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on behalf of the CHIWOS Research Team

Sexuality Research and Social Policy

ISSN 1868-9884

Sex Res Soc Policy

DOI 10.1007/s13178-020-00432-2



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Sexual Anxiety Among Women Living with HIV in the Era of Antiretroviral Treatment Suppressing HIV Transmission

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Abstract

Introduction Sustained undetectable viral loads (UDVLs) on antiretroviral therapy (ART) eliminate sexual HIV transmission. We measured prevalence and correlates of sexual anxiety among women living with HIV.

Methods We used questionnaire data collected between August 2013 and May 2015 from 1422 women ≥ 16 years in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study. Among women reporting consensual sex in the past month ($n = 474$), we determined the proportion who reported high anxiety ("always/usually became anxious or inhibited during sexual activity with a partner"), low anxiety ("sometimes/seldom"), and no anxiety. Logistic regression identified medical, psychological, relational, and social correlates, including awareness of ART prevention benefits (i.e., "makes the risk of transmitting HIV a lot lower").

Results Cohort diversity is reflected in age (range 17–66; median 39), gender (5.7% trans), ethnicity (41.6% White, 24.5% Indigenous, 27.0% African/Caribbean/Black), sexual orientation (14.2% lesbian/queer), and time living with HIV (range 18 days–30 years.). Overall, 58.6% reported feeling no sexual anxiety, while the remainder said that they always/usually (14.6%) or sometimes/seldom (26.8%) became anxious or inhibited during sex. Current sex work, previous illicit drug use, and depression were associated with higher adjusted odds of sexual anxiety, while greater emotional closeness and more equitable relationship power were associated with lower odds. There was no correlation between awareness of ART prevention benefits and sexual anxiety.

Conclusions Relatively few women reported high anxiety during sex with a partner. This was more socially and relationally influenced than linked to understanding ART prevention benefits.

Policy Implications Women living with HIV should be supported to have great sex, free from worry, by tackling unequal power in women's intimate relationships, lack of access to resources, and mental health difficulties.

Keywords HIV · Women · Sexual anxiety · Antiretroviral therapy · Canada · CHIWOS

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People living with HIV who take antiretroviral therapy (ART) as prescribed and maintain an undetectable viral load (UDVL) cannot sexually transmit the virus to others (Eisinger, Dieffenbach, & Fauci, 2019; Rodger et al., 2016a; Rodger et al., 2019; Vernazza & Bernard, 2016; Vernazza, Hirschel, Bernasconi, & Flepp, 2008). This medical strategy of “treatment as prevention” (TasP) (Montaner, 2011) or “Undetectable=Untransmittable” (U=U) (Prevention Access Campaign, 2017) may help liberate people living with HIV from the acquired fear of HIV transmission in the late 1980s and early 1990s. For example, recent qualitative research with gay and heterosexual couples of mixed HIV serostatus in Australia has shown how advances in HIV treatment and care are re-shaping sexuality and intimacy in meaningful ways (Persson, 2016; Persson, Ellard, & Newman, 2016a). Evidence of such changes is also apparent in women’s own writings and accounts of U=U as it intersects with sexual behaviors and sexual feelings (Life and Love with HIV, 2017). From stories of love and pleasure to changes in sexual desires and the meanings of sexuality, it is clear that communities are beginning to repurpose this public health strategy to destigmatize sex and improve the overall quality of their intimate lives (Life and Love with HIV, 2017; Persson, 2016; Persson, Ellard, Newman, & Culture, 2016b). As HIV activist and author Juno Roche argues, however, caution is needed when assigning labels: even positive ones like U=U can be burdensome, opening up public space for some women to think and talk about sex in new and varied ways, while confining and silencing others who may be unable to achieve an UDVL for various social and structural reasons (Roche, 2018).

It is hypothesized that the increased feelings of sexual freedom are made possible through reduced anxieties around sexual risk and potential HIV transmission. Indeed, one theme that is prominent in both the quantitative (Bova & Durante, 2003; Courtenay-Quirk, Zhang, & Wolitski, 2009; El Fane et al., 2011; Goggin, Engelson, Rabkin, & Kotler, 1998; Hankins, Gendron, Tran, Lamping, & Lapointe, 1997; Lambert, Keegan, & Petrak, 2005; Zierler et al., 1999) and qualitative (Beckerman & Auerbach, 2002; Cranson & Caron, 1998; Keegan, Lambert, & Petrak, 2005; Lawless, Crawford, Kippax, & Spongberg, 1996a; Nevedal & Sankar, 2015; Persson, 2005; Rispel, Metcalf, Moody, Cloete, & Caswell, 2011; Siegel & Schrimshaw, 2003; van der Straten, Vernon, Knight, Gomez, & Padian, 1998; VanDevanter, Thacker, Bass, & Arnold, 1999) literature on women’s sexuality and HIV, across decades, countries, and socio-demographic groups, is women’s fear and concern about their condition being infectious or contagious. These feelings, caused by decades of stigma and fear-based HIV prevention campaigns (Albarracín et al., 2005) and media coverage (Mykhalovskiy, Hastings, Sanders, Hayman, & Bisailon, 2016; Persson & Newman, 2008), have consequences in women’s sexual lives, including low sexual desire, diminished sexual power and

freedom, feelings of unworthiness as romantic partners, and worries of being touched (Gurevich, Mathieson, Bower, & Dhayanandhan, 2007). Recent qualitative studies, however, highlight that U=U may be lessening fears of transmitting HIV and, in turn, reducing anxieties and inhibitions during sex (Persson, 2016; Persson et al., 2016a). To our knowledge, these hypotheses have yet to be studied using quantitative methods. In addition, much of the existing body of research in the current TasP era has examined changes in sexual behaviors (e.g., condomless sex) rather than sexual *feelings*—often from a medical perspective rather than a social or relational lens (Chen, 2013a; Crepaz, Hart, & Marks, 2004b; Hanif et al., 2014; Hasse et al., 2010; Kouyos et al., 2015; Patterson et al., 2017; Wilson et al., 2007), with some exceptions (Patterson et al., 2017).

