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

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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

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**Introduction**

Women’s sexual health in the context of HIV has been pathologized, moralized, medicalized, and stigmatized. Globally, more than 19 million women and girls are living with HIV, including more than 14,500 women in Canada. Women’s bodies have been primarily viewed as vectors of disease, 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. Consequently, discourse on sexual wellbeing, satisfaction, and pleasure has been missing. Even with combination antiretroviral treatment shifting HIV from being considered a lethal disease to a chronic, sexually non-transmissible one among many persons, socio-cultural norms of silence and stigma surrounding sexuality means many women living with HIV continue to be denied access to basic human rights. 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.

Sexual health and wellbeing has been defined in different ways. 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.” Critically, sexual pleasure and sexual rights are deemed essential elements of sexual health and wellbeing, including freedom from coercion, discrimination, and violence. 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. 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. 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).

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 and are sexually satisfied, whether sexually active or not. Love and sexual pleasure are crucial in women’s lives, including older women living with HIV, with studies having shown strong ties to physical and mental health, self-esteem, and quality of life, 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, structural initiatives that can foster resilience, and positive social and cultural relationships. Women are also developing a pleasure-focused narrative, in public and digital spaces, that reaffirms their sexual desires and rights. 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. 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 effec-
tively address quality-of-life concerns, cultivate feelings
of acceptance, and retain a sense of normality.\textsuperscript{5,34} Peers and
Internet communication are also highly valued as impor-
tant sources of emotional support, normalization, and reas-
surance among women living with HIV.\textsuperscript{35} 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.\textsuperscript{36} When discussions are docu-
mented, studies suggest that healthcare providers tend to
ask about sexual activity and sexual behavior in ways that
almost entirely focused around risk\textsuperscript{37}—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.\textsuperscript{1}

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, we hypothesized that a substantial pro-
portion of women living with HIV would report experienc-
ing sexual concerns following their HIV diagnosis and that
distress levels would be equally high for emotional con-
cerns as for behavioral concerns. In addition, age, depres-
sive 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.\textsuperscript{1} Finally, we hypothesized that many women
would have never talked to anyone about the impact of liv-
ing 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) 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.\textsuperscript{38,39} A central component of our approach to
research is the meaningful involvement of women living
with HIV.\textsuperscript{40} We operationalized this by hiring, training,
and supporting 40 women living with HIV as Peer
Research Associates (PRAs),\textsuperscript{41} who shared social identi-
ties and living experiences with the study population of
women living with HIV across Canada who have histori-
cally been under-represented in research. PRAs were
hired to contribute to all stages of the research process,
including study design, participant recruitment, data col-
lection, 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 prac-
tices to maximize data quality, while also receiving guid-
ance in community-based research principles, knowledge
translation, and ethical issues.\textsuperscript{41} The baseline question-
naire (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 gen-
dered and social barriers women face to participation in
HIV research.\textsuperscript{42} 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 organi-
zations and non-HIV-specific community settings, such as
women’s shelters.\textsuperscript{42} 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 prov-
inces: British Columbia, Ontario, and Quebec.\textsuperscript{38} All
women were screened for eligibility by a trained PRA or a
provincial coordinator and were provided with informa-
tion 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.\textsuperscript{38}

