



# Prevalence and correlates of sexual concerns and associated distress among women living with HIV in Canada

Women's Health  
Volume 18: 1–19  
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DOI: 10.1177/17455065221074877  
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## Abstract

**Objectives:** We assessed the prevalence and correlates of sexual concerns and associated distress among women living with HIV in Canada.

**Methods:** We analyzed cross-sectional survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (2017–2018). Self-identified women living with HIV were asked about sexual concerns post-HIV diagnosis and associated distress (none, mild, moderate, severe). Five areas of concern were assessed, including difficulties related to sexual self-esteem, sexual function, relationships, and emotional and behavioral aspects of sex. Logistic regression analyses identified correlates of reporting any sexual concerns and severe distress about these concerns.

**Results:** Of 906 participants (median age 48, Q1–Q3=41–55), 596 (65.8%) reported sexual concerns post-HIV diagnosis. We found a high prevalence of concerns related to relationships (43.3%), sexual self-esteem (49.4%), and emotional aspects of sex (45.4%), relative to sexual functioning (38.4%) and behavioral aspects (33.7%). Of those with sexual concerns, 36.7% reported severe distress. Reports of severe distress were the highest for relationship difficulties (32.5%), relative to other areas of concern (21.4%–22.8%). In adjusted analyses, women reporting sexual dissatisfaction and high HIV-related stigma had significantly higher odds of reporting sexual concerns. Conversely, those reporting higher resilience, better mental health, African, Caribbean, and Black identity, and sex as somewhat unimportant, not

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at all important, or neutral to their lives had lower adjusted odds. Factors associated with severe distress about sexual concerns included older age, body dissatisfaction, sexual dissatisfaction, and high HIV-related stigma, while better mental health and getting support from someone living with HIV were protective. While 84.4% of women had discussed with a provider how viral load impacts transmission risk, only 40.6% had conversations about sexual wellbeing.

**Conclusion:** More attention to women's sexual wellbeing within social and relational contexts is critical to ensure the sexual rights of women living with HIV are upheld.

## Keywords

HIV, mental health, sexual wellbeing, social determinants, women

Date received: 30 September 2021; revised: 19 December 2021; accepted: 4 January 2022

## Introduction

Women's sexual health in the context of HIV has been pathologized, moralized, medicalized, and stigmatized.<sup>1</sup> Globally, more than 19 million women and girls are living with HIV,<sup>2</sup> including more than 14,500 women in Canada.<sup>3</sup> Women's bodies have been primarily viewed as vectors of disease,<sup>4</sup> constituting a "public health risk" to those they might infect. Consequently, most research has focused on HIV prevention and treatment to maximize reductions in HIV acquisition and transmission. Far less research has focused on supporting women's sexual health and wellbeing, improving understanding of barriers to sexual health, and exploring opportunities for positive physical, emotional, mental, and social outcomes in relation to sexuality and reproduction.<sup>5</sup> Consequently, discourse on sexual wellbeing, satisfaction, and pleasure has been missing.<sup>6,7</sup> Even with combination antiretroviral treatment shifting HIV from being considered a lethal disease to a chronic, sexually non-transmissible one among many persons,<sup>8</sup> socio-cultural norms of silence and stigma surrounding sexuality means many women living with HIV continue to be denied access to basic human rights.<sup>9,10</sup> This includes the right to have and enjoy safe and pleasurable sexual experiences of their choosing and to have adequate access to information and services about matters pertaining to their sexuality, free from discrimination, coercion, exploitation, and violence.<sup>7,11</sup>

Sexual health and wellbeing has been defined in different ways.<sup>12–15</sup> The World Health Organization has defined sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality . . . not merely the absence of disease, dysfunction or infirmity."<sup>16</sup> Critically, sexual pleasure and sexual rights are deemed essential elements of sexual health and wellbeing, including freedom from coercion, discrimination, and violence.<sup>9</sup> The social, relational, and psychological impact that HIV can have on a woman's sexual health and wellbeing is significant, including their sexual self-esteem, which can be defined as how one views their sense of self as a sexual being.<sup>5</sup> Numerous studies have documented the diverse range of sexual and intimate difficulties some women face

following diagnosis, such as fear of passing the virus onto others, difficulties negotiating safer sex, fear of HIV disclosure and its consequences (including partner violence, judgment, rejection, and abandonment), anxiety about changes in body weight and shape, diminished sexual activity and interest, and feelings of "loss," usually relating to identity, intimacy, and perceived sexual freedom.<sup>4,17–21</sup> A recent review of this topic posits that many of these issues and challenges are due to socio-cultural, political, and economic factors (e.g. stigma and criminalization of HIV non-disclosure), partner and relationship factors (e.g. inequitable gendered power relations), mental health and violence factors (e.g. depression and trauma), and, to a lesser extent, medical factors (e.g. side effects of treatment).<sup>1</sup>

At the same time, and yet for many years, women have been pushing back against HIV stigma and overcoming obstacles to sexual wellbeing. Research in Canada has shown that many women living with HIV in Canada view sex as an important aspect of their lives<sup>22</sup> and are sexually satisfied,<sup>23</sup> whether sexually active or not. Love and sexual pleasure are crucial in women's lives,<sup>24,25</sup> including older women living with HIV,<sup>26</sup> with studies having shown strong ties to physical and mental health, self-esteem, and quality of life,<sup>27</sup> which applies to many women without HIV. Studies have also suggested that many of the obstacles women face in relation to HIV can be overcome with multi-level stigma interventions with families and communities,<sup>28</sup> structural initiatives that can foster resilience,<sup>29</sup> and positive social and cultural relationships.<sup>5</sup> Women are also developing a pleasure-focused narrative, in public and digital spaces, that reaffirms their sexual desires and rights.<sup>30–32</sup> However, studies about women's sexual health concerns and desires for information about sexuality are rare. Moreover, no identified studies have examined whether women communicate with health professionals and others, such as peers, about intimate and sexual changes following an HIV diagnosis, beyond discussing HIV treatment and prevention.

Health professionals have a vital role to play in supporting the sexual and reproductive health and rights of women living with HIV.<sup>33</sup> Appropriate counseling and effective

communication about sexuality and intimacy after a life-changing diagnosis, such as cancer, have been shown to be consistently desired by patients, as these discussions effectively address quality-of-life concerns, cultivate feelings of acceptance, and retain a sense of normality.<sup>5,34</sup> Peers and Internet communication are also highly valued as important sources of emotional support, normalization, and reassurance among women living with HIV.<sup>35</sup> However, resources about sexual wellbeing after an HIV diagnosis are limited, and frank and open discussions of sexual health issues with women living with HIV are often neglected in clinical care.<sup>36</sup> When discussions are documented, studies suggest that healthcare providers tend to ask about sexual activity and sexual behavior in ways that almost entirely focused around risk<sup>37</sup>—both to the woman and her partners (e.g. Are you sexually active? One partner or multiple? Consensual or not? Do you use condoms? Recent symptoms of STI?). Conversations about social and relational issues concerning HIV and its impact on women's sexual functioning and psychological wellbeing are much rarer.<sup>1</sup>

To address women's unmet needs and inform sexual health promotion as an essential part of caring for women living with HIV, we sought to answer the following research questions in a Canadian cohort: (1) What are the prevalence and types of sexual concerns among women living with HIV?; (2) What level of distress, if any, have these concerns caused?; (3) How do social, relational, structural, and health factors shape patterns of concern and distress?; and (4) What is the frequency of discussions regarding the impact of living with HIV on sexual wellbeing and which sources of information are most effective in helping women cope with their experiences? Based on the existing literature,<sup>1</sup> we hypothesized that a substantial proportion of women living with HIV would report experiencing sexual concerns following their HIV diagnosis and that distress levels would be equally high for emotional concerns as for behavioral concerns. In addition, age, depressive symptoms, violence, and a higher degree of HIV-related stigma were postulated to be associated with higher odds of reporting sexual concerns and severe sexual distress.<sup>1</sup> Finally, we hypothesized that many women would have never talked to anyone about the impact of living with HIV on their sexual wellbeing and, of those who have had such conversations, HIV physicians and peers would be the most common and most helpful sources.