In this paper, we examined the prevalence and correlates of sexual anxiety among women living with HIV in Canada. Our aims were twofold. First, we sought to test the emerging hypothesis that women living with HIV who are aware of the HIV prevention benefits of ART will be less likely to report anxiety or inhibition during sexual activity with a partner. At the same time, as feminist clinicians and social scientists, we wanted to interrogate the current biomedical framing of HIV-positive women’s sexual problems strictly in relation to the virus (Carter et al., 2017b). Because of the invisibility of women in discussions of U=U, the influence of social inequalities related to gender, class, ethnicity, and HIV continues to be largely ignored (Carter et al., 2017b). Yet recent empirical studies in Canada show that women’s social environment (e.g., poverty, violence, depression, substance use, sex work, unequal power in relationships, and laws against non-disclosure of HIV status) shapes multiple aspects of sexual well-being, including love, sexual satisfaction, and pleasure (Carter et al., 2018a; Carter et al., 2019; Carter et al., 2018b; Kaida et al., 2015; Logie et al., 2017). These cultural and relational factors were recently fit into four categories in a new theoretical framework for understanding the complicated issues affecting women’s lives and thus sexualities in the context of HIV: medical concerns, mental health and violence, relationship characteristics, and social and political context (Carter et al., 2017b). Using this feminist-based biopsychosocial model as guidance, the second aim of this article was to account for contextual factors that may affect sexual anxiety, in addition to the biomedical factors, and encourage the development of more women-centered models of sexuality and HIV.

Methods

Study Design

Our analysis drew on baseline questionnaire data from the Canadian HIV Women’s Sexual and Reproductive Health

Cohort Study (CHIWOS, www.chiwos.ca) (Loutfy et al., 2016). CHIWOS, Canada's largest community-based research (CBR) study of women living with HIV, was developed with the goal of creating new knowledge about women's sexual, reproductive, and mental health in specific social and medical contexts in order to build new or improve existing women-centered HIV services that fully address their unique needs. The study was conducted by the Simon Fraser University, the British Columbia Centre for Excellence in HIV, the Women's College Hospital, and the McGill University Health Centre, in collaboration with dozens of HIV clinics, AIDS service organizations, and many women living with HIV. Following ethical approval at these sites, participants were recruited through non-random sampling via peer networks, provider referrals, clinic and community outreach, and online networks between August 27, 2013 and May 1, 2015 (Webster et al., 2018). Women were eligible for inclusion if they were aged ≥ 16 years, self-identified as a woman living with HIV, and resided in one of the three study provinces. 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., access to an on-call counselor, list of local resources), to make an *informed* and *voluntary* decision to participate in the study. Following this, interviews were conducted by Peer Research Associates (PRAs) in English ($n = 1081$) or French ($n = 343$), either face-to-face (in women's homes, clinics, or community organizations) or by phone or Skype, using a web-based survey platform (FluidSurveys™). PRAs received on-going comprehensive research training about the questionnaire and best interviewing practices to maximize data quality (Kaida et al., 2019); they also received guidance in ethics, recruitment, knowledge translation, CBR principles, and various ethical issues common to HIV studies (e.g., traversing patient/researcher roles, unlearning prejudices, strategies for self-care, diversity of participants, power (im)balances in research teams) (Kaida et al., 2019). Participants and PRAs received 50 CAD and 75 CAD, respectively, for completing the survey, which lasted, on average, 2 h (interquartile range (Q1, Q3), 90–150 min). Women living with HIV contributed to all stages of the research, including study design (Loutfy et al., 2017), participant recruitment (Webster et al., 2018), data collection (Abelsohn et al., 2014), interpretation of results, and manuscript co-authorship. Follow-up was completed at 18 months and 36 months. The analysis presented here reflects baseline data.

Study Sample and Inclusion/Exclusion Criteria

In all, 1422 gender and socially diverse women living with HIV aged 16–72 participated in CHIWOS; they lived in British Columbia, Ontario, and Quebec (Loutfy et al., 2017), which are the Canadian provinces with the largest population

of women living with HIV (Public Health Agency of Canada, 2012). This analysis on sexual anxiety was restricted to participants who completed the sexual health section of the questionnaire ($n = 1339$, 94.2%) and who reported engaging in consensual partnered sex during the month prior to interview ($n = 485$, 34.1%). In designing the survey, we understood that for many women living with HIV, answering questions about sexual health might be emotional and difficult. We, thus, provided an option to complete this section on their own, with a PRA, or to skip this section. We did not collect information regarding why participants chose to not complete the sexual health section. Among these 485 women, an additional 11 were excluded because they provided invalid or missing responses to the primary outcome (sexual anxiety) or explanatory (TasP awareness) variable, yielding an analytic sample size of 474. In our first run of the regression model, the final sample size was 370, as observations with “do not know,” “prefer not to answer,” or otherwise missing responses to correlates were removed (i.e., missing 20% of 474). To retain the sample size, we created a separate response level (i.e., “don't know or prefer not to answer”) for categorical variables that had 15 or more missing observations (i.e., VL, income, violence, and communication of sexual desires or preferences), yielding a sample size of 423 (i.e., missing 11% of 474). In bivariable analyses, we determined that the sample that was missing data differed significantly from the analysis sample (i.e., they were more likely to be sex workers and report lower income and education). Thus, to retain the sample size further, we imputed the mean value for missing observations in continuous variables (i.e., sexism, HIV stigma, relationship power, and depression, which are described below in detail). As the amount of missing data in continuous variables was relatively small ($n = 6$ to $n = 13$), mean imputation did not have an appreciable effect on the results. The final “ n ” was 455 (96% of the sample).

