

Beyond prevention: Recognizing the concerns about sexual wellbeing among women post HIV diagnosis

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Background

The issue

While research on disease prevention with women living with HIV has been extensive over the past four decades, markedly less information is available to support health promotion, particularly their needs related to sexual health and wellbeing, including satisfaction and pleasure. Previous research has shown that approximately half of women living with HIV in Canada view sex as an important aspect of their lives. Distinct health needs relate not only to HIV prevention but also intimacy, relationships, body satisfaction, self-esteem, and disclosure and its consequences including intimate partner violence.

Reference: Carter, A., et al. (2017). The problematization of sexuality among women living with HIV and a new feminist approach for understanding and enhancing women's sexual lives. *Sex Roles*, 77(11-12), 779-800.

Research questions

To guide the development of affirmative resources to ensure that sexual health promotion becomes an essential part of caring for women living with HIV, we sought to answer the following questions:

1. What sexual health concerns do women have post-diagnosis?
2. What level of distress, if any, have these concerns caused?
3. How do social factors shape patterns of concern and distress?
4. Are women's needs for sexual health information being met?

Hypotheses

We hypothesized that most women would report ever experiencing sexual concerns following an HIV diagnosis and that distress levels will be equally high for emotional concerns as for physical concerns. We also hypothesized that age, depressive symptoms, violence and a higher degree of HIV-related stigma would be associated with higher odds of having had a sexual concern and severe sexual distress. 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.

Methods

Study design

We used questionnaire data collected between February 2016 and September 2019 from women living with HIV in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS, www.chiwos.ca). CHIWOS is Canada's largest community-based research study of women living with HIV. We hired and trained 40 women living with HIV as Peer Research Associates (PRAs). PRAs contributed to all stages of the research, including study design, participant recruitment, data collection, interpretation of results, and manuscript co-authorship.

Eligibility

Women were eligible if they were aged ≥ 16 years, self-identified as a woman living with HIV (inclusive of cis, trans, and gender diverse women), and resided in one of the three study provinces: British Columbia, Ontario, and Quebec. Women were screened for eligibility and provided with information about key ethical issues (e.g., privacy and confidentiality, the sensitive nature of questions), as well as available supports (e.g., an on-call counselor, list of local resources).

Methods (Continued)