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 organi-
zations) 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. 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: 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/mm³, or don’t know), and physical health-related quality of life (measured via SF-12, score range 0–100). Mental health and violence factors included any physical, sexual, verbal, or controlling violence as an adult (≥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 ≥10 suggesting probable depression), resiliency (measured via the 14-item resiliency scale, score range, Cronbach’s alpha =0.88), 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/
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., 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% or 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)). The median rating on the 10-item HSS was 53 (Q1–Q3: 40–65) and on the 14-item resiliency 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 (%) |
|-----------------------|-------|-------|
|                        |       |       |
| 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/mm³        | 32    | (4.3)  |
| 200–500 cells/mm³      | 182   | (24.6) |
| > 500 cells/mm³        | 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                  |
|--------------------------------------------------------------------------------------|------------------------|
|                                                                                      | n  | n (%)     |
| 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                    |
| Sexism (Everyday Discrimination Scale)                                               | 899                    |
| Racism (Everyday Discrimination Scale)                                               | 901                    |
| Time living with HIV at interview (years)                                            | 877                    |
| HIV Stigma Scale (HSS)                                                               | 893                    |
| Resilience Scale (14-item resiliency scale)                                          | 903                    |
| Depression Scale (CES-D 10)                                                         | 894                    |
| Mental health-related quality of life (SF-12)                                        | 890                    |
| Physical health-related quality of life (SF-12)                                      | 890                    |

* 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: 40–65). 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
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

![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).]
Table 2. Bivariate 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 | Ever experienced sexual concerns | p-value |
|------------------------------------------------------------|-------|----------------------------------|---------|
|                                                            |       | Yes                               | No      |
|                                                            | n     | n (%)                            | n (%)   |
| **Social and political factors**                           |       |                                  |         |
| 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)             |         |
| **Mental health and violence factors**                      | 853   |                                  | <0.001   |
| Yes                                                         | 522 (92.6)     | 243 (84.1)             |         |
| No                                                          | 42 (7.4)       | 46 (15.9)              |         |
| **Feel isolated as a woman living with HIV in my community**| 904   |                                  | <0.001   |
| Strongly agree/agree                                        | 271 (45.6)     | 87 (28.1)              |         |
| Neither agree nor disagree/disagree/strongly disagree       | 323 (54.4)     | 223 (71.9)             |         |
| **Get support from someone living with HIV**                | 903   |                                  | 0.046   |
| Yes                                                         | 344 (58.0)     | 201 (64.8)             |         |
| No                                                          | 249 (42.0)     | 109 (35.2)             |         |
| **Medical and physical health factors**                     | 904   |                                  | 0.044   |
| On antiretroviral therapy at Wave 3 interview date          |       |                                  |         |
| Yes (currently)                                             | 563 (94.5)     | 300 (97.4)             |         |
| No (never/neverpreviously)                                 | 33 (5.5)       | 8 (2.6)                |         |
| **Most recent viral load**                                 | 878   |                                  | 0.291   |
| Undetectable (below 50 copies/mL)                           | 535 (92.4)     | 282 (94.3)             |         |
| Detectable (above 50 copies/mL)                             | 44 (5.5)       | 17 (5.7)               |         |
| **Most recent CD4**                                         | 740   |                                  | 0.297   |
| <200 cells/mm³                                              | 18 (3.5)       | 14 (6.0)               |         |
| 200–500 cells/mm³                                           | 127 (25.0)     | 55 (23.7)              |         |
| >500 cells/mm³                                              | 363 (71.5)     | 163 (70.3)             |         |
| **Sex and relationship factors**                            | 904   |                                  | 0.112   |
| Current legal relationship status                           |       |                                  |         |
| Single                                                      | 287 (48.3)     | 129 (41.6)             |         |
| 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   |                                  | 0.152   |
| Yes                                                         | 296 (49.8)     | 138 (44.8)             |         |
| No                                                          | 298 (50.2)     | 170 (55.2)             |         |

