years)	0–5	1
	6–15	8
	>15	3
Marital status	Partner	6
	Single	6
Parental status (Child/ren)	Yes	10
	No	2
Country of birth	Sweden	5
	Abroad	7
Sexual identity/orientation	Heterosexual	11
	Queer	1



the interview. Thereafter, all transcripts were analysed using thematic analysis to examine recurring themes in the informants' stories.<sup>21</sup> The analysis used an abductive approach, which means a combination of both inductive (data-driven) and deductive (driven by the theoretical framework) approaches. This meant in our study that the interview transcripts were coded and analysed inductively while focusing on SRHR aspects. Swedish transcripts were coded in Swedish, and English codes were assigned to English transcripts; thereafter Swedish quotes were translated into English. The following steps described by Braun and Clarke were applied iteratively in the analysis process<sup>21</sup>: (1) reading through the interview transcripts (FKNK, IL) and subsequently discussing thoughts and preliminary interpretations within the research group (FKNK, AKH, IL); (2) the two researchers who conducted the interviews (FKNK, IL) coded each other's interviews (FKNK, IL), which meant that both became familiar with the data set; (3) the generated codes and themes were discussed within the research group (FKNK, AKH, IL); (4) a final list of codes, subthemes and themes was compiled; (5) themes and subthemes were synthesised and described (FKNK, IL).<sup>21</sup> Analytical notes were kept continuously, and preliminary themes were noted (FKNK, IL).

### Ethical considerations

Both HIV and SRHR can be sensitive issues. Ethical considerations were therefore important throughout the entire research process. Consent to participate was obtained prior to the interview after the participant had received both oral and written information about the study and their right to withdraw from the study at any time without consequences. The names in the results section are pseudonyms. Participants were also asked to contact the interviewer again if they felt the need to reflect on something that came up during the interview or to get guidance on where to seek support and help. The study was granted ethical approval by the Ethical Review Authority on 14 August 2019 (Dnr: 2019-02468).

### Results

One main theme, three themes and seven subthemes were identified after the analysis (see Figure 1).

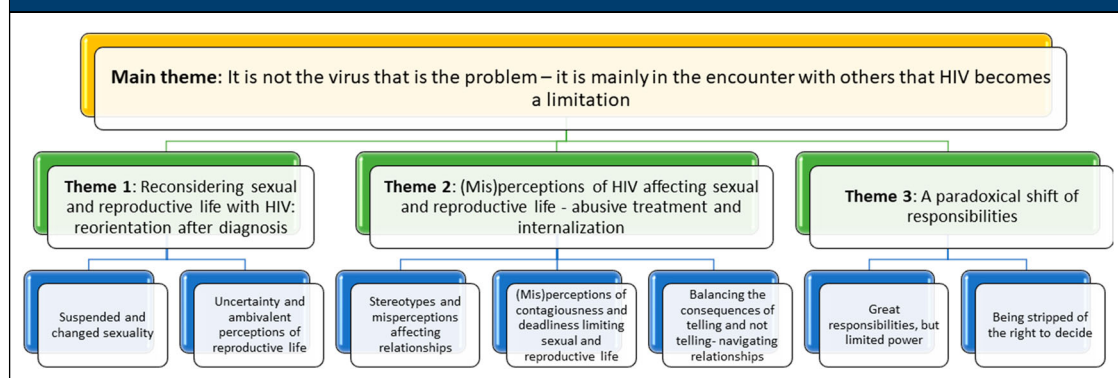
**It is not the virus that is the problem – it is mainly in the encounters with others that HIV becomes a limitation.**

The main theme described participants' experience and perception that it is not primarily HIV, in terms of a virus, that creates limitations for their sexual and reproductive lives. Rather, limitations emerge mostly in the encounters with other people due to stereotypes, prejudice and misconceptions about the disease. Olivia, an older adult migrant, expressed this as follows: *"Discrimination is harder to live with than the disease itself"*. When Anna, a young adult native Swede, compared her sex life before and after being diagnosed with HIV, she said: *"Yes, a social difference. You internalize, and when you have to tell before [having sex], you start to select a little more"*. However, the limitations to a sexual and reproductive (SR) life experienced by participants varied and did not always stem from the direct expressions of prejudices, abuses or stigmatisation from others. In some cases, such as for Anna, it was rather an expectation of negative reactions or internalised stigma, which for some was believed to be linked to previous experiences of negative reactions or abuses. In other words, the social prejudices and beliefs surrounding HIV are something that has become internalised, making some participants limit themselves when it comes to their sexual and reproductive lives.

This main theme is based on three themes that together describe the participants' experiences and perceptions of their SRHR.