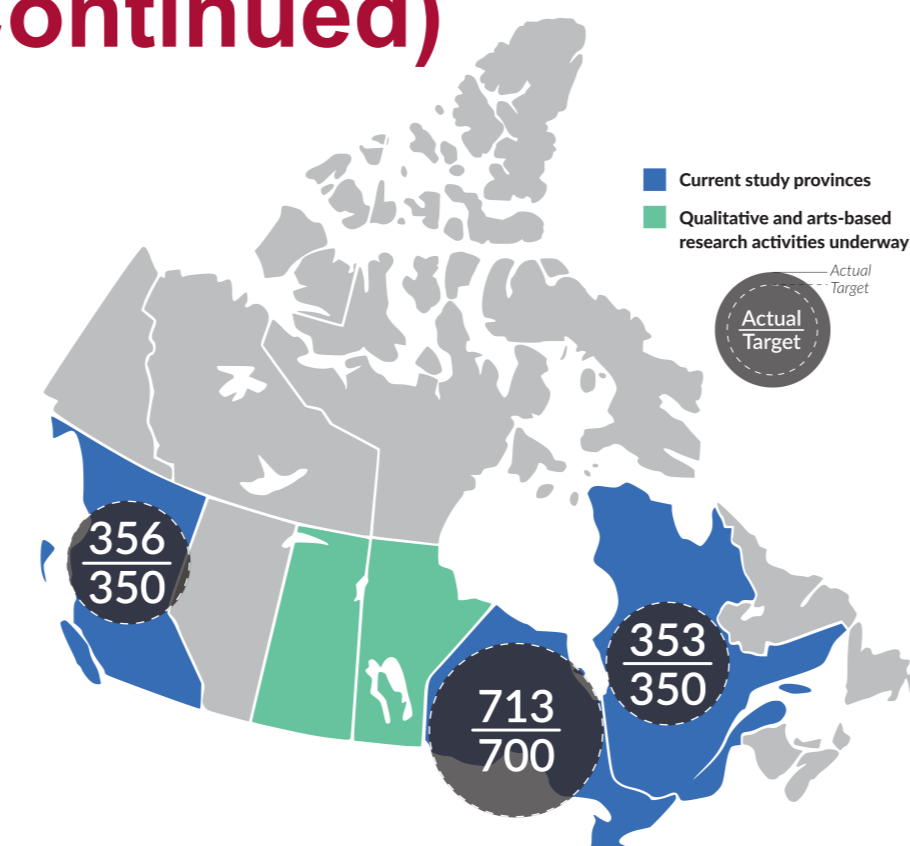


Figure 1. Map of participants recruited into study in Canada

Interviews

Interviews were conducted by PRAs in English or French, either face-to-face (in women's homes, clinics, or community organizations) or by phone or Skype, using a web-based survey platform. PRAs received comprehensive training on the questionnaire and best interviewing practices to maximize data quality. They also received guidance in community-based research principles, knowledge translation, and ethical issues. Participants and PRAs received \$50 CAD and \$75 CAD, respectively. Surveys lasted 2 hours (Q1, Q3: 90–150 min).

Variables

Women were asked: "Since knowing your HIV status, have you ever experienced any concerns about your sexual wellbeing?" Response options were sexual self-esteem (e.g., feeling sexually unattractive), emotional aspects of sex (e.g., sexual dissatisfaction), physical aspects of sex (e.g., sexual practices), sexual function (e.g., orgasm difficulties), relationships (e.g., abusive partners), and/or other (open-text field). Women reporting any concerns were asked: "How much distress, if any, did this concern cause you?" Responses were no, mild/moderate, or severe distress. Correlates were selected based on *a priori* literature review and classified into the four categories: medical factors, mental health and violence factors, social and political factors, and relationship factors. We also assessed whether women had ever talked to anyone about the impact of living with HIV on their sexual wellbeing, the information sources, and how helpful they were.

Analyses

We calculated the prevalence of sexual concerns and distress about sex and tested crude associations with all correlates via the Pearson's chi-squared test for categorical variables (Fisher's exact test for small cell counts) and the Kruskal-Wallis test for continuous variables. We ran 2 multivariable logistic regression models to identify factors independently associated with (1) ever experiencing a sexual concern and (2) experiencing severe distress about a sexual concern.

Results

Socio-demographics

1,116 women included in this analysis were diverse in gender (4% trans), sexual orientation (12% lesbian, gay, bisexual, two-spirited, queer), race (42% White, 32% African, Caribbean, and Black, 22% Indigenous women) and age (M: 46; Q1-Q3: 38-54). 88% were taking HIV treatment and 84% had an undetectable VL. 80% reported physical, sexual, or emotional violence as an adult, 62% as a child.

Results (Continued)

Sexual concerns and distress

56% of women reported ever experiencing sexual concerns post-diagnosis. Top areas of concerns are shown below. Reports of severe distress were highest for relationships (31%), but prevalent across all areas of concern (21–22%).