Measures

The primary outcome measure was sexual anxiety, and the potential correlates were selected based on a priori literature review and classified into the four categories outlined in the new theoretical framework pertaining to women's sexual difficulties with HIV: medical factors, mental health and violence factors, social and political factors, and partner and relationship factors (Carter et al., 2017b).

Sexual Anxiety

Sexual anxiety was measured using a question from the validated Brief Index for Sexual Functioning for Women (BISF-W) (Mazer, Leiblum, & Rosen, 2000): “Overall, during the past month, how frequently have you become anxious or inhibited during sexual activity with a partner?” Likert scale

response options were “Always became anxious or inhibited;” “Usually, about 75% of the time;” “Sometimes, about 50% of the time;” “Seldom, less than 25% of the time;” “Not at all anxious or inhibited;” or “I have not had a partner in the past month.” We combined responses due to low sample size into three levels: high anxiety (“always/usually”), low anxiety (“sometimes/seldom”), and no anxiety (“not at all”). Those without a partner were excluded.

Medical Factors

Awareness of ART prevention benefits was measured via the question: “How do you think taking ART changes your risk of transmitting HIV?” For consistency with the science showing zero risk of transmission with UDVL (Rodger et al., 2016a), we defined awareness as “makes the risk of transmission a lot lower” and compared this to all other responses (i.e., “makes the risk of transmission a little lower,” “makes no difference to risk of transmission,” “makes the risk of transmission a little higher/a lot higher,” and “do not know”). Other medical factors were self-reported use of ART (currently, previously, vs. never) and self-reported most recent VL (undetectable vs. detectable, cutoff < 50 copies/mL). Self-reported VL was previously validated via linkage of survey data with laboratory data in British Columbia; the positive predictive value was 93.7 (95% CI 90.2–96.2) indicating that there were 94% of women who self-reported being undetectable (Carter et al., 2017a).

Violence and Mental Health Factors

Violence and mental health measures included any violence as an adult, any violence as a child, and depression. Violence as a child was defined as those who said “yes” to having ever experienced physical, sexual, or verbal violence before 16 years of age (yes vs. no). Violence as an adult included any physical, sexual, verbal, or controlling violence at 16 years of age or older (in the past 3 months, ever but not in the past 3 months, vs. never). Depression was assessed via the 10-item Centre for Epidemiologic Studies Depression Scale, which scores depressive symptoms (e.g., “I felt depressed”) in the past week on a 3-point scale (score range = 0 to 30, with ≥ 10 suggesting probable depression; Cronbach $\alpha = 0.74$) (Radloff, 1977; Zhang et al., 2012).

Social and Political Factors

Social and political factors included age at interview, gender (cis vs. trans/gender diverse women), sexual orientation (heterosexual vs. lesbian/bisexual/two-spirited/queer), ethnicity (Indigenous, African/Caribbean/Black, other/multiple ethnicities vs. White), annual personal income (< \$20,000 vs. \$20,000 or more), education level (less than high school, high school vs. more than high school), sex work in the last

6 months (yes vs. no), illicit drug use (in the past 3 months, ever but not in the past 3 months, vs. never), experiences of sexism (score range = 8 to 48; Cronbach $\alpha = 0.94$) and racism (score range = 8 to 48; Cronbach $\alpha = 0.94$) (Williams, Yan, Jackson, & Anderson, 1997), and HIV stigma (score range = 0 to 100; Cronbach $\alpha = 0.84$) (Berger, Ferrans, & Lashley, 2001; Wright, Naar-King, Lam, Templin, & Frey, 2007). Sexism (Cronbach $\alpha = 0.94$) and racism (Cronbach $\alpha = 0.96$) were assessed via the Everyday Discrimination Scale (Williams et al., 1997), which measures how often (“never” to “almost everyday”) sexist or racist events occur because of one’s gender or race (e.g., “you are treated with less courtesy,” “you receive poorer service”). HIV stigma was measured over one’s lifetime via the 10-item HIV Stigma Scale (Cronbach $\alpha = 0.85$) (Berger et al., 2001; Wright et al., 2007), which measures agreement (“Strongly disagree” to “Strongly agree”) on four subscale components: personalized or enacted stigma (e.g., “I have stopped socializing with some people because of their reactions to my having HIV”), internalized stigma (e.g., “I feel that I am not as good a person as others because I have HIV”), disclosure concerns (e.g., “I am very careful who I tell that I have HIV”), and public attitudes (e.g., “Most people think that a person with HIV is unclean”). Higher scores indicate higher sexism, racism, and HIV stigma.

Relationship Factors

Relationship factors included body satisfaction (satisfied/very satisfied vs. neutral/dissatisfied/very dissatisfied), relationship status (single, separated/divorced/widowed, other, vs. legally married/common-law/in relationship), regular sex partner (yes vs. no), casual sex partner (yes vs. no), affectionate support (i.e., felt love for and wanted by someone, all/most of the time vs. a little/none/some of the time), emotional closeness in sex life (satisfactory vs. non-satisfactory), ability to communicate sexual desires or preferences (always/usually vs. sometimes/seldom/not at all), and sexual relationship power, measured via the 15-item relationship control subscale of the Sexual Relationship Power Scale, score range = 15 to 60, with higher scores indicating more equitable sexual relationship power) (Pulerwitz, Gortmaker, & DeJong, 2000).