## Materials and methods

### Study design

We used questionnaire data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS, [www.chiwos.ca](http://www.chiwos.ca)) for this analysis. CHIWOS is Canada's largest community-based research study of women living with HIV and is focused on investigating

factors affecting overall mental, sexual, and reproductive health.<sup>38,39</sup> A central component of our approach to research is the meaningful involvement of women living with HIV.<sup>40</sup> We operationalized this by hiring, training, and supporting 40 women living with HIV as Peer Research Associates (PRAs),<sup>41</sup> who shared social identities and living experiences with the study population of women living with HIV across Canada who have historically been under-represented in research. PRAs were hired to contribute to all stages of the research process, including study design, participant recruitment, data collection, interpretation of results, co-presenting results, and manuscript co-authorship. Participation on the research team was supported through a comprehensive training curriculum enabling PRAs to receive training in both questionnaire design and good interviewing practices to maximize data quality, while also receiving guidance in community-based research principles, knowledge translation, and ethical issues.<sup>41</sup> The baseline questionnaire (Wave 1) was fielded between 2013 and 2015, with two follow-up visits occurring 18 months (Wave 2, 2016–2017) and 36 months (Wave 3, 2017–2018) later. Only Wave 3 data are reported on here.

### Study methods

Women living with HIV were first recruited into CHIWOS through a range of strategies aimed at addressing the gendered and social barriers women face to participation in HIV research.<sup>42</sup> This included word-of-mouth through PRA networks, referrals through HIV clinics, sharing via social media platforms and community advisory board members, and advertisements at both AIDS service organizations and non-HIV-specific community settings, such as women's shelters.<sup>42</sup> Through this form of purposeful sampling, we were able to enroll women from important but understudied and underserved communities who are often assumed to be "hard to reach" and thus excluded or left out of research. Women were eligible if they were: (1) aged  $\geq 16$  years; (2) self-identified as a woman living with HIV (inclusive of cisgender, transgender, and gender diverse women); and (3) resided in one of the three study provinces: British Columbia, Ontario, and Quebec.<sup>38</sup> All women were screened for eligibility by a trained PRA or a provincial coordinator and were provided with information about the kinds of questions to be asked as well as support mechanisms in place, in order to make an informed decision about whether or not to participate.<sup>38</sup>

A total of 1422 participants were enrolled into CHIWOS. After consenting, participants completed a computer-based questionnaire administered by PRAs at each wave. Interviews were conducted in English or French (and when necessary, with a translator), either face-to-face (in women's homes, clinics, or community organizations) or by phone or secure audio-visual teleconferencing software (e.g. Skype). The interviews covered a range of

topics including: socio-demographics, medical and HIV history information, health care and support service utilization, reproductive health, sexual health, emotion wellbeing, substance use, violence and abuse, stigma and discrimination, and resiliency.<sup>38</sup> All sections, including those involving sensitive topics such as violence and abuse, were administered by PRAs to ensure data quality and provide participants with both practical and emotional support. Participants had the option to select “don’t know” or “prefer not to answer” for every question. This study analyzed data from women who participated in Wave 3 ( $n=937$ ). Several methods were used to minimize risks of loss-to-follow-up at Wave 3, including collecting comprehensive contact information from participants, utilizing online social media platforms to communicate study updates, and close partnerships with community-based organizations. Total study retention over 36 months was 66%. The Wave 3 questionnaire had a median completion time of 1.58 h (interquartile range (IQR) Q1–Q3: 80–120 min).

### Ethics

Ethical approval was gained from Research Ethics Boards at Simon Fraser University, University of British Columbia/ Providence Health, Women’s College Hospital, McGill University Health Centre, and independent ethics board of participating clinics (Research Ethics Board Number H12-03326). Participants provided voluntary informed consent and received an honorarium of \$50 CAD at each study visit. PRAs received \$75 CAD.

### Study variables

**Primary outcomes.** The primary outcome variables were sexual concerns after diagnosis with HIV and sexual distress. Women were asked: “*Since knowing your HIV status, have you ever experienced any concerns about your sexual wellbeing?*” Response options covered five areas of concern: (1) sexual self-esteem (e.g. feeling sexually unattractive, poor body image, shame, and guilt), (2) emotional aspects of sex (e.g. sexual dissatisfaction, sexual anxiety, or inhibition), (3) behavioral aspects of sex (e.g. sexual behaviors and practices), (4) sexual function (e.g. low desire, orgasm difficulties, and pain during sex), and (5) relationships (e.g. abusive partners and difficulties finding a partner). Participants could also report “*Other*” (open-text field) or “*I have not experienced any concerns.*” Women reporting any type of the abovementioned concerns were then asked: “*How much distress, if any, did this concern cause you?*” Response options included no distress or mild, moderate, or severe distress. In analyses (discussed below), ever having a sexual concern post-diagnosis and ever having severe distress about at least one sexual concern was the event of interest. Importantly, if a woman

was not sexually active at the time of interview, either with a partner or with herself, her data were still analyzed since the period of interest was any time after diagnosis.

**Secondary outcomes.** We also asked all women two questions about patient–provider sexual health communication, regardless of whether they reported sexual concerns. The first question was, “*Since your last CHIWOS interview, have you discussed with a healthcare provider the impact of your viral load on the risk of transmitting HIV?*” The second question was, “*Since knowing your HIV status, have you ever talked to anyone about the impact of living with HIV on your sexual wellbeing? This may include partners, friends, or healthcare providers. For the purposes of this question, this does NOT include discussions about safer sex strategies to minimize HIV transmission like condom use or having a low viral load.*” For those who responded affirmatively to the second question, we asked: “*Which of the following people did you talk to about these concerns?*” Response options were partner, peer/women living with HIV, other friends (not living with HIV), HIV physician, family doctor, nursing staff, counseling, social worker, peer worker, community worker, therapist who specialized in women’s sexuality, and therapist who specializes in trauma. We also asked, “*Of the people you talked to, how useful were they in helping you cope with your experience?*” Responses were very helpful, a little bit helpful, not at all helpful.

**Correlates.** Correlates were selected based on a priori literature review and classified into four categories, consistent with the classification scheme proposed in a recent critical review of HIV and women’s sexuality:<sup>43</sup> medical and physical health factors, mental health and violence factors, sex and relationship factors, and social and political factors. First, medical and physical health factors included taking antiretroviral therapy at Wave 3 interview (No and Yes), most recent viral load (undetectable below 50 copies/mL and detectable above 50 copies/mL), most recent CD4 ( $<200$ ,  $200–500$ ,  $>500$  cells/mm<sup>3</sup>, or don’t know), and physical health-related quality of life (measured via SF-12, score range 0–100).<sup>44</sup> Mental health and violence factors included any physical, sexual, verbal, or controlling violence as an adult ( $\geq 16$  years) (No and Yes), receive support from someone living with HIV (Yes and No), depression (measured via 10-item Centre for Epidemiological Studies Depression Scale (CES-D 10), score range 0–30, Cronbach’s  $\alpha=0.70$ , with a score of  $\geq 10$  suggesting probable depression),<sup>45</sup> resiliency (measured via the 14-item resiliency scale, score range, Cronbach’s  $\alpha=0.88$ ),<sup>46</sup> and mental health-related quality of life (measured via the 12-Item Short Form Survey (SF-12), score range 0–100). Sex and relationship factors included current legal relationship status (single, legally married/common-law/in a relationship, and separated/divorced/



widowed), consensual sex in the past 6 months (No and Yes), body satisfaction (5-point Likert-type, dichotomized), sexual satisfaction (5-point Likert-type, dichotomized), and the importance of sex in one's life (5-point Likert-type, trichotomized). Factors that we conceptualized as related to the social and political context of women's lives included the following: age at Wave 3 interview, race/ethnicity, sexual orientation, time living with HIV, HIV stigma (measured via the 10-item HIV Stigma Scale (HSS), score range 0–100, Cronbach's alpha=0.81),<sup>47,48</sup> sexism (Cronbach's alpha=0.94), and racism (Cronbach's alpha=0.96; both measured via the 6-item Everyday Discrimination Scale, score range 8–48).<sup>49</sup> The median scores for various scales represent the average for the sample (i.e. the point on the scale that divides the distribution of scores in half), with higher scores indicating better health, higher stigma, and more discrimination than the average for the sample.