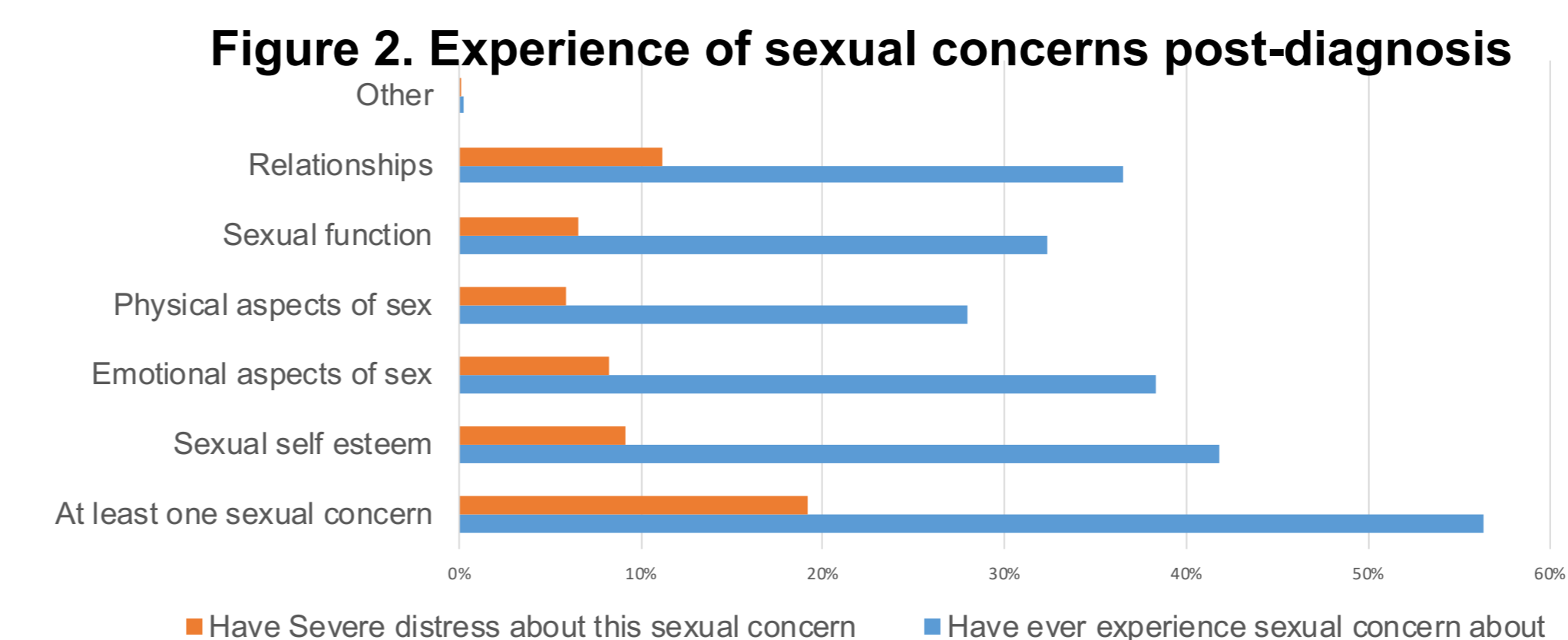


Table 1. Logistic regression model of factors associated with sexual concerns (ever) in women living with HIV (n=1,116)