### Reconsidering a sexual and reproductive life with HIV: reorientation after diagnosis

Several participants stated that nowadays it is possible to live a "normal life" with HIV as a woman in Sweden, with a functioning sexual and reproductive life. Although HIV diagnosis for many meant a shock or drastic change in life, some participants recounted that after 10–20 years living with the diagnosis, they got used to it, as stressed by Ines, a middle-aged migrant: *"I can go several months without me thinking about it [HIV] at all"*, or they only thought about HIV when they took medication. For other participants, HIV was more present and had a perceptible impact on their SR life despite the U=U context. Nadia, a middle-aged migrant, said: *"No, I don't want to, I don't want a relationship*

**Figure 1. An overview of subthemes, themes and main theme**

or more children, I just want to live with my children and raise them”. This was also stressed by Olivia, an old adult migrant, when she said: “Yes, I have decided to do that, to live without sex”.

#### *Suspended and changed sexuality*

The diagnosis and the time following the diagnosis were described as including specific experiences and thoughts about sexuality. Several participants described how they believed they would never have sex, or a sexual relationship, again, as voiced by Karin, an older adult native Swede: “Well, at first, I thought ‘well, I’ll never be able to have sex again’, but it hasn’t been that bad again”. For Ingrid, another older native Swede, it was still the case that she had no sexual feelings and could not imagine having sex since she had received the diagnosis. She said: “I haven’t even had sexual feelings at all. It’s like a lid has been put on that”. Abstaining from sexual relations was described as being a matter of guilt and shame and was also believed to be related to the moment of transmission for participants who acquired HIV through sex and an expression of fear of rejection.

Fear of transmitting HIV to a sexual partner was experienced by some participants as altering both sexual desire and practices. For example, Cynthia, a young adult migrant, gave an account of how she constantly avoided oral sex due to a fear of transmission and found it strange to consistently use condoms within her marriage: “You know, condoms, it’s still very strange for a married couple to use a condom”. Lena, an older native Swede, mentioned that she was more

afraid of transmitting HIV than her partner who was HIV negative:

*“It was, I think, more difficult for me in the beginning than it was for him. He wasn’t infected. And before I could find my way back ... Find my way to be able to relax and not always be afraid that, oh-oh, as long as he does not get infected.”*

Several participants also talked about a constant fear that the condom would break during sex, preventing them from relaxing during sex. One participant recounted how she took her partner to the hospital for testing after the condom broke.

Unlike these accounts, Carol, a middle-aged migrant, felt that the HIV diagnosis had not made such a big difference to her sex life. When asked about how she found her sex life after being diagnosed with HIV, she responded: “... as usual we have a normal functioning sex life. When you have time, because you’re so busy with work and kids and stuff like that”.

Thus, some participants challenged the idea that HIV drastically changed their sex life. Ines, a middle-aged migrant, also challenged the idea that HIV affected her sexuality when she said: “So I think it’s much better now than before in some way”. She felt that her sexuality was more limited in her home country (before her HIV diagnosis) due to widespread taboos around sex compared to Sweden. On the other hand, another participant believed that HIV felt more stigmatised in sexual relationships in Sweden where it was more uncommon than in her home country.

There were direct expressions of internalised stigma but also experiences that could be interpreted as self-stigma, such as the ideas that others

may not fall in love or want to have sex with someone living with HIV. Lena, an older adult native Swede, said:

*“So, it took me a very long time before I realized that, even though he had known about it [the HIV diagnosis] for a long time, (that) he could still be interested in me. It wasn’t in my world. That is why, incredibly, he needed to convince me before I could understand it.”*

In other words, participants felt that ideas around HIV were internalised and could be difficult to overcome and they therefore had to cope with them. Overall, HIV diagnosis was described as changing the perceptions and experiences of sexuality and reproduction. While some described having regained lust and the desire to have sex and children, other participants were still struggling to reorient their sexual and reproductive lives despite the new evidence regarding U = U.

#### *Uncertainty about, and ambivalent perceptions of, reproductive life*

Participants described how the HIV diagnosis raised existential questions and particularly questions about childbearing. When diagnosed in connection with pregnancy, a major concern among participants was starting ARV treatment and how it may affect the unborn child. Anna, a young adult native Swede, said: *“There was a risk that my medication would be a risk to the child. But I had already been pregnant a couple of weeks ... And the most critical phase had passed, so we did not change the treatment”*. Passing HIV on to a child was perceived as frightening, both for those who had children after being diagnosed with HIV and those who were considering having (more) children. Sarah, a young adult migrant, said: *“I didn’t know what would happen to me, am I dying and am I going to have this child? Will the child have the disease? /.../ will I die and leave the children?”* Participants were also afraid that they would become seriously ill and unable to cope as a parent. The risk of passing on HIV to a child was the reason why some participants avoided becoming pregnant again despite being aware of the U = U message, as illustrated in the quote below:

*“I feel like I could have two or more children, but I feel so limited. Because in my head I feel like, if I get pregnant, then the baby will come out positive. Even though I know the medications work and so*

*on. But I feel quite limited.”* (Cynthia, a young adult migrant)

For other participants, a second pregnancy could mean a more relaxed experience. Ines, a middle-aged migrant who struggled during her first pregnancy, stated:

*“I already knew that the baby would be born absolutely healthy, so I had no worries at all. It was a pretty happy pregnancy without any stress, no depression, nothing like that, because I was ready.”*

Based on her previous experience where she did not transmit HIV to her first child during pregnancy or birth, she was able to avoid feeling worried and instead felt happiness during her second pregnancy.