Analysis

We calculated the prevalence of sexual anxiety 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. Following this, we used multinomial logistic regression to identify factors independently associated with sexual anxiety. Candidates for model inclusion were variables having $p < 0.05$ in the bivariable analysis. Model selection was determined by minimizing the Akaike information criterion (AIC)

and maintaining type III p values. Both unadjusted and adjusted odds ratios (ORs and AORs) and 95% confidence intervals (CIs) were reported, which describe the strength of associations with “always/usually” or “sometimes/seldom” becoming anxious or inhibited, using the “not at all” category as the reference level. In addition, in post hoc analyses, we ran a confounder model to isolate the effect of awareness of ART prevention benefits ($n = 117$); this analysis was restricted to women reporting an UDVL, HIV-negative/unknown status male partner, and inconsistent condom use, and we adjusted for factors that were associated with both TasP awareness and sexual anxiety. All analyses were conducted using SAS 9.4 software (SAS Institute Inc., Cary, NC).

Results

Participants

As shown in Table 1, the majority of women included in this analysis identified as cisgender (94.3%) and heterosexual (85.8%) and the median age was 39 (Q1, Q3; 32.0, 45.0). Forty-two percent of women identified as White, 24.5% as Indigenous, and 27.0% as African, Caribbean, or Black. Fifty-eight percent reported being legally married, common-law, or in a relationship. Many had annual personal incomes of < 20,000 CAD (69.3%) and reported experiencing violence, at one time or another, as an adult (85.2%) or as a child (71.5%). Twelve percent were currently engaged in sex work and 25.2% were currently using illicit drugs. The median HIV-related stigma score in the sample was 55.0 (Q1, Q3; 40.0, 70.0), the median Center for Epidemiologic Studies Depression Scale (CES-D) score was 8.0 (Q1, Q3; 3.0, 14.0), and the median sexism and racism scores were 17.0 (Q1, Q3; 10.0, 27.0) and 16.0 (Q1, Q3; 8.0, 28.0), respectively. Most participants were on ART (81.3%) and self-reported an UDVL (77.6%).

Sexual Anxiety and Medical Factors

The majority of the sample (58.6%) reported feeling no anxiety during sexual activity with a partner in the past month, while the remainder said that they “always/usually” (14.6%) or “sometimes/seldom” (26.8%) became anxious or inhibited during sex. In addition, most women were aware of the prevention benefits of ART (72.4%). The prevalence of high sexual anxiety (i.e., “always/usually”) was *lower* in women who were aware of ART’s preventive benefits (13.4%) relative to those who were unaware (17.6%); however, this was not statistically different ($p = 0.508$). Examining the outcome by self-reported VL revealed the opposite effect to that hypothesized: the prevalence of high sexual anxiety was *greater*

in those who had an undetectable (16.8%) versus detectable (5.9%) VL ($p = 0.033$).

Sexual Anxiety and Social, Psychological, and Relational Factors

Table 1 shows all bivariable associations in further detail. Both mental health and violence were significantly associated with sexual anxiety ($p < 0.001$). For example, the prevalence of high sexual anxiety was greatest in women who were currently experiencing violence (22.0%) compared with those who have never experienced violence (13.4%, $p < 0.001$). The median CES-D score was also greatest among women reporting high sexual anxiety (13.0 (Q1, Q3; 8.0, 20.0)), relative to those reporting low sexual anxiety (10.0 (Q1, Q3; 5.0, 15.0)) and no sexual anxiety (5.0 (Q1, Q3; 2.0, 11.0)). In terms of social factors, higher levels of sexual anxiety were reported among trans and gender diverse women, less educated women, lower income-earning women, women currently using illicit drugs, and women currently engaged in sex work. For example, 31.6% of current sex workers reported high sexual anxiety compared with 12.0% of non-sex workers ($p < 0.001$). Structural influences such as HIV stigma and sexism were also significantly associated with women’s sexual anxiety. Women’s median HIV stigma and sexism scores were 60.0 (Q1, Q3; 46.3–80.0) and 22.5 (Q1, Q3; 14.5–28.5), respectively, at the highest level of the outcome (“always/usually” anxious or inhibited); these scores were much lower at the lowest level of the outcome (“not at all” anxious or inhibited), specifically 52.5 (Q1, Q3; 40.0–67.5) and 16.0 (Q1, Q3; 8.0–24.0), respectively. Finally, sexual anxiety was also associated ($p < 0.05$) with all measures related to relationships. Specifically, reports of “always/usually” becoming anxious or inhibited during sex were highest among those reporting body dissatisfaction, single relationship status (versus married), casual sexual partners, lower sexual relationship power, not enough emotional closeness in sex life, lower frequency of feeling love for and wanted by someone, and lower ability to communicate sexual desires or preferences.

Multivariable Model of Factors Associated with Sexual Anxiety

Table 2 presents the unadjusted and adjusted odds, with 95% CIs, of reporting high or low anxiety during sex in the past month, in reference to no anxiety. Consistent with the aforementioned bivariable analyses, awareness of the prevention benefits of ART was not associated with sexual anxiety, while having a detectable VL was significant at one outcome level (i.e., high anxiety AOR 0.25, 95% CI 0.08, 0.83; low anxiety AOR 0.74, 95% CI 0.37, 1.49). Current depression was also significant, but at both outcome levels (i.e., high anxiety AOR 1.10, 95% CI 1.05, 1.16; low anxiety AOR 1.04, 95% CI 1.00,

Table 1 Baseline characteristics and bivariable associations with sexual anxiety among women living with HIV in Canada: Canadian HIV Women's Sexual and Reproductive Health Study (*n* = 474)