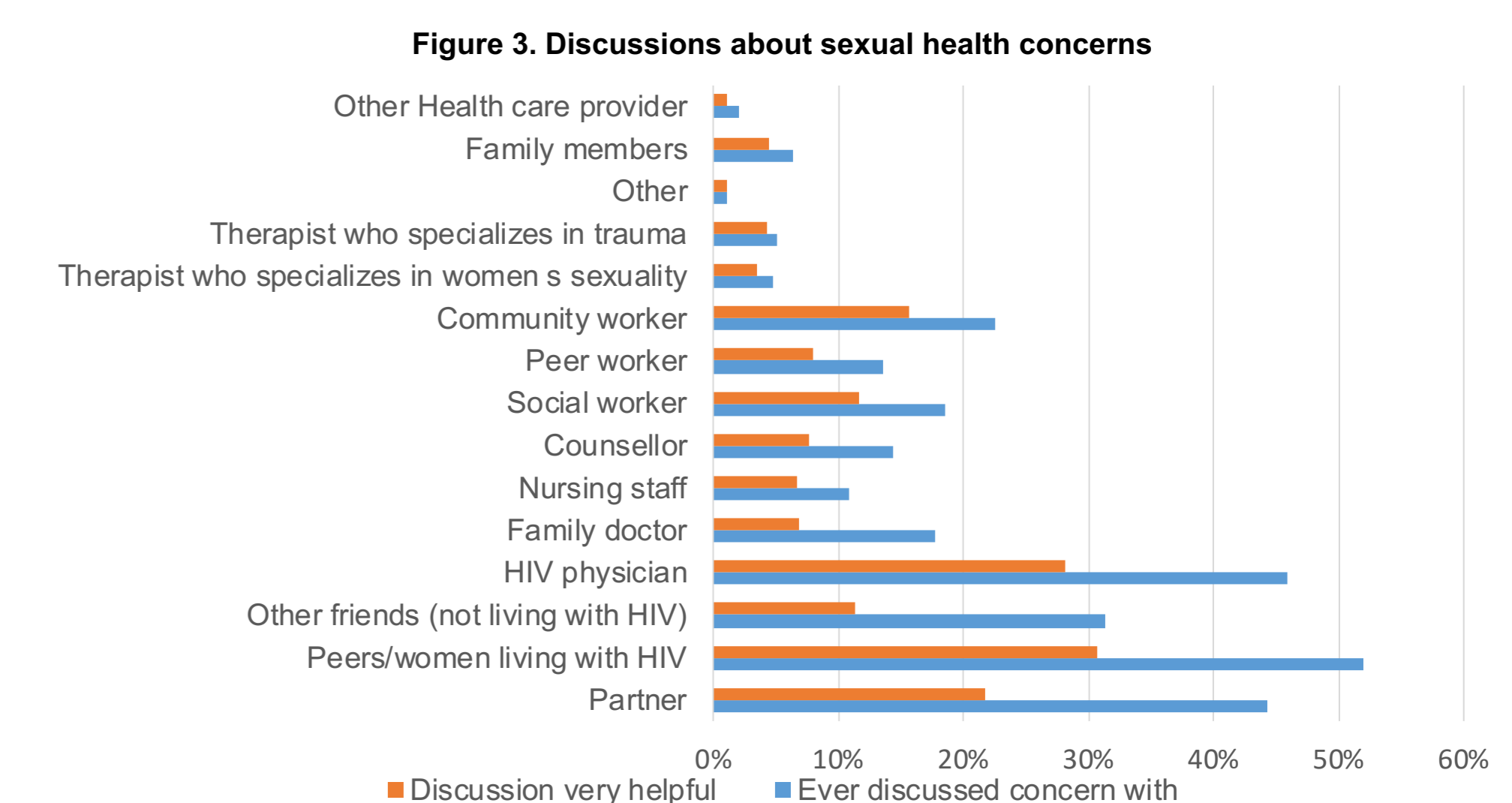
| Variable | Unadjusted OR (95% CI) | Adjusted OR (95% CI) |
|--|------------------------|----------------------|
| Race/Ethnicity | | |
| White | 1.00 (-) | 1.00 (-) |
| Indigenous | 0.47 (0.34, 0.64) | 0.58 (0.38, 0.87) |
| African, Caribbean, Black | 0.91 (0.69, 1.21) | 0.97 (0.67, 1.41) |
| Other | 0.9 (0.52, 1.55) | 0.7 (0.36, 1.38) |
| Sexual orientation | | |
| Heterosexual | 1.00 (-) | Not selected |
| LGBTQ | 1.43 (0.98, 2.07) | |
| Any violence as an adult | | |
| No | 1.00 (-) | 1.00 (-) |
| Yes | 3.76 (2.64, 5.34) | 2.02 (1.31, 3.11) |
| Get support from someone living with HIV | | |
| No | 1.00 (-) | Not selected |
| Yes | 1.13 (0.89, 1.43) | |
| On cART at wave 3 interview date | | |
| No (Never/Previously) | 1.00 (-) | 1.00 (-) |
| Yes (Currently) | 2.6 (1.77, 3.83) | 1.63 (0.93, 2.88) |
| Most recent VL | | |
| Detectable (above 50 copies/mL) | 1.00 (-) | Not selected |
| Undetectable (below 50 copies/mL) | 1.95 (1.33, 2.86) | |
| Most recent CD4 | | |
| 200-500 cells/mm3 | 1.00 (-) | 1.00 (-) |
| <200 cells/mm3 | 1.13 (0.56, 2.31) | 0.99 (0.39, 2.5) |
| >500 cells/mm3 | 1.78 (1.33, 2.36) | 1.39 (0.97, 1.99) |
| DK/PNTA | 0.83 (0.58, 1.19) | 0.89 (0.55, 1.43) |
| Current legal relationship status | | |
| Single | 1.00 (-) | 1.00 (-) |
| Legally married / Common-law / In a relationship | 0.98 (0.75, 1.27) | 0.65 (0.44, 0.96) |
| Separated/Divorced / Widowed | 1.19 (0.85, 1.65) | 0.94 (0.6, 1.47) |