### Final analytic sample

A total of 937 women living with HIV completed the Wave 3 questionnaire. Of this total, 906 participants had non-missing responses to the primary outcome variable, "ever had sexual concerns post-HIV diagnosis," and were included in baseline statistics. Those who reported "don't know" or "prefer not to answer" to the primary outcome variable ( $n=31$ ), as well as missing data on any of the correlates ( $n=198$ ), were excluded from the first logistic regression model pertaining to sexual concerns (final sample size=708). Of those with sexual concerns ( $n=596$ ), all responded to the question about sexual distress. After removing non-missing values for correlates, the final sample size for the second model on sexual distress was 499.

### Analysis plan

We described characteristics of the cohort, using frequencies ( $n$ ) and proportions (%) for categorical variables and medians and IQRs for continuous measures. We calculated the prevalence of sexual concerns and distress overall and by key characteristics. We then tested crude associations with all correlates via the Pearson chi-square test for categorical variables (Fisher's exact test for small cell counts) and the Wilcoxon Rank Sum test for continuous variables. Following this, two multivariable logistic regression models were run to identify factors independently associated with (1) increased odds of ever experiencing a sexual concern post-HIV diagnosis (vs never) and, among those reporting concerns, (2) increased odds of experiencing severe distress about a sexual concern (using no, mild, or moderate distress as the referent). We also ran a sensitivity analysis, combining moderate and severe distress into the same category. Both unadjusted and adjusted odds ratios (ORs and AORs, respectively) and 95% confidence

intervals (95% CIs) were reported. Bivariable results were used to summarize and examine variables. All candidate variables entered into the model were selected based on prior literature review. We then conducted a modified backward stepwise elimination, described and validated by Lima et al.,<sup>50</sup> removing most non-significant variables one by one until the final model had optimal fit (i.e. lowest Akaike's information criterion) while maintaining covariates with Type III  $p$ -values  $< 0.2$ . We performed sensitivity analyses of splitting data set into two portions, one (90% of data) to fit model using our modified backward selection technique and one (10% of data) to validate the fitted model. These analyses produced the same final model as the one presented in the article. When fit on the remaining 10% of data, the true outcome variable and fitted outcome variable were validated using McNemar's test ( $p$ -value=0.166 for severe distress model and  $p$ -value=0.157 for sexual concern model). These are consistent with and support our multivariate analyses in this article. All analyses were conducted using SAS version 9.4 (SAS, North Carolina, USA).

## Results

### Baseline characteristics

Table 1 shows the baseline characteristics of the study population. The 906 women in the analysis had diverse identities, backgrounds, and varying lived experiences, including racialized women (14.5% being Indigenous and 38.1% African, Caribbean, and Black) and sexually diverse women (88.2% heterosexual and 11.8% lesbian, bisexual, two-spirit, and queer). The majority of women (95.6%) were cisgender, while 2.9% identified as transgender, and 1.5% other genders. The median age was 48 years (Q1–Q3: 41–55) and the median amount of time lived with HIV at the Wave 3 interview date was 15 years (Q1–Q3: 10–21). Most of the participants reported experiencing violence as an adult (89.7%) and had incomes less than \$20,000 CAD (61.2%). A majority of participants (95.5%) were on antiretroviral therapy at the time of the Wave 3 interview date and had an undetectable viral load (93.1%). Table 1 also shows that at least half of the women (54.2%) felt sexual activity to be very or somewhat important to them, and 71.7% reported their present sex life to be completely, very, or reasonably satisfactory. Less than half of the women (40.6%) were single, with 33.1% either legally married, common-law, or in a relationship. Overall, median physical and mental health scores were 39 (Q1–Q3: 34–45) and 40 (Q1–Q3: 31–51), respectively, which is significantly lower than estimates for the general population of Canadian women (mental: 49.7 (standard deviation (SD)=9.4) and physical: 50.9 (SD=9.6)).<sup>51</sup> The median rating on the 10-item HSS was 53 (Q1–Q3: 40–65) and on the 14-item resilience scale was 91 (Q1–Q3: 84–96).

**Table 1.** Characteristics of women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (N=906).

Categorical variables	Total	
	n	n (%)
Social and political factors		
Gender	906	
Cis women		866 (95.6)
Trans women		26 (2.9)
Other		15 (1.5)
Race/ethnicity	902	
Indigenous		131 (14.5)
African, Caribbean, and Black Canadian		344 (38.1)
White		372 (41.2)
Other		55 (6.1)
Sexual orientation	904	
Heterosexual		797 (88.2)
Lesbian, bisexual, two-spirit, and queer		107 (11.8)
Personal income (\$CAD)	891	
<20,000		545 (61.2)
≥20,000		346 (38.8)
Current sex work	810	
Yes		31 (3.8)
No		779 (96.2)
Mental health and violence factors		
Any violence as an adult	853	
Yes		765 (89.7)
No		88 (10.3)
Feel isolated as a woman living with HIV in my community	904	
Strongly agree/agree		358 (39.6)
Neither agree nor disagree/disagree/strongly disagree		546 (60.4)
Get support from someone living with HIV	903	
Yes		545 (60.4)
No		358 (39.6)
Medical and physical health factors		
On antiretroviral therapy at Wave 3 interview date	904	
Yes (currently)		863 (95.5)
No (never/previously)		41 (4.5)
Most recent viral load	878	
Undetectable (below 50 copies/mL)		817 (93.1)
Detectable (above 50 copies/mL)		61 (6.9)
Most recent CD4	740	
<200 cells/mm <sup>3</sup>		32 (4.3)
200–500 cells/mm <sup>3</sup>		182 (24.6)
>500 cells/mm <sup>3</sup>		526 (71.1)
Sex and relationship factors		
Current legal relationship status	904	
Single		416 (40.6)
Legally married/common-law/in a relationship		300 (33.1)
Separated/divorced/widowed		188 (20.8)
Consensual sex in past 6 months	902	
Yes		434 (48.1)
No		468 (51.9)
Body satisfaction	895	
Very satisfied/somewhat satisfied		536 (59.9)

(Continued)

**Table 1.** (Continued)

Categorical variables	Total	
	<i>n</i>	<i>n</i> (%)
Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied		359 (40.1)
How important a part of your life is sexual activity	889	
Very/somewhat important		482 (54.2)
Neither important nor unimportant		131 (14.7)
Somewhat unimportant/not at all important		276 (31.0)
How satisfactory or unsatisfactory is your present sex life	848	
Completely satisfactory/very satisfactory/reasonably satisfactory		608 (71.7)
Not very satisfactory/not at all satisfactory		240 (28.3)
Continuous variables		Median (Q1–Q3)
Age at interview (years)	906	48 (41–55)
Sexism (Everyday Discrimination Scale)	899	16 (8–25)
Racism (Everyday Discrimination Scale)	901	12 (8–25)
Time living with HIV at interview (years)	877	15 (10–21)
HIV Stigma Scale (HSS)	893	53 (40–65)
Resilience Scale (14-item resiliency scale)	903	91 (84–96)
Depression Scale (CES-D 10)	894	9 (4–15)
Mental health-related quality of life (SF-12)	890	40 (31–51)
Physical health-related quality of life (SF-12)	890	39 (34–44)

*n* varies due to missing values (don't know or prefer not to answer). Only sexually active women were asked the Sexual Relationship Power Scale.