Several participants also emphasised that nowadays an HIV diagnosis does not mean the same as it did 20–30 years ago. Some participants had received their HIV diagnosis at a time when HIV was seen a “death sentence” while they were now experiencing and talking about living with a chronic disease. Lena, an older adult native Swede, said: *“So right now, I don’t feel like I’m living with a death threat like I did before”*. Moreover, as time went by, participants could also change their perceptions, as Ines, a middle-aged migrant, reflected:

*“I hope that many people come to realize that it is possible to have a good sex life, you can have a family and be happy, you can work wherever you want, do what you want without feeling limited. I think that the limitation is much more mental than physical.”*

Thus, the diagnosis could be traumatic, but several participants who have lived with HIV for a long time described how it became part of everyday life and how they learnt to live with it.

#### **(Mis)perceptions of HIV affecting sexual and reproductive life – abusive treatment and internalisation**

Participants said they had come across diverse beliefs about HIV both in the past and in the present, and that these beliefs affected their relationships with friends and (potential) sexual partners, and their likelihood of becoming pregnant. It was mainly prejudicial ideas and beliefs about who has HIV, but also in some cases the truth about HIV being a contagious, deadly disease if left untreated and its transmission being potentially



criminalised. Together, these beliefs restricted their sexual and reproductive lives in different ways.

#### *Stereotypes and (mis)perceptions affecting relationships*

Participants described encountering stereotypical and prejudicial ideas about people living with HIV and who gets HIV, including beliefs about people living with HIV being drug users or sex workers. Some participants gave accounts of people being stunned that they were living with HIV because they did not fit into any stereotypes, such as being homosexual or migrants. There were also accounts about how ideas about HIV are woven together with normative ideas about sexuality, (dis)ability and age. Normative beliefs about different people's sexuality were perceived as contributing to delayed HIV diagnosis. Ingrid, an older adult native Swede, said:

*"That is why I am such a late [HIV] tester. A lot has been written about this. I'm a woman, I have no addiction problem, I seem too normal, or whatever ... I'm pretty much part of it, I am considered a normal person. And I was over 50 at that time [when I was diagnosed]. Also, I'm living with a physical disability, which I have not mentioned before, which I can imagine is also a contributing factor. They might think, 'Well, yes, she's not having sex or something like that. Who wants her?'"*

One participant said that since she had been diagnosed with HIV, she had been "marked". There were also accounts of HIV being perceived as an "ugly disease", as voiced by Ines, a middle-aged migrant: *"[while] people no longer see it [HIV] as a deadly disease, they [still] see it as a dangerous disease"*. Participants have come across such beliefs in different ways and situations, including new sexual contacts or while dating. Participants who experienced several privileges, such as being native Swedes, heterosexual and having a job, also argued that they had a certain responsibility to "go ahead" and break taboos and challenge HIV-related stigma.

#### *(Mis)perceptions of contagiousness and deadliness limiting sexual and reproductive life*

For several participants, the fear of transmitting HIV was a critical factor when considering sexual relationships, childbearing or motherhood. This could be an expression of persistent ideas of HIV contagiousness that the participants had

internalised and that still made them hesitant, despite very low or undetectable viral levels ( $U = U$ ). But it could also be seen as an expression of the difficulty of overcoming fear that they had been living with for quite a long time, since some participants had been diagnosed with HIV before the ARV era or before the evidence of " $U = U$ " became available.

The risk of passing on HIV is also identified as the reason why *other* people around them did not encourage them to have children, or rather discouraged them from doing so. They mentioned not only healthcare professionals but also close relatives and friends. Sarah, a young adult migrant, commented: *"A lot of people around me said, 'You have HIV and you're having children, why would you have children'"* The possibility of passing on HIV also raised concerns about abortion, as illustrated in the following quote from Ines, a middle-aged migrant: *"And then when I found out I was HIV positive, I just felt yes, but maybe I could have had an abortion anyway, how am I going to live with a child who is HIV positive?"*

Other participants pointed out that considerations around abortion can be complicated by religious beliefs that oppose abortion. Some participants also recalled how healthcare staff encouraged them to undergo an abortion at the beginning of the HIV pandemic while others found they were not encouraged to become mothers. In more recent times (thanks to the  $U = U$  message), meanwhile, participants felt they had been encouraged to have children and received support both within and outside the healthcare setting, as described by Cynthia, a young adult migrant:

*"I am still considering [having more children]. Especially after, you know, I spoke to my doctor here. I kind of feel like it changed a little bit, because before I was not even thinking about it. It was almost, you know, I was almost thinking that I will never have another child. But now, sometimes I do think that I might, you know?"*

Thus, there are different experiences among the participants regarding (a lack of) support in relation to reproductive rights.