(Continued)
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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. 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 2. (Continued) |
|----------------------|
| **Categorical variables** |
| **Total** | **Ever experienced sexual concerns** | **p-value** |
| | **Yes** | **No** |
| | **n** | **n (%)** | **n (%)** |
| **Body satisfaction** | 895 |
| Very satisfied/somewhat satisfied | | |
| Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied | 332 (56.0) | 204 (67.5) | 0.001 |
| **How important a part of your life is sexual activity** | 889 |
| Very/somewhat important | | |
| Neither important nor unimportant | 341 (57.9) | 141 (47.0) | 0.004 |
| Somewhat unimportant/not at all important | 85 (14.4) | 46 (15.3) |
| **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** | **Ever experienced sexual concerns** | **p-value** |
| | **Yes** | **No** |
| | **n** | **Median**<br>(Q1–Q3) | **Median**<br>(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.
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 | Ever experienced severe distress about sexual concerns | p-value |
|--------------------------------------------|-------|--------------------------------------------------------|---------|
|                                            | n     | Yes          | No          |         |
| Social and political factors               |       |             |             |         |
| 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)  |         |
| Mental health and violence factors         |       |             |             |         |
| 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)  |         |
| Medical and physical health factors        |       |             |             |         |
| 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/mm³                             |       | 7 (3.9)     | 11 (3.4)    | 0.649   |
| 200–500 cells/mm³                          |       | 41 (22.7)   | 86 (26.3)   |         |
| >500 cells/mm³                             |       | 133 (73.5)  | 230 (70.3)  |         |
| Sex and relationship factors               |       |             |             |         |
| 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 (%) | 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 |
|                       |       | Yes | No |        |        |
|                       | n | 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.