### Sexual concerns and associated distress

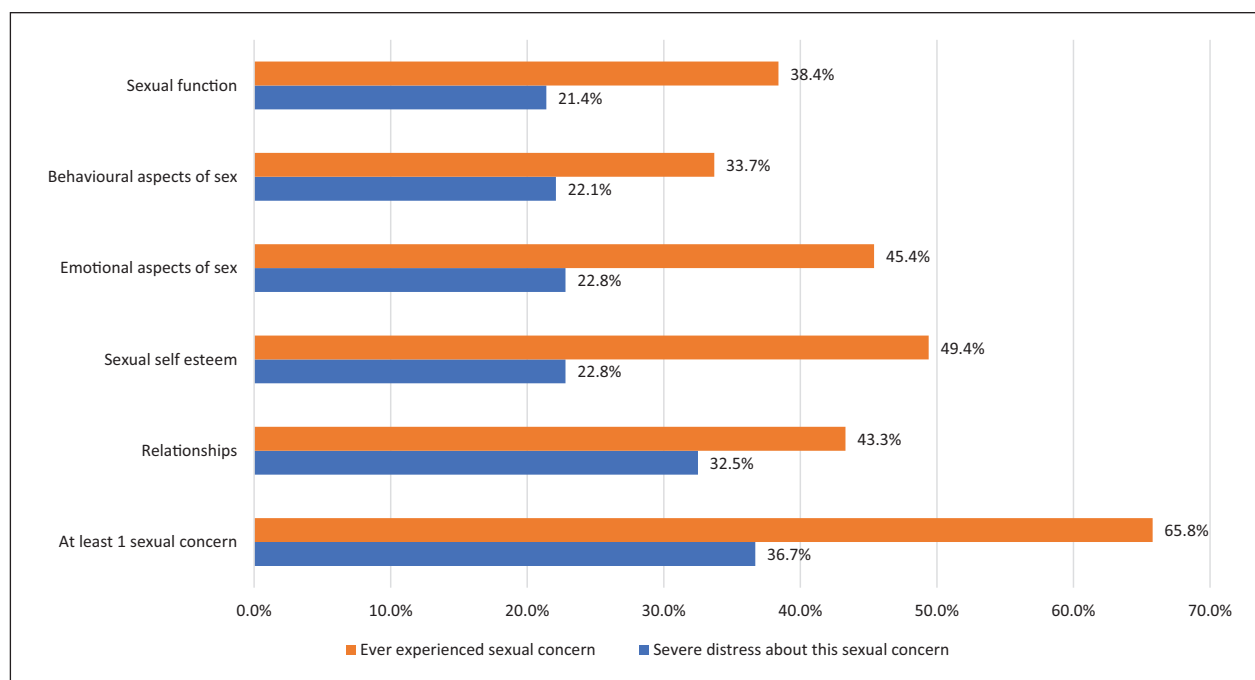
Figure 1 reports the prevalence of sexual concerns post-HIV diagnosis and associated distress, as well as sources of sexual health information. Of the 906 participants, 596 (65.8%) experiencing some form of sexual concern post-diagnosis. We found a high prevalence of concerns related to relationships (43.3%), sexual self-esteem (49.4%), and emotional aspects of sex (45.4%), relative to sexual functioning (38.4%) and behavioral aspects (33.7%). Of those experiencing sexual concerns, 36.7% reported severe distress for at least one sexual concern. Reports of severe distress were the highest for relationship difficulties (32.5%), but still prevalent for about one in five women across all areas of concern, including sexual self-esteem (22.8%), emotional (22.8%) and behavioral (22.1%) aspects of sex, and sexual function (21.4%).

### Bivariable associations with sexual concerns and severe distress

Table 2 shows bivariable associations between baseline characteristics and sexual concerns among women living with HIV. A range of factors were crudely associated ( $p < 0.05$ ) with reporting sexual concerns, including race/ethnicity (i.e. White), sexual orientation (i.e. lesbian, bisexual, two-spirit, and queer), any violence as an adult, not being on antiretroviral therapy, perceiving sex to be a very or somewhat important part of one's life, body

dissatisfaction, sexual dissatisfaction, higher sexism, higher HIV-related stigma, lower resilience, higher depression, poorer mental health-related quality of life, feeling isolated as a woman living with HIV, and lacking of support from someone living with HIV. For instance, women who reported experiencing sexual concerns had a lower (poorer) median score on the mental health-related quality of life SF-12 scale at 38 (Q1–Q3: 30–49) and those who did not report so had a higher (better) median score at 45 (Q1–Q3: 34–52). A significant, observable pattern was seen with the HSS, with higher (harsher stigma) scores recorded among women reporting sexual concerns (55, Q1–Q3: 43–68) versus those not reporting sexual concerns (48, Q1–Q3: 35–60). Women with sexual concerns were also more likely to report their present sex life to be not very or not at all satisfactory (34.3%), while a lower prevalence of those who did not experience sexual concerns reported their present sex life as such (15.9%,  $p < 0.001$ ).

Table 3 shows bivariable associations between baseline characteristics and severe distress about sexual concerns among women living with HIV. Similar to Table 2, significant correlates ( $p < 0.05$ ) were race/ethnicity, perceiving sex to be a very or somewhat important part of one's life, body dissatisfaction, sexual dissatisfaction, higher sexism, higher HIV-related stigma, lower resilience, higher depression, poorer mental health-related quality of life, feeling isolated as a woman living with HIV, and lacking support from someone living with HIV; whereas other factors were no longer significant (i.e. sexual orientation, any violence



**Figure 1.** Experiences of sexual concern and associated distress among women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

as an adult, and not being on antiretroviral therapy). For instance, women who reported severe distress were less likely to have received support from someone else living with HIV (50.2%), in comparison to those who did not report severe distress (62.4%,  $p=0.005$ ). Those who reported experiencing severe distress had also experienced more stigma, scoring a median score of 60 (Q1–Q3: 48–75) on the HSS, compared to a median score of 53 (Q1–Q3: 38–63) for those who did not report severe distress.

### Multivariable associations

Table 4 presents the multivariable logistic regression results of factors associated with sexual concerns and severe distress in women living with HIV. In adjusted analyses, those more likely to report sexual concerns were women who reported higher HIV-related stigma (AOR=1.18, 95% CI=1.07–1.29) and feeling not very/not at all satisfied with their present sex life (AOR=2.34, 95% CI=1.56–3.52), while the effect of violence weakened. Conversely, those less likely to report sexual concerns were African, Caribbean, and Black Canadian women (AOR=0.58, 95% CI=0.38–0.86; referent: White women), women who reported higher resilience scores (AOR=0.98, 95% CI=0.96–0.99) and better mental health-related quality of life (AOR=0.99, 95% CI=0.97–1.00), and women who reported sexual activity to be somewhat unimportant or not at all important to their lives (AOR=0.53, 95% CI=0.36–0.77), or neither important nor unimportant to their lives (AOR=0.60, 95%

CI=0.37–0.96). Correlates of severely distressing sexual concerns included age (AOR=1.29, 95% CI=1.06–1.56), body dissatisfaction (AOR=1.58, 95% CI=1.06–2.37), sexual dissatisfaction (AOR=1.53, 95% CI=1.01–2.30), and HIV-related stigma (AOR=1.27, 95% CI=1.14–1.43), whereas mental health-related quality of life (AOR=0.97, 95% CI=0.96–0.99) as well as getting support from someone living with HIV (AOR=0.55, 95% CI=0.37–0.82) were protective. In sensitivity analyses, combining the two outcome levels of moderate and severe distress appeared to weaken effects, with fewer correlates emerging as significant (namely, sexual dissatisfaction, HIV-related stigma, and mental health-related quality of life), suggesting that age and the benefit of peer support may depend on how much distress the sexual concern has caused.