Other participants also shared experiences of abusive treatment in connection with sexual encounters or in intimate relationships, which according to them were due to beliefs and ideas about the contagiousness of HIV. Sarah, a young

adult migrant, shared her experiences of how sexual partners repeatedly treated her as contagious: *“Every time they had sex with me, they ran to the bathroom to wash. So, it was like, they’re doing something afterwards because they feel like it’s disgusting.”*

Sarah also mentioned experiences of sexual violence, including rape:

*“They never wanted to use a condom, and neither did this man. That’s why I had a lot of kids because he didn’t want [to use] a condom. So, it was rape. He was the one who decided, not me.”*

Another participant, Anna, a young adult native Swede, gave an account of repeated rejections in a sexual relationship: *“I have also been in a relationship where a partner refused to have sex with me for almost a year”*. This had a major impact on her self-esteem and mental health. She continued:

*“I felt very bad, but now I talk in the past, because I reflected on it, how I was, as a whole, as a person, what I was worth purely sexually, and that if no one wanted to be with me, there was something wrong with all of me.”*

#### *Balancing the consequences of telling and not telling: navigating relationships*

Participants described how they struggled to balance the consequences of sharing and not sharing their positive HIV status while dating and meeting potential sex partners, both in the past and in the present. These balancing thoughts were related to a fear of rejection but also a fear that people would change their behaviours and attitudes towards them, that they would feel sorry for them, start gossiping about them or that they might discriminate against, stigmatise or marginalise them. Telling was perceived as closely related to HIV being considered an “invisible disease”. Some participants felt that telling was self-evident for them because they “do not want to fool someone else”, and others described a smooth, relaxed or unstressed sharing. In some cases, these balancing thoughts were about whether to tell or not, while in other cases it was more about *when* and *how* they should share their HIV status. In relation to dating, Ines, a middle-aged migrant, said she would rather tell earlier and take the risk of being rejected sooner rather than later: *“It’s just as good, it [telling] feels hard but it is good before it goes too far”*. Others mentioned

that they needed to get to know the other person first and feel safe enough with them before telling. Such balancing was also about giving the other person an opportunity to get to know them before finding out about their HIV diagnosis.

Both telling and not telling were described as having consequences for one’s relationships with sexual/romantic partners. Not only did not telling have direct consequences in terms of not allowing the other to know, but it could also be about “*constantly guarding your tongue*” as Lena, an older adult native Swede, expressed it, for fear of unintentionally sharing your status. For Elisabet, another older adult native Swede, it was “*like lying a little bit if you are going to tell others why you go and have blood tests or to see the doctor*”. Several participants gave accounts of how their partners took a break when they found out about their HIV status as they needed time to think and gain more knowledge about HIV. Ines, a middle-aged migrant, said: *“When I felt it was getting serious, that yes, this relationship was getting serious, then I told him. So, he took his time to think and learn about the disease.”*

Carol, a middle-aged migrant, shared a similar experience:

*“Because when I told him, it took a few days... I knew he was somewhere thinking, but then he told me he got in touch with a friend who was a doctor and asked questions and read some things on the Internet and stuff like that, did some searching, that’s what he did.”*

Although it was not made obvious that the relationship would continue after telling, it did for both Ines and Carol, two middle-aged migrants, and knowledge about HIV was described as being crucial.

Telling and not telling also had specific consequences in relation to reproductive health. Sarah, who shared her HIV status with close friends, described how they started questioning her right to have children (see subtheme: (Mis)perceptions of contagiousness and deadliness limiting sexual and reproductive life). On the other hand, one participant with a migrant background also described how motherhood in her culture is closely linked to breastfeeding, and not doing it could make people suspicious. She declared: *“They will ask questions, and maybe they will come and visit you, and you are not breastfeeding. They are going to ask questions, so one should just find ways to answer”* (Carol, middle-aged migrant).

### A paradoxical shift of responsibilities

Participants felt that they were compelled to take on greater responsibilities in terms of protecting others from acquiring HIV. In addition, they had to obtain information about HIV and related legislation and be aware of their rights. At the same time, some felt they were being paradoxically stripped of their right to decide how to give birth and whether to breastfeed or not. Thus, the shift in responsibilities was described in both directions.

#### *Greater responsibilities, but limited power*

Participants perceived that their sex life was restricted by the legal obligation to share their HIV status and other rules of conduct, which according to them were vague. According to some participants, it not only placed all responsibility on them to be knowledgeable and protect others, but it also made them feel like criminals. Ines, a middle-aged migrant, described her experience of it: *“But for me personally, I take it a little hard. It feels like you’re a criminal just because you are affected by a disease”*. Another participant, Sarah, a young adult migrant, stated: *“If you sleep with someone and you don’t tell them [that you’re living with HIV], you could end up in jail”*. It was mainly participants with a migrant background who expressed these feelings. One participant even mentioned being fearful of deportation. Regardless of their country of origin, participants felt that the rules of conduct and information about the Communicable Diseases Act were unclear.