| Any intimate relationship in past 6 months | | |
| No | 1.00 (-) | 1.00 (-) |
| Yes | 1.59 (1.25, 2.02) | 1.69 (1.13, 2.53) |
| Consensual sex in past 6 months | | |
| No | 1.00 (-) | Not selected |
| Yes | 1.42 (1.12, 1.8) | |
| Body satisfaction | | |
| Very satisfied / Somewhat satisfied | 1.00 (-) | Not selected |
| Neutral / Somewhat dissatisfied / Very dissatisfied | 1.19 (0.94, 1.52) | |
| How importance a part of your life is sexual activity | | |
| Very / Somewhat important | 1.00 (-) | 1.00 (-) |
| Neither important nor unimportant | 0.48 (0.35, 0.66) | 0.53 (0.35, 0.8) |
| Somewhat unimportant / Not at all important | 0.76 (0.58, 1.01) | 0.69 (0.46, 1.04) |
| How satisfactory is your present sex life | | |
| Completely / Very / Reasonably satisfactory | 1.00 (-) | 1.00 (-) |
| Not very / Not at all satisfactory | 3.72 (2.66, 5.21) | 2.47 (1.64, 3.7) |
| Age at wave 3 interview date (per 10 years) | 1.24 (1.11, 1.39) | 1.13 (0.97, 1.33) |
| Everyday Discrimination Scale - Sexism (per 10 units) | 1.2 (1.06, 1.37) | Not selected |
| Time living with HIV (per 10 years) at wave 3 interview | 1.48 (1.24, 1.77) | Not selected |
| HIV Stigma Scale (HSS) (per 10 units) | 0.98 (0.92, 1.04) | Not selected |
| Resilience Scale (14-item resiliency scale) | 0.94 (0.92, 0.95) | 0.96 (0.94, 0.98) |
| Mental health related quality of life (SF-12) | 0.95 (0.94, 0.96) | 0.97 (0.96, 0.99) |
| Depression scale (CES-D 10) | 1.09 (1.07, 1.11) | Not selected |