### Discussions about sexual wellbeing

In the cohort overall ( $n=906$ ), 765 (84.4%) women had ever discussed with a provider how viral load impacts transmission risk and 812 (89.6%) were aware of the prevention benefits of treatment. Yet only 368 (40.6%) had talked to anyone about the impact of living with HIV on their sexual wellbeing beyond safer sex strategies like condom use and having a low viral load. Sources of support are shown in Figure 2, the most common being peers/women living with HIV (52.3%), HIV physicians (46.8%), and partners (44.7%). Most women reported that these sources were “very useful” in helping women cope with their experience, particularly peers (59.9%) and HIV



**Table 2.** Bivariable associations with sexual concerns among women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (N=906).

Categorical variables	Total <i>n</i>	Ever experienced sexual concerns		<i>p</i> -value
		Yes	No	
		<i>n</i> (%)	<i>n</i> (%)	
<b>Social and political factors</b>				
Gender	906			
Cis women		597 (95.1)	299 (96.5)	0.551
Trans women		18 (3.0)	8 (2.6)	
Other		11 (1.8)	<5 (1.0)	
Race/ethnicity	902			
Indigenous		81 (13.7)	50 (16.1)	0.003
African, Caribbean, and Black Canadian		206 (34.8)	138 (44.5)	
White		270 (45.6)	102 (32.9)	
Other		35 (5.9)	20 (6.5)	
Sexual Orientation	904			
Heterosexual		513 (86.1)	284 (92.2)	0.007
Lesbian, bisexual, two-spirit, and queer		83 (13.9)	24 (7.8)	
Personal income (\$CAD)	891			
<20,000		365 (62.1)	180 (59.4)	0.439
≥20,000		223 (37.9)	123 (40.6)	
Current sex work	810			
Yes		24 (4.5)	7 (2.5)	0.173
No		511 (95.5)	268 (97.5)	
<b>Mental health and violence factors</b>				
Any violence as an adult	853			
Yes		522 (92.6)	243 (84.1)	<0.001
No		42 (7.4)	46 (15.9)	
Feel isolated as a woman living with HIV in my community	904			
Strongly agree/agree		271 (45.6)	87 (28.1)	<0.001
Neither agree nor disagree/disagree/strongly disagree		323 (54.4)	223 (71.9)	
Get support from someone living with HIV	903			
Yes		344 (58.0)	201 (64.8)	0.046
No		249 (42.0)	109 (35.2)	
<b>Medical and physical health factors</b>				
On antiretroviral therapy at Wave 3 interview date	904			
Yes (currently)		563 (94.5)	300 (97.4)	0.044
No (never/previously)		33 (5.5)	8 (2.6)	
Most recent viral load	878			
Undetectable (below 50 copies/mL)		535 (92.4)	282 (94.3)	0.291
Detectable (above 50 copies/mL)		44 (5.5)	17 (5.7)	
Most recent CD4	740			
<200 cells/mm <sup>3</sup>		18 (3.5)	14 (6.0)	0.297
200–500 cells/mm <sup>3</sup>		127 (25.0)	55 (23.7)	
>500 cells/mm <sup>3</sup>		363 (71.5)	163 (70.3)	
<b>Sex and relationship factors</b>				
Current legal relationship status	904			
Single		287 (48.3)	129 (41.6)	0.112
Legally married/common-law/in a relationship		193 (32.5)	107 (34.5)	
Separated/divorced/widowed		114 (19.2)	74 (23.9)	
Consensual sex in past 6 months	902			
Yes		296 (49.8)	138 (44.8)	0.152
No		298 (50.2)	170 (55.2)	

(Continued)

**Table 2.** (Continued)

Categorical variables	Total <i>n</i>	Ever experienced sexual concerns		<i>p</i> -value
		Yes	No	
		<i>n</i> (%)	<i>n</i> (%)	
Body satisfaction	895			
Very satisfied/somewhat satisfied		332 (56.0)	204 (67.5)	0.001
Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied		261 (44.0)	98 (35.5)	
How important a part of your life is sexual activity	889			
Very/somewhat important		341 (57.9)	141 (47.0)	0.004
Neither important nor unimportant		85 (14.4)	46 (15.3)	
Somewhat unimportant/not at all important		163 (27.7)	113 (37.7)	
How satisfactory or unsatisfactory is your present sex life	848			
Completely satisfactory/very satisfactory/reasonably satisfactory		376 (65.7)	232 (84.1)	<0.001
Not very satisfactory/not at all satisfactory		196 (34.3)	44 (15.9)	
Continuous variables	Total <i>n</i>	Ever experienced sexual concerns		<i>p</i> -value
		Yes	No	
		Median (Q1–Q3)	Median (Q1–Q3)	
Age at interview (years)	906	48 (41–54)	49 (40–56)	0.227
Sexism (Everyday Discrimination Scale)	899	16 (9–25)	14 (8–24)	0.003
Racism (Everyday Discrimination Scale)	901	13 (8–25)	12 (8–26)	0.537
Time living with HIV at interview (years)	877	16 (11–22)	15 (10–21)	0.161
HIV Stigma Scale (HSS)	893	55 (43–68)	48 (35–60)	<0.001
Resilience Scale (14-item resiliency scale)	903	90 (83–95)	92 (85–98)	<0.001
Depression Scale (CES-D 10)	894	10 (5–16)	7 (3–13)	<0.001
Mental health-related quality of life (SF-12)	890	38 (30–49)	45 (34–52)	<0.001
Physical health-related quality of life (SF-12)	890	39 (33–45)	40 (35–45)	0.165

Column percentages are shown. *n* varies due to missing values (don't know or prefer not to answer). Only sexually active women were asked the Sexual Relationship Power Scale.

physicians (61.6%), followed by partners (48.8%). Other sources of support were also found to be “very useful,” such as nurses, social workers, and therapists who specialize in trauma and women's sexuality, although these were utilized less frequently. When asked who (if anyone) they would feel most comfortable talking with about sexual wellbeing, 14.2% said no one, while the remainder were most likely to name peers/women living with HIV (39.8%), their partner (35.5%), and their HIV physician (36.8%) (data not shown).

## Discussion

This community-based research study revealed that a substantial proportion of women living with HIV in Canada face both sexual concerns (65.8%) and severe sexual distress (36.7%). In adjusted analyses, women reporting sexual dissatisfaction and high HIV-related stigma had significantly higher odds of reporting sexual concerns. Conversely, those reporting higher resilience, better mental health, African, Caribbean, and Black identity, and sex as somewhat unimportant, not at all important, or neutral to their

lives had lower adjusted odds. Factors associated with severe distress about sexual concerns included older age, body dissatisfaction, sexual dissatisfaction, and high HIV-related stigma, while better mental health and getting support from someone living with HIV were protective. With such a wide range of factors influencing women's sexual wellbeing, focusing solely on reducing transmission and lowering viral load in caring for women living with HIV, is evidently unlikely to promote sexual health and sexual wellbeing. Yet conversations about sexual wellbeing beyond safer sex strategies appear to be relatively infrequent.

To our knowledge, this study is unique in investigating the prevalence and factors associated with sexual concerns and associated distress following an HIV diagnosis. Most research has focused on sexual dysfunction, using varied definitions and questions, and usually without measuring distress.<sup>52–55</sup> Thus, it is difficult to compare prevalence estimates with other HIV cohorts. Previous population health research suggests a fairly high prevalence of sexual difficulties in the general population, ranging between 22% and 59%, depending on the domain measured and sample characteristics (e.g. age and sexual activity

**Table 3.** Bivariable associations with severe distress about sexual concerns among women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (N=596).