The legal obligation to share their HIV status had consequences for whether, where and how the participants dared to date or find sex partners. Having this obligation lifted was described as a relief and made one feel healthy, non-infectious and in control over when and with whom they could share their HIV status. It was also perceived as facilitating dating and casual sex. However, only some of the participants stated that they had had their obligation to share their HIV status lifted, while others mentioned that this issue had never been raised in their encounters with healthcare providers, as voiced by Karin, an older adult native Swede:

*“Yes, I know [that you can have your obligation to disclose lifted]. No, I haven’t talked to my doctor about it, but I guess it has to do with me being married and stuff like that.”*

Hence, the possibility of having the obligation to tell lifted was perceived as being dependent on one’s marital status, but participants also stressed that it could also depend on the goodwill of their doctor. Elisabet, an older adult native Swede, had her obligation to tell lifted as soon as she changed to a new doctor. Other participants, especially those who had recently moved to Sweden and thus had limited proficiency in Swedish, stated that they were not even aware of the possibility of having it lifted, as pointed out by Dorcas, a middle-aged migrant: *“I have not received new information”*. Some participants felt it was up to them to act and raise the issue in their encounters with healthcare staff. This can be understood as a responsibility that is placed on people living with HIV who are assumed to be knowledgeable about their rights and able to “self-request” to have the obligation to tell lifted. What having the obligation to tell lifted actually meant was also not fully understood by some participants. Elisabet, an older adult native Swede, explained that while she had had her duty to tell lifted by the doctor, the HIV nurse (at the infectious diseases clinic) insisted on urging her to be honest:

*“She started talking about, ‘Yes, it is about honesty’, and that you shouldn’t just have a one-night stand and so on. I don’t have one-night stands or a date or anything. I thought it felt quite contradictory, that the doctor removed the obligation to inform when the nurse insisted on being honest. Yes, I found that pretty harsh.”*

This can be interpreted as the nurse trying to put forward a moral opinion despite changes in the legal framework and it be considered a form of structural violence.

Some participants also gave accounts of seeking and reading medical facts about HIV in order to be well-informed and up-to-date. Examples included keeping an eye on the risk of cell changes and gynaecological cancers and whether women LWH need to go for Pap smear tests more often, as expressed by Ingrid, an older adult native Swede: *“From what I have understood, there is a risk that you can get vaginal cancer, I think”*. For Carol, a middle-aged migrant, it was also about being well-informed about the Swedish Communicable Disease Act: *“When I arrived ... I googled a bit and read a bit about the law and stuff like that. /.../ I read a lot online about the latest research too”*.

Like Carol, a middle-aged migrant, participants who moved to Sweden from other countries mentioned that they felt a need to acquire knowledge about the Swedish legislation on HIV and stressed that they did not always receive that kind of information (e.g. rules of conduct) from healthcare providers. Meanwhile, other participants were uninterested in acquiring more knowledge on HIV. Ines, a middle-aged migrant, said: *“However, I have not read so much about HIV because, because I feel like: ‘why should I sit and read about it all the time?’”*

Thus, there are very different needs and experiences, but also different possibilities in terms of acquiring knowledge about HIV, which can result in inequalities in abilities to claim rights within health care.

#### *Being stripped of the right to decide*

While participants experienced increased responsibility in several situations, some also felt that in other situations they could not influence decisions – for example, concerning the mode of delivery (vaginal or caesarean section) and infant feeding (breastfeeding or not). Participants felt that in this respect it was the care provider that often decided. For some participants, this felt reasonable, and they made it clear that they trusted providers’ guidelines and decisions, which they believed were often motivated based on the “best interests of the child”. Dorcas, a middle-aged migrant, expressed it this way:

*“No, you have to be very realistic. I didn’t want to transmit the virus to the children. But I understood that breastfeeding was important for their health, for the immune system, for everything. They have explained it to me. But on the other hand, I don’t want to expose my children to the source of infection. And that is why I refrained from feeding them from my breasts; I relied on formula feeding.”*

In contrast, other participants had mixed feelings. They found that not being allowed to make their own choice about infant feeding or how to deliver was paradoxical and difficult to understand in relation to other messages they were receiving from healthcare providers, such as their virus load being undetectable, and not being able to transmit it further (U = U). They also mentioned that it could be more difficult to keep track of changes in guidelines and practices that occurred over time. Carol, a middle-aged migrant,

described how guidelines and practices changed between her two pregnancies:

*“Back then [with the first child] the rules were that everyone had to deliver through C-section. And then with the boy, they had changed the rules, you could give birth vaginally. But I wasn’t allowed to breastfeed.”*

Not being allowed to breastfeed or deliver vaginally was described by some participants as affecting their experience of womanhood or motherhood, as Cynthia, a young adult migrant, described:

*“I had to deliver through C-section, and I didn’t breastfeed. So that’s another part that’s quite tough, because you don’t feel like a normal woman walking around the streets and having a child. I have never felt labour pain and I have never felt what it is like to breastfeed a child.”*

Thus, some participants perceived it as being deprived of experiences associated with womanhood and motherhood, while others had a more straightforward relationship with these decisions.