Characteristics (<i>N</i> (%) or median (IQR))	Overall	Frequency of becoming anxious or inhibited during sex			<i>p</i> value
		Always/usually ("high anxiety," <i>N</i> = 69, 14.6%)	Sometimes/seldom ("low anxiety," <i>N</i> = 127, 26.8%)	Not at all ("no anxiety," <i>N</i> = 278, 58.6%)	
Medical factors					
Aware of the prevention benefits of ART					0.508
Yes	343 (72.4)	46 (13.4)	94 (27.4)	203 (59.2)	
No	131 (27.6)	23 (17.6)	33 (25.2)	75 (57.3)	
Use of combination antiretroviral therapy					0.091
Currently	383 (81.3)	61 (15.9)	108 (28.2)	214 (55.9)	
Previously but not currently	29 (6.2)	5 (17.2)	6 (20.7)	18 (62.1)	
Never	59 (12.5)	<5 (5.1)	13 (22.0)	43 (72.9)	
Most recent viral load					0.033
Undetectable (< 50 copies/mL)	368 (77.6)	62 (16.8)	99 (26.9)	207 (56.3)	
Detectable (≥ 50 copies/mL)	68 (14.3)	4 (5.9)	16 (23.5)	48 (70.6)	
Do not know	19 (4.0)	<5 (10.5)	8 (42.1)	9 (47.4)	
Never accessed care/results	19 (4.0)	<5 (5.3)	<5 (21.1)	14 (73.7)	
Most recent CD4					0.258
< 200 cells/mm ³	28 (7.0)	<5 (10.7)	8 (28.6)	17 (60.7)	
200–500 cells/mm ³	129 (32.2)	23 (17.8)	26 (20.2)	80 (62.0)	
> 500 cells/mm ³	226 (56.4)	30 (13.3)	69 (30.5)	127 (56.2)	
Mental health and violence factors					
Any violence as adult					< 0.001
Never	67 (14.8)	9 (13.4)	8 (11.9)	50 (74.6)	
Currently	123 (27.1)	27 (22.0)	40 (32.5)	56 (45.5)	
Previously but not currently	264 (58.1)	30 (11.4)	73 (27.7)	161 (61.0)	
Do not know/prefer not to answer	20	<5 (15.0)	6 (30.0)	11 (55.0)	
Any violence as child					0.042
No	129 (28.5)	17 (13.2)	25 (19.4)	87 (67.4)	
Yes	323 (71.5)	49 (15.2)	96 (29.7)	178 (55.1)	
Center for Epidemiologic Studies Depression Scale	8 (3.0–14.0)	13 (8.0–20.0)	10 (5.0–15.0)	5 (2.0–11.0)	< 0.001
Relationship factors					
Body satisfaction					0.043
Satisfied	318 (67.1)	43 (13.5)	76 (23.9)	199 (62.6)	
Dissatisfied	156 (32.9)	26 (16.7)	51 (32.7)	79 (50.6)	
Affectionate support					< 0.001
All/most of the time	355 (76.0)	40 (11.3)	84 (23.7)	231 (65.1)	
A little/none/some of the time	112 (24.0)	28 (25.0)	41 (36.6)	43 (38.4)	
Emotional closeness in sex life					< 0.001
Adequate	256 (54.4)	16 (6.3)	59 (23.0)	181 (70.7)	
Not adequate	215 (45.6)	53 (24.7)	67 (31.2)	95 (44.2)	
Communication of sexual desires or preferences					< 0.001
Always/usually	336 (73.4)	37 (11.0)	70 (20.8)	229 (68.2)	
Sometimes/seldom/not at all	122 (26.6)	28 (23.0)	52 (42.6)	42 (34.4)	
Do not know/prefer not to answer	16	<5 (25.0)	5 (31.3)	7 (43.8)	
Legal relationship status					
Legally married/common-law/in relationship	274 (57.9)	28 (10.2)	65 (23.7)	181 (66.1)	0.002
Single	155 (32.8)	34 (21.9)	48 (31.0)	73 (47.1)	
Separated/divorced/widowed	40 (8.5)	7 (17.5)	13 (32.5)	20 (50.0)	

Table 1 (continued)