Categorical variables	Total <i>n</i>	Ever experienced severe distress about sexual concerns		<i>p</i> -value
		Yes <i>n</i> (%)	No <i>n</i> (%)	
<b>Social and political factors</b>				
Gender	596			
Cis women		207 (96.3)	3360 (94.5)	0.462
Trans women		<5 (1.9)	14 (3.7)	
Other		<5 (1.9)	7 (1.8)	
Race/ethnicity	592			
Indigenous		33 (15.5)	48 (12.7)	0.028
African, Caribbean, and Black Canadian		64 (30.0)	142 (37.5)	
White		109 (51.2)	161 (42.5)	
Other		7 (3.3)	28 (7.4)	
Sexual Orientation	596			
Heterosexual		186 (86.5)	327 (85.8)	0.817
Lesbian, bisexual, two-spirit, and queer		29 (13.5)	54 (14.2)	
Personal income (\$CAD)	588			
<20,000		134 (63.2)	244 (61.4)	0.617
≥20,000		77 (36.8)	149 (38.6)	
Current sex work	535			
Yes		8 (4.1)	16 (4.7)	0.746
No		187 (95.9)	324 (95.3)	
<b>Mental health and violence factors</b>				
Any violence as an adult	536			
Yes		197 (94.7)	325 (91.3)	0.136
No		11 (5.3)	31 (8.7)	
Feel isolated as a woman living with HIV in my community	594			
Strongly agree/agree		123 (57.5)	148 (38.9)	<0.001
Neither agree or disagree/disagree/strongly disagree		91 (42.5)	232 (61.1)	
Get support from someone living with HIV	593			
Yes		107 (50.2)	237 (62.4)	0.004
No		106 (49.8)	143 (37.6)	
<b>Medical and physical health factors</b>				
On antiretroviral therapy at Wave 3 interview date	596			
Yes (currently)		200 (93.0)	363 (95.3)	0.248
No (never/previously)		15 (7.0)	18 (4.7)	
Most recent viral load	579			
Undetectable (below 50 copies/mL)		194 (92.8)	341 (92.2)	0.773
Detectable (above 50 copies/mL)		14 (7.2)	29 (7.8)	
Most recent CD4	508			
<200 cells/mm <sup>3</sup>		7 (3.9)	11 (3.4)	0.649
200–500 cells/mm <sup>3</sup>		41 (22.7)	86 (26.3)	
>500 cells/mm <sup>3</sup>		133 (73.5)	230 (70.3)	
<b>Sex and relationship factors</b>				
Current legal relationship status	594			
Single		111 (51.6)	176 (46.4)	0.057
Legally married/common-law/in a relationship		57 (26.5)	136 (35.9)	
Separated/divorced/widowed		47 (21.9)	67 (17.7)	
Consensual sex in past 6 months	594			
Yes		102 (47.7)	194 (51.1)	0.428
No		112 (52.3)	186 (48.9)	

(Continued)

**Table 3.** (Continued)

Categorical variables	Total	Ever experienced severe distress about sexual concerns		p-value
		Yes	No	
		n (%)	n (%)	
Body satisfaction	593			
Very satisfied/somewhat satisfied		98 (45.8)	234 (61.7)	<0.001
Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied		116 (54.2)	145 (38.3)	
How important a part of your life is sexual activity	589			
Very/somewhat important		113 (53.6)	228 (60.3)	0.052
Neither important nor unimportant		27 (12.8)	58 (15.3)	
Somewhat unimportant/not at all important		71 (33.6)	92 (24.3)	
How satisfactory or unsatisfactory is your present sex life	572			
Completely satisfactory/very satisfactory/reasonably satisfactory		116 (56.9)	260 (70.7)	0.001
Not very satisfactory/not at all satisfactory		88 (43.1)	108 (29.3)	
Continuous variables	Total	Ever experienced severe distress about sexual concerns		p-value
	n	Yes	No	
		Median (Q1–Q3)	Median (Q1–Q3)	
Age at interview	596	49 (42–55)	47 (40–54)	0.068
Sexism (Everyday Discrimination Scale)	589	19 (12–26)	16 (8–24)	0.002
Racism (Everyday Discrimination Scale)	592	13 (8–28)	15 (10–21)	0.352
Time living with HIV (years) at interview	581	16 (11–22)	15 (10–21)	0.186
HIV Stigma Scale (HSS)	586	60 (48–75)	53 (38–63)	<0.001
Resilience Scale (14-item resiliency scale)	594	89 (82–94)	90 (84–95)	0.023
Depression Scale (CES-D 10)	588	13 (6–18)	9 (4–14)	<0.001
Mental health-related quality of life (SF-12)	586	34 (27–44)	41 (32–51)	<0.001
Physical health-related quality of life (SF-12)	586	38 (31–45)	40 (34–45)	0.125

Column percentages are shown. *n* varies due to missing values (don't know or prefer not to answer). Only sexually active women were asked the Sexual Relationship Power Scale.

status).<sup>56–58</sup> Distress about sexuality among women in the general population also varies, from 24% to 51%.<sup>56,59</sup> In the context of HIV, women often struggle with issues of sexuality and intimacy, with previous qualitative research revealing experiences of on-going guilt, shame, and rejection, all of which lead to reduced sexual desires and inhibited intimacy.<sup>5</sup> Our finding that concerns related to relationships, sexual self-esteem, and emotional aspects of sex were most prevalent, and that relationships caused the most severe distress, has important implications for the design of programs to promote positive adaptation or resilience in sexuality following an HIV diagnosis.

Correlates of sexual concerns and sexual distress following an HIV were markers of social, sexual, relational, and emotional wellbeing. Women living with HIV face high rates of physical and sexual violence,<sup>60</sup> as well as HIV-related stigma and discrimination,<sup>61,62</sup> with both associated with increased depression and psychological trauma among

women living with HIV.<sup>63,64</sup> Stigma spans multiple interacting levels,<sup>65</sup> including interpersonal (violence, rejection from partners), structural (discriminatory laws, healthcare provider discrimination), and community (cultural norms of social exclusion, violence, and persecution) levels, and its impacts on sexuality are well-documented in the qualitative literature.<sup>5</sup> Past research has also found that sexual satisfaction and sexual function are highly correlated,<sup>66</sup> and this domain predicted both sexual concerns and severe distress. In contrast, mental health and getting support from someone living with HIV were protective, while HIV clinical factors were not related to either outcome. These findings are consistent with a recent review of determinants of sexual activity, function, and satisfaction among women living with HIV globally,<sup>1</sup> which concluded that sexual difficulties are very often historically, socially, and structurally situated, rather than medically determined. It is also consistent with the findings of women in national probability samples.<sup>56,59</sup>



**Table 4.** Multivariable logistic regression results showing factors associated with sexual concerns and severe distress in women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