## **Discussion**

The findings showed that despite the progress in HIV treatment and evidence supporting U = U messaging on sexual transmission, HIV-related stigma, discrimination, policies and guidelines continue to have an impact on the experiences of SRHR of women LWH. “Discrimination is harder to live with than the disease itself” is identified as a central theme that described participants’ experiences of social relationships, intimate encounters and reproductive life. Participants described how they reconsidered or reoriented their sexual and reproductive lives after their diagnosis due to their own and others’ outdated beliefs and (mis)perceptions that in some cases led to abusive treatment and internalisation. They also mentioned a paradoxical shift of responsibilities as they felt they were compelled to take greater responsibilities in some situations and were stripped of the right to decide in others. However, all participants believed that HIV has become less deadly and a natural part of their life, thanks to the availability and accessibility of effective ARV treatment. At the same time, nowadays living with HIV as a woman in Sweden can mean different things to different people depending on their life circumstances.



### Different experiences of SRHR and coping strategies

Our results confirm previous studies that also suggest that HIV-related stigma and discrimination stemming from misconceptions and outdated beliefs negatively affect the sexual and reproductive lives of women LWH to varying degrees.<sup>6,14,16</sup> To some extent, the various experiences of women LWH in Sweden can be understood in relation to time since diagnosis, whether they are migrants or not, or their relationships and marital status. Yet, there are individual variations that cannot be directly attributed to such demographic factors. For instance, the sexual desire of women LWH has been reported to change over time, as they tend to report decreased sexual desire in the early stage of antiretroviral treatment compared to later, when their health has improved.<sup>14,22</sup> Other studies suggest that HIV and its treatment affect women's sexuality and sexual health,<sup>23–25</sup> leading to poor sexual health outcomes, feelings of loss of womanhood, abstinence and altered body image.<sup>6,15,22,24–26</sup> The fear of transmitting the virus to partners and the perception of being “non-sexual” subjects, have been identified as the underlying causes of these poor outcomes and feelings.<sup>27</sup> Overall, this and other studies seem to suggest that both time since diagnosis and age play a role in the experiences of women LWH in relation to SRHR.

Previous studies also found that the perception of being contagious limited the opportunities of women LWH to freely choose their partners and how they would practise sex and consider childbearing.<sup>9,11</sup> Consequently, and in line with our results, some women LWH used different coping strategies, including suggesting condoms and thus having sex without sharing their HIV-positive status, or carefully planning sexual activities to find the right time to inform sexual partners about having HIV or hiding their status.<sup>3</sup> Not sharing your HIV status without being exempt from the obligation to tell by the attending doctor is still unlawful in Sweden despite the U = U message.<sup>4,18</sup> Yet, our and previous results suggest that women with HIV can experience sexual violence from their partners after sharing their HIV status and might not negotiate safe sex because of the fear of rejection or internalised/self-stigma and a sense of disadvantage in relationships.<sup>14,28</sup> Meanwhile

their rights to have children have been questioned in some cases.

### HIV-related regulations and guidelines affecting women's experiences of SRHR

Based on the results, the sexual and reproductive rights of women LWH also seem to be restricted by HIV-related legislations, regulations and guidelines that compel them to share their HIV status with potential partners and place great responsibility on them to protect others in the case of sexual contact. Such legislations have the potential to reinforce HIV-related stigma and discrimination. Other studies have also suggested that the sexuality and sexual health of women LWH are negatively affected by the obligation to share their HIV status as well as various legislations that criminalise the withholding of HIV status, exposure and transmission.<sup>14,22,24</sup> The authors of the above-mentioned studies argue that such laws could actually be counterproductive to public health and human rights and thus harm women LWH instead of helping them.<sup>22,24</sup> In fact, these laws can increase the fear of telling and prosecution and the risk of violence against women as they are often the first to receive an HIV diagnosis in relationships because of antenatal HIV testing policies and practices. Moreover, international human rights bodies and experts argue that HIV criminalisation not only impedes HIV treatment and prevention but also violates human rights, including the rights to health, privacy, equality and non-discrimination.<sup>29</sup> According to the United Nations Committee on Economic, Social and Cultural Rights, HIV criminalisation impedes the exercise of the right to sexual and reproductive health.<sup>29</sup> This is partly in line with our results, which show that being exempt from the obligation to share HIV status was experienced as being free from the virus/non-contagious, and (re)gaining the power/being in control to decide whom and when to tell.