Characteristics (<i>N</i> (%) or median (IQR))	Frequency of becoming anxious or inhibited during sex						<i>p</i> value
	Overall	Always/usually ("high anxiety," <i>N</i> = 69, 14.6%)		Sometimes/seldom ("low anxiety," <i>N</i> = 127, 26.8%)		Not at all ("no anxiety," <i>N</i> = 278, 58.6%)	
Other	4 (0.8)	0 (0.0)	<5 (25.0)	<5 (75.0)			
Casual sexual partner							<i>< 0.001</i>
No	369 (80.7)	42 (11.4)	96 (26.0)	231 (62.6)			
Yes	88 (19.3)	24 (27.3)	23 (26.1)	41 (46.6)			
Regular sexual partner							0.058
No	26 (5.6)	7 (26.9)	9 (34.6)	10 (38.5)			
Yes	438 (94.4)	60 (13.7)	113 (25.8)	265 (60.5)			
Sexual Relationship Power Scale (SRPS)	48 (43.0–56.0)	45 (39.0–51.0)	45 (41.0–51.0)	52 (45.0–58.0)			<i>< 0.001</i>
Social and political factors							
Gender identity							<i>0.021</i>
Woman	447 (94.3)	62 (13.9)	116 (26.0)	269 (60.2)			
Trans and gender diverse women	27 (5.7)	7 (25.9)	11 (40.7)	9 (33.3)			
Sexual orientation							0.260
Heterosexual	405 (85.8)	54 (13.3)	110 (27.2)	241 (59.5)			
Lesbian, bisexual, two-spirited, queer	67 (14.2)	14 (20.9)	16 (23.9)	37 (55.2)			
Ethnicity							0.505
Indigenous	116 (24.5)	15 (12.9)	30 (25.9)	71 (61.2)			
African, Caribbean, or Black	128 (27.0)	25 (19.5)	29 (22.7)	74 (57.8)			
White	197 (41.6)	24 (12.2)	57 (28.9)	116 (58.9)			
Other/multiple ethnicities	33 (7.0)	5 (15.2)	11 (33.3)	17 (51.5)			
Education level							<i>0.046</i>
Less than high school	75 (15.9)	19 (25.3)	21 (28.0)	35 (46.7)			
High school	172 (36.5)	22 (12.8)	45 (26.2)	105 (61.0)			
More than high school	224 (47.6)	27 (12.1)	60 (26.8)	137 (61.2)			
Personal gross yearly income							<i>0.009</i>
Less than \$20,000	318 (69.3)	54 (17.0)	80 (25.2)	184 (57.9)			
\$20,000 or more	141 (30.7)	9 (6.4)	43 (30.5)	89 (63.1)			
Do not know/prefer not to answer	15	6 (40.0)	<5 (26.7)	5 (33.3)			
Current sex work							<i>< 0.001</i>
No	408 (87.7)	49 (12.0)	108 (26.5)	251 (61.5)			
Yes	57 (12.3)	18 (31.6)	18 (31.6)	21 (36.8)			
Illicit drug use history							<i>0.033</i>
Currently	118 (25.2)	21 (17.8)	34 (28.8)	63 (53.4)			
Previously but not currently	134 (28.6)	19 (14.2)	46 (34.3)	69 (51.5)			
Never	217 (46.3)	28 (12.9)	46 (21.2)	143 (65.9)			
Age at interview	39 (32.0–45.0)	40 (34.0–47.0)	39 (33.0–45.0)	39 (32.0–45.0)			0.577
Years living with HIV	9.6 (5.6–15.5)	8.2 (3.8–14.8)	9.2 (5.6–16.4)	10.2 (5.7–15.2)			0.388
Genderism/sexism	17 (10.0–27.0)	22.5 (14.5–28.5)	22 (12.0–30.0)	16 (8.0–24.0)			<i>< 0.001</i>
Racism	16 (8.0–28.0)	21 (8.0–32.0)	15.5 (8.0–27.0)	15 (8.0–27.0)			0.232
HIV stigma	55 (40.0–70.0)	60 (46.3–80.0)	57.5 (45.0–67.5)	52.5 (40.0–67.5)			<i>0.010</i>

p values less than or equal to 0.05 were italicized. Do not know/prefer not to answer was not included in statistical tests. Row percentages are shown

1.08), while violence was not selected based on type III *p*-values and AIC. Social factors independently associated with sexual anxiety included sex work, illicit drug use, and sexism.

After adjusting for all factors shown in Table 2, sex work had the strongest effect: the adjusted odds of high sexual anxiety were more than four times greater for those reporting sex work

in the past 6 months, with the 95% CI showing a range of effects (AOR 4.54, 95% CI 1.63, 12.69). Regarding illicit drug use, the direction of the effect varied depending on whether women were current drug users (high anxiety AOR 0.35, 95% CI 0.13, 0.94) or previous drug users (low anxiety AOR 2.34, 95% CI 1.36, 4.04), relative to women who had never used illicit drugs. Finally, in terms of relationship factors, the adjusted odds of always/usually feeling anxious or inhibited during sex in the past month, relative to not at all, declined by 63% for those reporting adequate emotional closeness in their sex life (AOR 0.37, 95% CI 0.18, 0.76), and by 5–8% for each 1-point increase in sexual relationship power (i.e., high anxiety AOR 0.95, 95% CI 0.91, 0.99; low anxiety AOR 0.92, 95% CI 0.89, 0.95).

Discussion

In an era of knowledge that ART and an UDVL eliminate risk of sexual HIV transmission (Eisinger et al., 2019; Rodger et al., 2019; Rodger et al., 2016b; Vernazza & Bernard, 2016; Vernazza et al., 2008), relatively few women in our study reported that they “always/usually” became anxious or inhibited during sexual activity with a partner. In contrast to prevailing hypotheses about VL and transmissibility of HIV infection, the influence of biomedical factors showed inconsistent findings: awareness of the prevention benefits of ART had no effect, while a detectable VL was correlated with reduced sexual anxiety. Traditional gender-neutral narratives about U=U as universally sexually liberating become more complicated when considering these results. While this public health policy initiative may provide a release from fear of HIV transmission for some, other women may have a hard time fully trusting U=U after decades of socially enforced anxiety around contagion. The current analysis also demonstrated the central importance of relationships, emotional intimacy, mental health, and other social factors (e.g., sexism, drug use, sex work) to women’s sexual well-being, which are often ignored or minimized in sex research involving women living with HIV. These findings suggest that U=U is not a magic bullet for the social, political, relational, and psychological barriers to healthy sexuality for women living with HIV. Improving sexual health in this population requires gendering U=U and addressing the complicated issues of relationships, gender, and power present in women’s day-to-day lives.