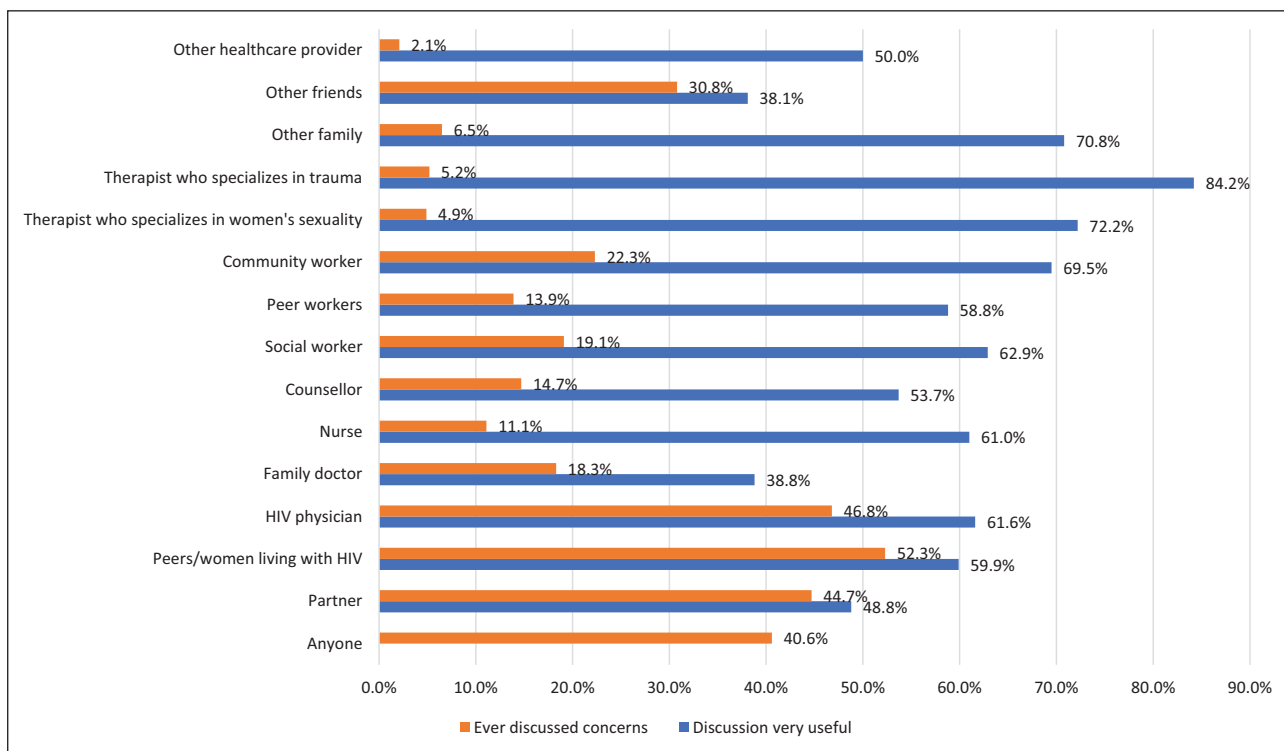
Categorical variables	Sexual concerns (n=731)		Severe distress (n=499)	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
<b>Social and political factors</b>				
<b>Race/ethnicity</b>				
White	1.00 (-)	1.00 (-)	1.00 (-)	Not selected
Indigenous	0.65 (0.41–1.02)	0.67 (0.41–1.10)	0.92 (0.53–1.58)	
African, Caribbean, and Black Canadian	<b>0.61 (0.43–0.87)</b>	<b>0.58 (0.38–0.86)</b>	0.70 (0.46–1.07)	
Other	0.68 (0.35–1.33)	0.57 (0.28–1.17)	0.41 (0.16–1.04)	
<b>Sexual orientation</b>				
Heterosexual	1.00 (-)	1.00 (-)		
Lesbian, bisexual, two-spirit, and queer	<b>1.81 (1.07–3.05)</b>	1.64 (0.93–2.87)		
<b>Mental health and violence factors</b>				
<b>Any violence as an adult</b>				
No	1.00 (-)	1.00 (-)	1.00 (-)	1.00 (-)
Yes	<b>2.01 (1.22–3.31)</b>	1.39 (0.81–2.38)	1.64 (0.78–3.45)	1.04 (0.46–2.34)
<b>Feel isolated as a woman living with HIV in my community</b>				
Neither agree nor disagree/disagree/strongly disagree			1.00 (-)	Not selected
Strongly agree/agree			<b>2.05 (1.41–2.97)</b>	
<b>Get support from someone living with HIV</b>				
No	1.00 (-)	Not selected	1.00 (-)	1.00 (-)
Yes	0.73 (0.53–1.01)		<b>0.57 (0.39–0.82)</b>	<b>0.55 (0.37–0.82)</b>
<b>Medical and physical health factors</b>				
<b>On antiretroviral therapy at wave 3 interview date</b>				
No (never/previously)	1.00 (-)	Not selected		
Yes (current)	0.58 (0.25–1.35)			
<b>Sex and relationship factors</b>				
<b>Current legal relationship status</b>				
Single	1.00 (-)	Not selected	1.00 (-)	Not selected
Legally married/common-law/in a relationship	1.36 (0.96–1.93)		<b>1.64 (1.07–2.51)</b>	
Separated/divorced/widowed	1.03 (0.67–1.57)		<b>1.95 (1.15–3.29)</b>	
<b>Consensual sex in past 6 months</b>				
No	1.00 (-)	Not selected		
Yes	1.1 (0.81–1.50)			
<b>Body satisfaction</b>				
Very satisfied/somewhat satisfied	1.00 (-)	Not selected	1.00 (-)	1.00 (-)
Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied	<b>1.49 (1.08–2.06)</b>		<b>1.99 (1.37–2.88)</b>	<b>1.58 (1.06–2.37)</b>
<b>How importance a part of your life is sexual activity</b>				
Very/somewhat important	1.00 (-)	1.00 (-)		
Neither important nor unimportant	0.66 (0.42–1.04)	<b>0.60 (0.37–0.96)</b>		
Somewhat unimportant/not at all important	<b>0.62 (0.44–0.88)</b>	<b>0.53 (0.36–0.77)</b>		
<b>How satisfactory or unsatisfactory is your present sex life</b>				
Completely satisfactory/very satisfactory/reasonably satisfactory	1.00 (-)	1.00 (-)	1.00 (-)	1.00 (-)
Not very satisfactory/not at all satisfactory	<b>2.57 (1.74–3.8)</b>	<b>2.34 (1.56–3.52)</b>	<b>1.82 (1.24–2.66)</b>	<b>1.53 (1.01–2.30)</b>
<b>Continuous variables</b>				
Age at interview	0.95 (0.82–1.11)	1.13 (0.97–1.33)	1.20 (1.00–1.43)	<b>1.29 (1.06–1.56)</b>
Sexism (Everyday Discrimination Scale)	1.07 (0.91–1.27)	Not selected	<b>1.33 (1.09–1.63)</b>	Not selected
Time living with HIV (years) at interview	1.11 (0.89–1.38)	Not selected	1.17 (0.91–1.52)	Not selected
HIV Stigma Scale (HSS)	<b>1.2 (1.10–1.30)</b>	<b>1.18 (1.07–1.29)</b>	<b>1.29 (1.17–1.44)</b>	<b>1.27 (1.14–1.43)</b>

(Continued)

**Table 4.** (Continued)

Categorical variables	Sexual concerns (n = 731)		Severe distress (n = 499)	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Resilience Scale (14-item resiliency scale)	<b>0.96 (0.95–0.98)</b>	<b>0.98 (0.96–0.99)</b>	<b>0.98 (0.96–0.99)</b>	Not selected
Mental health-related quality of life (SF-12)	<b>0.98 (0.96–0.99)</b>	<b>0.97 (0.96–0.99)</b>	<b>0.96 (0.94–0.98)</b>	<b>0.97 (0.96–0.99)</b>
Depression Scale (CES-D 10)	1.04 (1.01–1.06)	Not selected	<b>1.05 (1.03–1.08)</b>	Not selected
Physical health-related quality of life (SF-12)			0.98 (0.96–1.00)	Not selected

OR: odds ratio; CI: confidence interval.  
ORs excluding the null value are in bold.