Distress about sexuality among women in the general population also varies, from 24% to 51%.56,59 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.5 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,66 as well as HIV-related stigma and discrimination,61,62 with both associated with increased depression and psychological trauma among women living with HIV.63,64 Stigma spans multiple interacting levels,65 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.5 Past research has also found that sexual satisfaction and sexual function are highly correlated,66 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,7 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.56,59
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)    |
| Social and political factors                               |                         |                         |                         |                         |
| Race/ethnicity                                             |                         |                         |                         |                         |
| 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                     | 0.61 (0.43–0.87)        | 0.58 (0.38–0.86)        | 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)        |                         |
| Sexual orientation                                         |                         |                         |                         |                         |
| Heterosexual                                               | 1.00 (–)                | 1.00 (–)                |                         |                         |
| Lesbian, bisexual, two-spirit, and queer                   | 1.81 (1.07–3.05)        | 1.64 (0.93–2.87)        |                         |                         |
| Mental health and violence factors                         |                         |                         |                         |                         |
| Any violence as an adult                                   |                         |                         |                         |                         |
| No                                                         | 1.00 (–)                | 1.00 (–)                | 1.00 (–)                | 1.00 (–)                |
| Yes                                                        | 2.01 (1.22–3.31)        | 1.39 (0.81–2.38)        | 1.64 (0.78–3.45)        | 1.04 (0.46–2.34)        |
| Feel isolated as a woman living with HIV in my community   |                         |                         |                         |                         |
| Neither agree nor disagree/disagree/strongly disagree      |                         |                         | 1.00 (–)                | Not selected            |
| Strongly agree/agree                                        | 2.05 (1.41–2.97)        |                         |                         |                         |
| Get support from someone living with HIV                   |                         |                         |                         |                         |
| No                                                         | 1.00 (–)                | Not selected            | 1.00 (–)                | 1.00 (–)                |
| Yes                                                        | 0.73 (0.53–1.01)        |                         | 0.57 (0.39–0.82)        | 0.55 (0.37–0.82)        |
| Medical and physical health factors                         |                         |                         |                         |                         |
| On antiretroviral therapy at wave 3 interview date         |                         |                         |                         |                         |
| No (never/previous)                                        | 1.00 (–)                | Not selected            |                         |                         |
| Yes (current)                                              | 0.58 (0.25–1.35)        |                         |                         |                         |
| Sex and relationship factors                               |                         |                         |                         |                         |
| Current legal relationship status                          |                         |                         |                         |                         |
| Single                                                     | 1.00 (–)                | Not selected            | 1.00 (–)                | Not selected            |
| Legally married/common-law/in a relationship               | 1.36 (0.96–1.93)        | 1.64 (1.07–2.51)        |                         |                         |
| Separated/divorced/widowed                                 | 1.03 (0.67–1.57)        | 1.95 (1.15–3.29)        |                         |                         |
| Consensual sex in past 6 months                            |                         |                         |                         |                         |
| No                                                         | 1.00 (–)                | Not selected            |                         |                         |
| Yes                                                        | 1.1 (0.81–1.50)         |                         |                         |                         |
| Body satisfaction                                          |                         |                         |                         |                         |
| Very satisfied/somewhat satisfied                          | 1.00 (–)                | Not selected            | 1.00 (–)                | 1.00 (–)                |
| Neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied | 1.49 (1.08–2.06) | 1.99 (1.37–2.88) | 1.58 (1.06–2.37) |
| How importance a part of your life is sexual activity       |                         |                         |                         |                         |
| Very/somewhat important                                   | 1.00 (–)                | 1.00 (–)                |                         |                         |
| Neither important nor unimportant                          | 0.66 (0.42–1.04)        | 0.60 (0.37–0.96)        |                         |                         |
| Somewhat unimportant/not at all important                  | 0.62 (0.44–0.88)        | 0.53 (0.36–0.77)        |                         |                         |
| How satisfactory or unsatisfactory is your present sex life |                         |                         |                         |                         |
| Completely satisfactory/very satisfactory/reasonably satisfactory | 1.00 (–) | 1.00 (–) | 1.00 (–) | 1.00 (–) |
| Not very satisfactory/not at all satisfactory              | 2.57 (1.74–3.8)         | 2.34 (1.56–3.52)        | 1.82 (1.24–2.66)        | 1.53 (1.01–2.30)        |
| Continuous variables                                       |                         |                         |                         |                         |
| Age at interview                                           | 0.95 (0.82–1.11)        | 1.13 (0.97–1.33)        | 1.20 (1.00–1.43)        | 1.29 (1.06–1.56)        |
| Sexism (Everyday Discrimination Scale)                    | 1.07 (0.91–1.27)        | Not selected            | 1.33 (1.09–1.63)        | 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)                                     | 1.2 (1.10–1.30)         | 1.18 (1.07–1.29)        | 1.29 (1.17–1.44)        | 1.27 (1.14–1.43)        |
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) | 0.96 (0.95–0.98)       | 0.98 (0.96–0.99)       | 0.98 (0.96–0.99)       | Not selected         |
| Mental health-related quality of life (SF-12) | 0.98 (0.96–0.99)       | 0.97 (0.96–0.99)       | 0.96 (0.94–0.98)       | 0.97 (0.96–0.99)     |
| Depression Scale (CES-D 10) | 1.04 (1.01–1.06)       | Not selected           | 1.05 (1.03–1.08)       | Not selected         |
| Physical health-related quality of life (SF-12) | Not selected           |                        | 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 and pleasure 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 healthcare providers, as found from previous studies. 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. 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 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.71 Since simple imputation methods often introduce more bias and are not reliable,72 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,73 offer new possibilities for advancing women sexual wellbeing in the context of HIV.7 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?).73 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,72 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.75 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.76 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,76 something seen in HIV research as well.35,75 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),28,77 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;78 these need to also address stigma toward sex and sexual pleasure11 and transform gender norms.79 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 partners80 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.

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References

1. Carter A, Greene S, Money D, et al. The problematization of sexuality among women living with HIV and a new feminist approach for understanding and enhancing women’s sexual lives. Sex Roles 2017; 77(11–12): 779–800.

2. UNAIDS. Global HIV & AIDS statistics: 2019 fact sheet. Geneva: UNAIDS, 2019

3. Public Health Agency of Canada. Summary: estimates of HIV incidence, prevalence and Canada’s progress on meeting the 90-90-90 HIV targets, 2016. Ottawa, ON, Canada: Public Health Agency of Canada, 2018.

4. Gurevich M, Mathieson CM, Bower J, et al. Disciplining bodies, desires and subjectivities: sexuality and HIV-positive women. Fem PsychoL 2007; 17(1): 9–38.