In contrast to reports that female sexual dysfunction is frequent in women living with HIV (Florence et al., 2004), nearly 60% of sexually active participants in our study reported being not at all anxious or inhibited during sex with a partner. Comparisons to other quantitative studies are difficult due to differences in measures (Moody, Starks, Grov, & Parsons, 2018; Whitfield et al., 2019). Nevertheless, this adds to a growing body of qualitative literature that is countering

dominant knowledge paradigms regarding sex and pleasure as taboo or dangerous topics for women living with HIV (Closson et al., 2015; Cooper, Moore, & Mantell, 2013; Cranson & Caron, 1998; Fair & Albright, 2012; Gurevich et al., 2007; Jarman, Walsh, & De Lacey, 2005; Keegan et al., 2005; Lawless et al., 1996b; Lawless, Kippax, & Crawford, 1996b; Maticka-Tyndale, Adam, & Cohen, 2002; Mazanderani, 2012; Nevedal & Sankar, 2015; Persson, 2005; Siegel, Schrimshaw, & Lekas, 2006; Siegel & Schrimshaw, 2003). It is important to note, however, that this finding was restricted to women having sex.

About two-thirds of women in CHIWOS reported not engaging in consensual partnered sex during the month prior to interview, and this might be due to HIV-related stigma and anxiety. Previous research suggests many women (and partners) do worry about the risk of HIV transmission (Closson et al., 2015; Cranson & Caron, 1998; Keegan et al., 2005; Nevedal & Sankar, 2015; Persson, 2005; Wamoyi, Mbonye, Seeley, Birungi, & Jaffar, 2011), owing to cultural depictions of HIV as easily transmissible and a lack of public knowledge of U=U (Conrad, 1989). This can result in avoidance of romantic relationships, fear of intimate touch, and decreased sexual pleasure. While overcoming these challenges is important, women’s sexuality is frequently painted as dysfunctional and defined solely by the virus in their bloodstream (Carter et al., 2017b). The fairly low prevalence of always/usually feeling anxious or inhibited during sex (14.6%) in our study is an important finding against this prevailing story, reconceptualizing sexuality for most women as carefree or unconcerned within the private realm of sexual interactions, despite continued public anxiety about HIV.

The U=U campaign is assumed to offer a safer sexual space for people living with HIV to express, experience, and enjoy their sexuality. There is certainly no shortage of stories, both within research (Persson, 2016; Persson et al., 2016a) and online blogs (Carter, 2018; Jones, 2018), that celebrate the liberating message of U=U in preventing HIV and also reduce the stigma and fear associated with the disease. However, our finding that sexual anxiety did not significantly differ between those aware and unaware of ART’s preventive benefits is inconsistent with these assumptions and our own hypotheses.

It is also worth acknowledging that in discussing these findings with our team of PRAs, who are women living with HIV, many stated that their personal experiences are opposite to these findings: U=U changed their sex lives for the better. This may highlight the limits of quantitative analyses in terms of unearthing diversity of experience. It could also be that our survey question (i.e., “How do you think taking ART changes your risk of transmitting HIV?”) and event of interest (i.e., “makes the risk a lot lower”) were not specific enough, or that we did not explicitly ask if women feel anxiety about transmitting HIV to others, or that the collection period (i.e., 2013–2015) predated the emergence of conclusive science in 2016

Table 2 Multivariable logistic regression results of feelings “always/usually” or “sometimes/seldom” anxious or inhibited during sex in the past month, in reference to “not at all,” among women living with HIV in Canada: Canadian HIV Women’s Sexual and Reproductive Health Study ($n = 455$)

	Always/usually (“high anxiety”)		Sometimes/seldom (“low anxiety”)	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Medical factors				
Perception of how cART changes HIV transmission risk				
Makes the risk of transmission a lot lower	Reference			
A little lower/no difference/a little or a lot higher/DK	1.35 (0.76, 2.42)	1.19 (0.61, 2.33)	0.92 (0.57, 1.49)	0.75 (0.44, 1.29)
Most recent viral load (categorical)				
Undetectable (< 50 copies/mL)	Reference			
Detectable (≥ 50 copies/mL)	0.31 (0.11, 0.89)	0.25 (0.08, 0.83)	0.69 (0.37, 1.3)	0.74 (0.37, 1.49)
Do not know/never accessed care or results	0.52 (0.15, 1.81)	0.49 (0.11, 2.11)	1.24 (0.58, 2.65)	1.71 (0.72, 4.07)
Mental health and violence factors				
Center for Epidemiologic Studies Depression Scale	1.14 (1.10, 1.19)	1.10 (1.05, 1.16)	1.08 (1.04, 1.11)	1.04 (1.00, 1.08)
Any violence as adult				
Never/previously	Reference			
Currently	2.70 (1.50, 4.86)	Not selected	1.85 (1.14, 3.01)	Not selected
Do not know/prefer not to answer	1.68 (0.44, 6.42)		1.53 (0.54, 4.36)	
Relationship factors				
Emotional closeness				
Enough	0.16 (0.09, 0.30)	0.37 (0.18, 0.76)	0.48 (0.31, 0.74)	0.91 (0.54, 1.54)
Not enough	Reference			
Communication of sexual desires or preferences				
Always/usually	0.26 (0.14, 0.48)	Not selected	0.27 (0.16, 0.43)	Not selected
Sometimes/seldom/not at all	Reference			
Do not know/prefer not to answer	0.92 (0.25, 3.46)		0.35 (0.09, 1.45)	
Social and political factors				
Personal gross yearly income				
Less than \$20,000	Reference			
\$20,000 or more	0.35 (0.17, 0.75)	0.49 (0.21, 1.13)	1.08 (0.68, 1.7)	1.52 (0.91, 2.53)
Do not know/prefer not to answer	3.41 (0.95, 12.25)	3.35 (0.83, 13.5)	1.78 (0.47, 6.83)	1.28 (0.29, 5.63)
Education level				
Less than high school	Reference			
High school	0.39 (0.19, 0.83)	Not selected	0.72 (0.38, 1.39)	Not selected
More than high school	0.40 (0.20, 0.80)		0.76 (0.41, 1.41)	
Current sex work				
No	Reference			
Yes	4.71 (2.32, 9.57)	4.54 (1.63, 12.69)	1.82 (0.91, 3.65)	1.62 (0.68, 3.86)
Illicit drug use history				
Current RDU	1.75 (0.91, 3.36)	0.35 (0.13, 0.94)	1.73 (1.004, 2.97)	0.94 (0.47, 1.91)
Not current but previous RDU	1.36 (0.70, 2.65)	1.2 (0.57, 2.54)	2.09 (1.26, 3.46)	2.34 (1.36, 4.04)
Never RDU	Reference			
Genderism/sexism	1.05 (1.02, 1.07)	1.01 (0.98, 1.04)	1.04 (1.02, 1.06)	1.03 (1.001, 1.05)
HIV Stigma Scale (HSS)	1.02 (1.01, 1.04)	Not selected	1.01 (0.999, 1.02)	Not selected
Sexual Relationship Power Scale (SRPS)	0.90 (0.87, 0.94)	0.95 (0.91, 0.99)	0.92 (0.89, 0.94)	0.92 (0.89, 0.95)