**Figure 2.** Discussions about sexual wellbeing among women living with HIV: Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

Earlier studies have confirmed the importance of sex<sup>67</sup> and pleasure<sup>26</sup> for women living with HIV. Our results support these findings, and also point to a need for continued and holistic sexual health support from health professionals and peers. Forty percent of women had spoken with someone about the impacts of living with HIV on their sexual wellbeing beyond safer sex strategies like condom use and having a low viral load. Speaking about and addressing broader wellbeing concerns is vital for promoting quality of life. Such support can be expressed when women have developed strong and trusting relationships with their health care providers, as found from previous studies.<sup>68</sup> This study also found that African, Caribbean, and Black women were less likely to report sexual concerns than White women. This is interesting, as racialized women

report experiencing high levels of violence in most studies.<sup>69,70</sup> Future research should explore programs for sexual health and sexual rights among diverse women living with HIV, taking into account the different cultural understandings of sexual wellbeing. Future research should also look into the barriers HIV providers face to discussing sexual wellbeing with their patients.

### Strengths and limitations

Strengths of this study include the use of community-based research principles<sup>41</sup> and the large sample, with 906 women surveyed, including women from marginalized backgrounds and experiences. However, there are also several limitations that need to be acknowledged. Since CHIWOS enrolled

women through purposive non-random sampling, the cohort may not be representative of all women living with HIV in Canada, and there is the possibility of bias within the sample. The present analyses were conducted with Wave 3 of this study. Some drop-out is inevitable in a large multi-year study. Participants who dropped out by Wave 3 and who were not included in the present analysis were more likely to be Indigenous, from lesbian/queer communities, and living with HIV for <6 years, compared with those who were included in the analysis. In addition, as CHIWOS data were collected through surveys, self-reporting presents the potential for participants to be subject to social desirability bias, in which respondents answer questions in a manner meant to be viewed favorably by others, potentially preventing truthful responses. This can hold particularly true in the context of more personal questions regarding sexual health and intimacy. To mitigate the impact of these reporting biases, surveys were conducted by trained PRAs, with the intention of creating trusting relationships with participants. In addition, the meaning of “sexual concerns” and “severe distress” might also be different between groups of women, based on sexual activity and various social identity factors, which could in turn affect the associations with correlates. The outcome measures were also not validated and referenced a long time period (i.e. “since knowing your HIV status”), which may have resulted in differences in accuracy or completeness of recall to memory of past experiences. Moreover, we did not measure whether women had sexual concerns *prior* to HIV diagnosis; thus, while the question stem refers to the period *after* diagnosis, and HIV unquestionably adds a new dimension to sexual concerns, it is possible that these may not reflect *new* concerns for some women. In fact, many underlying factors undermining sexual wellbeing could be present prior to diagnosis, and in the general population. Finally, missing data in this study came from a combination of the outcomes and covariates. Missing outcomes had to be excluded from analyses and most of the covariates did not have meaningful underlying theory to impute with a complex imputation method like model based multiple imputation.<sup>71</sup> Since simple imputation methods often introduce more bias and are not reliable,<sup>72</sup> we decided to exclude missing data from multivariate models. This may have reduced the statistical power of the analysis and produced biased estimates. Despite these limitations, the questions were designed together with women living with HIV and this study represents the first to investigate baseline prevalence and correlates of concerns and distress about specific aspects of sexual wellbeing. While this cross-sectional analysis cannot assess causality, it provides important evidence for future investigations.

### *Practice and research implications*

As the first line of support for many women living with HIV, this study underlines the importance of health professionals talking to women living with HIV about their

sexual wellbeing and offering support for those experiencing distressing sexual concerns. Clinicians are likely challenged by significant time pressure in clinical visits and a lack of training in sexual wellbeing history taking (beyond risk-related behavior and prevention) in medical school curricula. But examples of ways in which providers can discuss sexual pleasure, sexual health, and sexual rights, such as the *Pleasuremeter*,<sup>73</sup> offer new possibilities for advancing women sexual wellbeing in the context of HIV.<sup>7</sup> This novel tool involves asking brief, open-ended questions related to six enabling factors for sexual pleasure to contribute to sexual health and wellbeing: self-determination, consent, safety, privacy, confidence, and communication/negotiation (e.g. How free do you feel to make choices regarding your sexuality? How safe do you feel in your sexual relationships? How much pleasure do you have with your sexual experiences?).<sup>73</sup> Clinicians can also support their patients by having a basic understanding of the impact of HIV on women’s sexual wellbeing, providing non-judgmental and empathetic care, and ensuring appropriate services and referrals are available. Clinician-led discussions are important considering that people rarely seek help for sexual concerns, especially people in mid- and later life,<sup>74</sup> and that barriers in help-seeking are likely to be amplified for people living with a sexually transmissible infection.

Prior research has also shown the effectiveness of peer support for people living with HIV for those who are comfortable accessing it.<sup>75</sup> Yet because of stigma, some women may not be interested in peer support, which is another reason why providers should take the initiative in discussing sexuality. Cancer peer support, in contrast, is much accepted by patients and studies suggest that there is no difference between professionally led and peer-led cancer support groups, signifying it is the ability to present a safe space environment for emotional expression that ultimately has an impact.<sup>76</sup> Cancer studies also elucidate how support groups and general support networks can create communities, both in-person and online, for patients to combat effects of isolation, rejection, and shame,<sup>76</sup> something seen in HIV research as well.<sup>35,75</sup> Our findings additionally indicate that several multi-level factors, such as stigma, further influence women’s sexual wellbeing, thus suggesting a need for multi-level health promotion initiatives, including violence prevention, intersectional stigma reduction (e.g. addressing HIV-related stigma, gender inequity, and stigma toward sex),<sup>28,77</sup> and mental health support. Previous studies have suggested the implementation of community-based stigma interventions and use of mass media communications can change attitudes and behaviors toward people living with HIV;<sup>78</sup> these need to also address stigma toward sex and sexual pleasure<sup>11</sup> and transform gender norms.<sup>79</sup> Face-to-face and Internet-based support programs for sexual health have also been shown to be effective for improving the psycho-sexual concerns of cancer survivors and their partners<sup>80</sup> and could be

explored with this population. To inform such programs, qualitative research is undoubtedly important, including understanding how women living with HIV experience their sexuality, how this impacts their overall health and wellbeing, barriers, and facilitators to help-seeking, and what factors promote better sexual wellbeing.

## Conclusion

The findings from this study indicated that many Canadian women experience sexual concerns following their HIV diagnosis, which can result in severe distress. Age, HIV-related stigma, mental health, and sex and relationship factors predicted whether women reported sexual concerns and associated distress. While 84.4% had discussed with a provider how viral load impacts transmission risk, only 40.6% spoke to others about the impacts of living with HIV on their sexual wellbeing, and women said they would feel most comfortable having these discussions with peers, their partner, or their HIV physician. A reductive, risk-centered approach to sexual health perpetuates HIV-related stigma and overlooks the importance of broader elements of sexual pleasure, sexual wellbeing, and sexual justice in shaping quality of life among women living with HIV. More attention to women's sexual health and wellbeing *beyond* HIV prevention, sensitive to the social and relational context of women's sexual lives, is critical to ensure the sexual rights of women living with HIV are upheld.

## Acknowledgements

The authors thank all the women living with HIV who participated in CHIWOS for giving their time and voices to this study, and the Peer Research Associates for the enthusiasm, passion, and dedication they bring to their work with CHIWOS. The authors also thank the entire national team of co-investigators and collaborators.

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### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: CHIWOS has been awarded funding from the Canadian Institutes of Health Research (MOP-111041), the CIHR Canadian HIV Trials Network (CTN 262), the Ontario HIV Treatment Network (OHTN), and the Academic Health Science

Centres (AHSC) Alternative Funding Plans (AFP) Innovation Fund. Some authors are receiving salary support: S.P. from a Clinical Lectureship in Public Health awarded by the National Institute of Health Research (NIHR), A.d.P. from the Fonds de Recherche Santé Québec (FRSQ), and A.K. through a Tier 2 Canada Research Chair in Global Perspectives on HIV and Sexual and Reproductive Health.

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