Table 2. Logistic regression model of factors associated with severe sexual distress in women living with HIV (n=612)

| Variable | Unadjusted OR (95% CI) | Adjusted OR (95% CI) |
|--|------------------------|----------------------|
| Race/Ethnicity | | |
| White | 1.00 (-) | Not selected |
| Indigenous | 0.88 (0.54, 1.44) | |
| African, Caribbean, Black | 0.73 (0.49, 1.06) | |
| Other | 0.39 (0.17, 0.93) | |
| Any violence as an adult | | |
| No | 1.00 (-) | Not selected |
| Yes | 2.13 (1.07, 4.26) | |
| Feel isolated as a woman with HIV in my community | | |
| Neutral / Disagree / Strongly disagree | 1.00 (-) | Not selected |
| Strongly agree / Agree | 2 (1.43, 2.8) | |
| Get support from someone living with HIV | | |
| No | 1.00 (-) | 1.00 (-) |
| Yes | 0.62 (0.44, 0.86) | 0.56 (0.36, 0.86) |
| Number of women with HIV you know personally | | |
| 1 to 4 women | 1.00 (-) | 1.00 (-) |
| None | 1.71 (1.03, 2.82) | 1.43 (0.79, 2.59) |
| 5 to 19 women | 1.19 (0.77, 1.85) | 1.3 (0.77, 2.19) |
| 20 women or more | 1.95 (1.2, 3.16) | 2.12 (1.18, 3.81) |
| Current legal relationship status | | |
| Legally married / Common-law / In a relationship | 1.00 (-) | Not selected |
| Single | 1.46 (0.99, 2.15) | |
| Separated/Divorced / Widowed | 1.81 (1.12, 2.95) | |
| Body satisfaction | | |
| Very satisfied / Somewhat satisfied | 1.00 (-) | Not selected |
| Neutral / Somewhat dissatisfied / Very dissatisfied | 1.72 (1.23, 2.41) | |
| How satisfactory is your present sex life | | |
| Completely / Very / Reasonably satisfactory | 1.00 (-) | 1.00 (-) |
| Not very / Not at all satisfactory | 2.11 (1.47, 3.01) | 1.81 (1.2, 2.73) |
| Age at wave 3 interview date (per 10 years) | 1.25 (1.06, 1.47) | 1.25 (1.03, 1.52) |
| Everyday Discrimination Scale - Sexism (per 10 units) | 1.37 (1.14, 1.65) | Not selected |
| Time living with HIV (per 10 years) at wave 3 interview | 1.24 (0.97, 1.58) | Not selected |
| HIV Stigma Scale (HSS) (per 10 units) | 1.23 (1.12, 1.35) | 1.21 (1.08, 1.35) |
| Resilience Scale (14-item resiliency scale) | 0.97 (0.96, 0.99) | Not selected |
| Mental health related quality of life (SF-12) | 0.96 (0.94, 0.97) | 0.97 (0.95, 0.98) |
| Depression scale (CES-D 10) | 1.06 (1.04, 1.09) | Not selected |
| Physical health related quality of life (SF-12) | 0.98 (0.96, 1) | 0.97 (0.95, 0.99) |

Sources of information regarding sexual health

85% of women ever discussed with a provider how viral load impacts transmission risk. Yet only 34% 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. Top sources of information are shown below.



When asked who (if anyone) would they feel most comfortable talking about sexual wellbeing, 23% said no one, while the remainder were most likely to name peers/women living with HIV (36%), their partner (34%), and their HIV physician (31%).

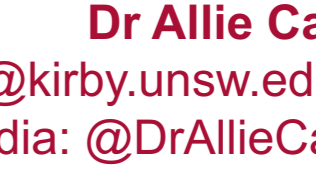
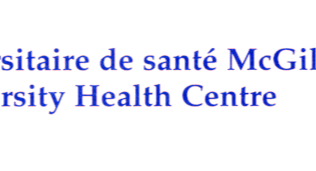
Conclusion

56% of women reported sexual concerns post-diagnosis, and about one-third reported severe distress about relationships. Health professionals should talk to women living with HIV about their sexual health and well-being beyond prevention and offer support for those experiencing distressing sexual concerns. Future research should explore the potential of multi-level sexual health promotion initiatives in improving outcomes, including sexual concern assessment, violence against women services, stigma reduction strategies, and peer support programs that build resiliency and mental health.

For a global sex-positive resource for women, please visit: lifeandlovewithhiv.ca



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