Moreover, findings from a recent study in Nordic countries suggest that while women LWH may experience a sense of normality in pregnancy, the latter does come with unique considerations and concerns, which strongly influence their experiences of pregnancy.<sup>30</sup> The concerns that have been raised in this study include not being allowed to decide about delivery mode and breastfeeding. The change of guidelines over time has, however, somewhat improved the



situation for those who are aware of the changes. For instance, contrary to previous guidelines, pregnant women LWH in Sweden who are on effective ARV treatment may deliver vaginally in the absence of obstetric reasons for a caesarean section (CS). However, misunderstandings can still occur if the woman is not informed about the reason why a CS is being performed as she could relate it to her HIV status. In addition, while there is a growing movement for shared decision-making and support for women LWH who wish to breastfeed in some high-income countries,<sup>8,9</sup> in Sweden, they are not allowed to breastfeed regardless of their treatment status, to protect the child from the risk of transmission.<sup>4</sup> Weinberg and Nachman<sup>31</sup> also argue in their recent editorial commentary that it is not at all established that the U = U concept for preventing HIV by sexual transmission applies to breastfeeding. They challenge Yusuf et al.'s<sup>32</sup> conclusions that there is a “need to bridge the gaps between current local and global guidelines” in increasing breastfeeding by women LWH in high-income countries. They suggest continuing to contraindicate breastfeeding in the absence of evidence.<sup>31</sup> Other scholars argue that while infant-feeding guidelines opposing breastfeeding are crucial for preventing vertical transmission, they can also be a source of concerns and challenges for women LWH in the context of “breast is best” and the era of U = U.<sup>10,11,33</sup> Some women LWH may choose to breastfeed despite these guidelines for individual, social and cultural reasons or for fear of unintentional sharing of their HIV status, which could lead to stigma.<sup>33</sup> Previous research recommends considering the diversity of women LWH and provides evidence about the risks and benefits of breastfeeding to support clinical guidance and enable an informed decision.<sup>11, 33</sup>

#### **Staff attitudes and unequal access to information can lead to inequalities in the ability to fulfil SRHR**

Our results further suggest that staff attitudes (self-righteousness) may contrast with existing guidelines and regulations and lead to restrictions being maintained. Even more worrisome is the fact that not all participants, particularly migrant women LWH, are aware of or understand these legislations, guidelines and practices, which they describe as vague or unclear. For example, it is not clear to all participants what it means and what is required to have the obligation to inform

lifted and who should take the initiative. It has been reported in a recent review that some healthcare providers withhold information about U = U, particularly for patients from marginalised populations. A lack of provider knowledge, disbelief in U = U, a fear of accountability, and negative and discriminatory attitudes have been identified as underlying factors.<sup>34</sup> While all women LWH need information to facilitate their informed decision-making, migrant women may face complex barriers in accessing updated, comprehensive and linguistically and culturally tailored information about the U = U message.<sup>34,35</sup> These gaps in knowledge can lead to limited power and inequalities in the ability to access services and fulfil the right to achieve and maintain good sexual and reproductive health.

#### **Trustworthiness**

To ensure trustworthiness, we have provided a thick description of the topic and the Swedish context, and details about the methods used, to allow the study to be repeated, comparisons to be made and transferability to be assessed. To decrease the risk of bias and the influence of personal beliefs, we used open-ended questions, and FKNK and IL coded each other's interviews.

Diversity in the research group, including both people with a migrant background and Swedes, facilitated an understanding of the participants' different living conditions. Among the researchers there is also extensive previous experience of HIV research, health system research and the inclusion of marginalised groups, which contributed to both the study design and the analysis process.

The participants included women with different socio-demographic backgrounds, places of residence and time since diagnosis, which resulted in a wide range of experiences. However, these experiences may not represent the experiences of all women LWH. Moreover, the use of telephone interviews, which made it possible to conduct interviews with women from different geographical areas and facilitated the participation of those who asked to remain anonymous, made it difficult to read body language/non-verbal communication cues. Telephone interviews created a safe space for participants to freely share their experiences as they had the opportunity to stay in settings that were comfortable to them. The participants could easily share sensitive information.

Finally, the use of interpreters further facilitated the inclusion of participants who did not

speak any of the languages in which the researchers were fluent. However, there is a risk of incorrect translation or loss of information when using an interpreter. It was therefore important to place emphasis on the conversation following a common thread and reflecting a coherent story. It was also sometimes difficult to ensure that the information given about consent was understood. In such a case, the participant was once again given information about the study and the right to withdraw their participation at the end of the interview.