5. Carlsson-Lalloo E, Rusner M and Mellgren Berg AM. Sexuality and reproduction in HIV-positive women: a metasynthesis. AIDS Patient Care STDS 2016; 30(2): 56–69.

6. Welbourn A. Desires denied: sexual pleasure in the context of HIV. In: Jolly S, Cornwall A and Hawkins K (eds) Women, sexuality and the political power of pleasure. London: Zed Books, 2013, pp. 142–161.

7. Mitchell KR, Lewis R, O’Sullivan LF, et al. What is sexual wellbeing and why does it matter for public health. Lancet Publ Health 2021; 6(8): e608–e613.

8. Rodger AJ, Cambiano V, Bruun T, et al. Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy. JAMA 2016; 316(2): 171–181.

9. World Association for Sexual Health. Declaration of sexual rights. Minneapolis, MA: World Association for Sexual Health, 2014.

10. Starrs AM, Ezeh AC, Barker G, et al. Accelerate progress: sexual and reproductive health and rights for all: report of the Guttmacher–Lancet Commission. Lancet 2018; 391(10140): 2642–2692.

11. Logie CH. Sexual rights and sexual pleasure: sustainable development goals and the omitted dimensions of the leave no one behind sexual health agenda. Glob Publ Health Epub ahead of print 18 July 2021. DOI: 10.1080/17441692.2021.1953559.

12. Edwards W and Coleman E. Defining sexual health: a descriptive overview. Arch Sex Behav 2004; 33(3): 189–195.

13. Fortenberry JD. The evolving sexual health paradigm: transforming definitions into sexual health practices. AIDS 2013; 27(Suppl. 1): S127–S133.

14. Impett E, Muise A and Breines J. From risk to pleasure: toward a positive psychology of sexuality. In: Hojvat M and Cramer D (eds) Positive psychology of love. New York: Oxford University Press, 2013, pp. 57–76.
15. Sandfort TG and Ehrhardt AA. Sexual health: a useful public health paradigm or a moral imperative? Arch Sex Behav 2004; 33(3): 181–187.

16. World Health Organization. Defining sexual health: report of a technical consultation on sexual health, 28-31 January 2002. Geneva: World Health Organization, 2006.

17. Beckerman NL and Auerbach C. Couples of mixed HIV status: psychosocial issues affecting intimacy. J Couple Relation Ther 2002; 1(4): 73–85.

18. Lawless S, Crawford J, Kippax S, et al. “If it’s not on...”: heterosexuality for HIV-positive women. Venerology 1996; 9(1): 15–23, http://search.informit.com.au/document Summary.dn=561250395072397;res=IELAPA

19. Crawford Lawless S and Kippax S. Positive women and heterosexuality: problems of disclosure of serostatus to sexual partners. In: Aggleton P, Davis P and Hart G (eds) AIDS: activism and alliances. Bristol, PA: Taylor & Francis, 1997, pp. 1–14.

20. Siegel K, Schrimshaw E and Lekas H-M. Diminished sexual activity, interest, and feelings of attractiveness among HIV-infected women in two eras of the AIDS epidemic. Arch Sex Behav 2006; 35(4): 437–449.

21. Van der Straten A, Vernon KA, Knight KR, et al. Managing HIV among serodiscordant heterosexual couples: serostatus, stigma and sex. AIDS Care 1998; 10(5): 533–548.

22. Carter A, Greene S, Money D, et al. The importance of sex in the lives of women living with HIV: a critical quantitative analysis. Int J Sex Health 2018; 30(1): 92–110.

23. Kaida A, Carter A, de Pokomandy A, et al. Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. J Int AIDS Soc 2015; 18(Suppl. 5): 20284–20294.

24. Carter A, Greene S, Money D, et al. Love with HIV: a latent class analysis of sexual and intimate relationship experiences among women living with HIV in Canada. Arch Sex Behav 2019; 48(4): 1015–1040.

25. Carter A, Greene S, Money D, et al. Supporting the sexual rights of women living with HIV: a critical analysis of sexual satisfaction and pleasure across five relationship types. J Sex Res 2018; 55(9): 1134–1154.

26. Taylor TN, Munoz-Plaza CE, Goparaju L, et al. “The pleasure is better as I’ve gotten older”: sexual health, sexuality, and sexual risk behaviors among older women living with HIV. Arch Sex Behav 2016; 46(4): 1137–1150.

27. Ford JY, Corona Vargas E, Finotelli I Jr, et al. Why pleasure matters: its global relevance for sexual health, sexual rights and wellbeing. Int J Sex Health 2019; 31(3): 217–230.

28. Rao D, Elshafei A, Nguyen M, et al. A systematic review of multi-level stigma interventions: state of the science and future directions. BMC Med 2019; 17(1): 41.

29. Harrison SE, Li X and Vermund SH. From surviving to thriving: the role of resilience in meeting global HIV goals. AIDS 2019; 33 (Suppl. 1): S1–S4.

30. McClelland A and Whitbread J. Poster virus: Claiming sexual autonomy for people with HIV through collective action. In: Orsini M and Kelly C (eds) Mobilizing metaphor: Art, culture and disability activism in Canada. Vancouver, BC: University of British Columbia Press, 2016.

31. Roche J. A radical space? Life and love with HIV, 2018, https://www.lifeandlovewithhiv.ca/a-radical-space/

32. Life and love with HIV, 2017, www.lifeandlovewithhiv.ca

33. World Health Organization. Consolidated guideline on sexual and reproductive health and rights of women living with HIV. Geneva: World Health Organization, 2017.

34. Zhou ES, Nekhlyudov L and Bober SL. The primary health care physician and the cancer patient: tips and strategies for managing sexual health. Transl Androl Urol 2015; 4(2): 218–231.

35. Carter A, Anam F, Sanchez M, et al. Radical pleasure: feminist digital storytelling by, with, and for women living with HIV. Arch Sex Behav 2021; 50(1): 83–103.

36. Malta M, Todd CS, Stichish MA, et al. Patient–provider communication and reproductive health among HIV-positive women in Rio de Janeiro, Brazil. Patient Educ Couns 2010; 81(3): 476–482.

37. Stewart ZA, Shipley K, Spellman T, et al. Factors associated with discussion of sexual activity and contraception in women with HIV. J Fam Plann Reprod Health Care 2016; 42(1): 12–16.

38. Loutfy M, de Pokomandy A, Kennedy VL, et al. Cohort profile: the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS). PLoS ONE 2017; 12(9): e0184708.

39. Loutfy M, Greene S, Kennedy VL, et al. Establishing the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS): operationalizing community-based research in a large national quantitative study. BMC Med Res Methodol 2016; 16(1): 101–110.

40. Carter A, Greene S, Nicholson V, et al. Breaking the glass ceiling: increasing the meaningful involvement of women living with HIV/AIDS (MIWA) in the design and delivery of HIV/AIDS services. Health Care Women Int 2015; 36(8): 936–946.

41. Kaida A, Carter A, Nicholson V, et al. Hiring, training, and supporting Peer Research Associates: operationalizing community-based research principles within epidemiological studies by, with, and for women living with HIV. Harm Red J 2019; 16(1): 47.

42. Webster K, Carter A, Proulx-Boucher K, et al. Strategies for recruiting women living with human immunodeficiency virus in community-based research: lessons from Canada. Prog Commun Health Partner 2018; 12(1): 21–34.

43. Carter A, Greene S, Money D, et al. The problematization of sexuality among women living with HIV and a new feminist approach for understanding and enhancing women’s sexual lives. Sex Roles 2017; 77(11): 779–800.

44. Carter A, Loutfy M, de Pokomandy A, et al. Health-related quality-of-life and receipt of women-centered HIV care among women living with HIV in Canada. Women Health 2018; 58(5): 498–518.

45. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1977; 1(3): 385–401.

46. Wagnild G and Young H. Development and psychometric validation of the resilience scale. J Nurs Meas 1993; 1: 165–178.

47. Berger BE, Ferrans CE and Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. Res Nurs Health 2001; 24(6): 518–529.

48. Wright ER, Wright DE, Perry BL, et al. Stigma and the sexual isolation of people with serious mental illness. Social Problems 2007; 54(1): 78–98.
49. Williams DR, Yan Jackson JS and Anderson NB. Racial differences in physical and mental health: socio-economic status, stress and discrimination. *J Health Psychol* 1997; 2(3): 335–351.

50. Lima VD, Bangsberg DR, Harrigan PR, et al. Risk of viral failure declines with duration of suppression on HAART, irrespective of adherence level. *J Acq Immune Def Syrd* 2010; 55(4): 460–465.

51. Hopman WM, Towheed T, Anastassiades T, et al. Canadian normative data for the SF-36 health survey. *Can Med Assoc J* 2000; 163(3): 265–271.

52. Florence E, Schrooten W, Dreezen C, et al. Prevalence and factors associated with sexual dysfunction among HIV-positive women in Europe. *AIDS Care* 2004; 16(5): 550–557.

53. Luzi K, Guaraldi G, Murri R, et al. Body image is a major determinant of sexual dysfunction in stable HIV-infected women. *Antivir Ther* 2009; 14(1): 85–92, https://www.intemedpress.com/serveFile.cfm?stUID=30dd51a2-3297-4da3-8ed0-bcac23a96ac0

54. Pinzone M, Gissu M, Bellissimo F, et al. Self-reported sexual dysfunction in HIV-positive subjects: a cross-sectional study. *Infectious Disease Tropical Medicine* 2015; 1(2): E104–E109, http://www.infectiousjournal.com/wp-content/uploads/sites/6/2015/07/IDTM—12-104-Celesia.pdf

55. Wilson TE, Jean-Louis G, Schwartz R, et al. HIV infection and women’s sexual functioning. *J Acquir Immune Defic Syndr* 2010; 54(4): 360–367.

56. Graham CA, Átulhofer A, Lange T, et al. Prevalence and predictors of sexual difficulties and associated distress among partnered, sexually active older women in Norway, Denmark, Belgium, and Portugal. *Arch Sex Behav* 2020; 49: 2951–2961.

57. Lee DM, Nazroo J, O’Connor DB, et al. Sexual health and well-being among older men and women in England: findings from the English longitudinal study of ageing. *Arch Sex Behav* 2016; 45(1): 133–144.

58. Mitchell KR, Jones KG, Wellings K, et al. Estimating the prevalence of sexual function problems: the impact of morbidity criteria. *J Sex Res* 2016; 53(8): 955–967.

59. Bancroft J, Loftus J and Long JS. Distress about sex: a national survey of women in heterosexual relationships. *Arch Sex Behav* 2003; 32(3): 193–208.

60. Campbell JC, Baty ML, Ghandour RM, et al. The intersection of intimate partner violence against women and HIV/AIDS: a review. *Int J Inj Contr Saf Promot* 2008; 15(4): 221–231.

61. Deering K, Logie C, Krusi A, et al. Prevalence and correlates of HIV stigma among women living with HIV in metro Vancouver, Canada. *AIDS Behav* 2021; 25(6): 1688–1698.

62. Logie CH, James LL, Tharao W, et al. HIV, gender, race, sexual orientation, and sex work: a qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PloS Med* 2011; 8(11): e1001124.

63. Machtinger E, Wilson T, Haberer JE, et al. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS Behav* 2012; 16(8): 2091–2100.

64. Logie CH, Marcus N, Wang Y, et al. A longitudinal study of associations between HIV-related stigma, recent violence and depression among women living with HIV in a Canadian cohort study. *J Int AIDS Soc* 2019; 22(7): e25341–e.