## Conclusion

This study suggests that despite the progress made in HIV treatment, stigma and discrimination stemming from outdated beliefs and persistent (mis)conceptions, ambiguous policies and guidelines and unequal access to information affect the perceptions and experiences of SRHR of women LWH more than the virus itself. There is a need to update knowledge and address outdated beliefs and misconceptions about HIV within healthcare settings and among the general public and clarify ambiguous legislations and guidelines. There is also a need to ensure equal access to information to enable all women LWH to take informed decisions and make fully informed choices and realise their SRHR. The findings also emphasise the need for shared decision-making and for taking the diversity of women LWH into consideration. More research is needed to explore how migrant status intersects with HIV status and other social categories to shape these experiences.

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## Authors' contributions

FKNK, AKH and IL conceptualised the study. FKNK and IL carried data collection and conducted analyses. FKNK and IL drafted the manuscript. All authors critically revised the manuscript for important intellectual content and approved the final version submitted.

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## Data availability

*Due to ethical concerns, supporting data cannot be made openly available. They are available on reasonable request from the corresponding author [FKNK].*

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## Résumé

En Suède, les femmes représentent près de 40% des personnes vivant avec le virus de l'immunodéficience humaine (VIH). Pourtant, on sait peu de choses sur leurs expériences, en particulier celles qui se rapportent à la santé et aux droits sexuels et reproductifs. Cette étude souhaite explorer les perceptions et les expériences de la santé et des droits sexuels et reproductifs chez les femmes vivant avec le VIH. Douze entretiens ont été menés avec des femmes séropositives entre septembre et octobre de 2019, et ont fait l'objet d'une analyse thématique. « La discrimination est plus difficile à vivre que la maladie elle-même » est le thème central qui décrit les expériences des participantes en matière de relations sociales, de rencontres intimes et de vie reproductive. L'analyse est fondée sur trois thèmes qui contiennent des sous-thèmes. Le thème 1 décrit comment les participantes revoient et réorientent leur vie sexuelle et reproductive après le diagnostic. Le thème 2 met en lumière comment les idées (erronées) sur le VIH influent sur la vie sexuelle et reproductive et conduisent à des traitements abusifs et à l'intériorisation. Le thème 3 décrit un déplacement paradoxal des responsabilités où les participantes sont contraintes d'assumer une plus grande responsabilité dans certaines situations et sont privées du droit de décider dans d'autres. Cette étude suggère qu'en dépit des progrès notables accomplis dans le traitement du VIH, la stigmatisation et la discrimination découlant de croyances obsolètes et d'idées erronées, de politiques et de directives ambiguës, et d'un accès inégal à l'information influent davantage sur les expériences des femmes vivant avec le VIH en matière de santé et droits sexuels et reproductifs que le virus lui-même. Les résultats mettent en évidence la nécessité: de mettre à jour les connaissances dans les établissements des soins de santé et parmi le grand public; de clarifier les législations et les directives ambiguës; de

## Resumen

Aproximadamente el 40% de las personas que viven con el virus de inmunodeficiencia humana (VIH) en Suecia son mujeres. Sin embargo, no se sabe mucho sobre sus experiencias, en particular aquellas relacionadas con la salud y los derechos sexuales y reproductivos (SDSR). Este estudio pretende explorar las percepciones y experiencias de SDSR entre mujeres que viven con VIH (MVVIH). Se realizaron 12 entrevistas con MVVIH de septiembre a octubre de 2019, las cuales se analizaron con análisis temático. "Es más difícil vivir con discriminación que con la enfermedad" es el tema central que describe las experiencias de las participantes con relaciones sociales, encuentros íntimos y su vida reproductiva. Se basa en tres temas que contienen subtemas. El tema 1 describe cómo las participantes reconsideran y reorientan su vida sexual y reproductiva después del diagnóstico. El tema 2 destaca cómo las percepciones (erróneas) del VIH afectan la vida sexual y reproductiva y propician un trato abusivo e internalización. El tema 3 describe un cambio paradójico de responsabilidades mediante el cual las participantes se sienten obligadas a asumir mayor responsabilidad en algunas situaciones y despojadas de su derecho a decidir en otras. Este estudio indica que, a pesar de notables avances en el tratamiento del VIH, el estigma y la discriminación derivados de creencias y conceptos (erróneos) obsoletos, políticas y directrices ambiguas, y acceso no equitativo a la información afectan las experiencias de SDSR de las MVVIH más que el virus. Los Resultados Ponen de Relieve la Necesidad de: Actualizar los Conocimientos en los Establecimientos de Salud y en el Público; aclarar legislaciones y directrices ambiguas; garantizar acceso equitativo a la información para que todas las MVVIH puedan tomar decisiones informadas, hacer elecciones completamente informadas y realizar

garantir l'accès sur un pied d'égalité à l'information afin de permettre à toutes les femmes vivant avec le VIH de prendre des décisions éclairées, de faire des choix pleinement informés et de réaliser leurs droits à la santé sexuelles et reproductive; de tenir compte de la diversité des femmes vivant avec le VIH et de permettre une prise de décision partagée.

su SDSR; y considerar la diversidad de MVVIH y permitir la toma de decisiones compartida.