OR odds ratio; 95% CIs excluding the null value were italicized

(Rodger et al., 2016b) and the worldwide advocacy that followed (Prevention Access Campaign, 2017). Although

awareness of U=U had begun in 2008 with the Swiss Statement (Vernazza et al., 2008), it took years, multiple large

studies, and wide dissemination of results to create a substantial discourse that could have an impact on an individual's risk assessment.

Despite the early timeframe, most women in our study were aware of the HIV prevention benefits of ART (>70%) and previous studies (Chen, 2013b; Crepaz, Hart, & Marks, 2004a; Hanif et al., 2014; Hasse et al., 2010; Kouyos et al., 2015; Patterson et al., 2017; Wilson et al., 2007; Wilson & Minkoff, 2001), including our own (Patterson et al., 2017), link this knowledge to changes in sexual behavior (e.g., condomless sex). Nevertheless, according to clinicians on our team, some women articulate a persistent concern about transmission in clinical interactions, even though they intellectually understand the science, especially women who have lived in fear for a long time. Further, it is one thing for women to be convinced about U=U but it is a separate challenge for their current or potential sex partners to accept the evidence. There is a need for additional research to examine if and how recent developments in awareness of the impact of undetectability on transmission may decrease sexual anxiety and increase pleasure among both women and their partners. Researchers should look at cause-effect relationships between U=U and changes in sexual anxiety over time through the use of longitudinal research design.

Importantly, however, we caution against the use of VL status to grant or deny women access to sexual pleasure (Roche, 2018). We also caution against “virologic reductionism,” or the way biomedical frameworks can reduce women's sexual concerns by viewing them through a lens of HIV-related immune function (e.g., CD4 decline) and viral detectability. Consistent with past quantitative (Carter et al., 2018a; Carter et al., 2018b; Carter et al., 2017b) and qualitative (Gurevich et al., 2007; Persson, 2005; Squire, 2003) research, our findings underscore that there is a larger context to consider, including sex work, drug use, mental health, sexism, and power dynamics in relationships. The strongest social determinant of sexual anxiety in this study was sex work; this may be because of a lack of supportive social policies for safer sex work in Canada, including on-going criminalization of sex work and a high prevalence of gender-based violence and socio-economic marginalization (Shannon, 2010; Shannon, Bright, Gibson, & Tyndall, 2007; Shannon et al., 2008b; Shannon, Kerr, Bright, Gibson, & Tyndall, 2008b; Shannon et al., 2008a; Shannon et al., 2009). Affective dimensions of sexuality beyond prevention are rarely studied in sex workers and warrant further scholarly attention (Benoit et al., 2013). Moreover, all women living with HIV in Canada are subject to laws that criminalize non-disclosure of HIV status (Patterson et al., 2019). The anxieties produced by these structural forces cannot be alleviated by U=U. Indeed, it remains unclear how U=U messaging can or should be taken up to re-appropriate sexual health and rights of women living with HIV, in the context of HIV criminalization (Kaida et al., 2015). Social

policies that aim to promote sexual rights and collective responsibility for sexual health promotion are needed.

Many women in our study reported high levels of depressive symptoms and substance use, and these factors were strongly linked with sexual anxiety. However, women who were actively using substances reported less sexual anxiety. As theorized by a woman on our team with living experience of both HIV and substance use, this finding may relate to a possible numbing effect that drugs may have on women's emotional pain and stress, causing some women who use substances to be less in tune with their own sexual well-being (Carter, 2018). Similarly, the finding that detectable VL was correlated with reduced sexual anxiety may be explained by the theory that other dominant life stressors (e.g., food insecurity, housing instability, difficulties engaging in medical care) may make sex feel like a non-anxiogenic activity. Alternatively, this may be due to residual confounding. Despite these challenges, our findings also demonstrate a positive link to egalitarian relationships, emotional intimacy, and other markers of relational well-being (e.g., communication of sexual desires and preferences). Collectively, these results are consistent with feminist (Tiefer, 2002) and psychosocial (Bancroft, Graham, Janssen, & Sanders, 2009) theories of the range of differing social, cultural, economic, political, relational, psychological, and medical processes that may influence women's sexual inhibition and excitation systems. It is clear from this analysis that women's experiences of sexual anxiety are complex and are affected by the interaction of several factors, as opposed to being solely biologically or solely socially determined.

Limitations

The taboo subject of HIV and sex in society, and the fear of judgment from others, may have precluded some participants from responding truthfully to the survey, perhaps underreporting experiences of anxiety or choosing to forgo questions altogether. The involvement of peer researchers with living experiences of the topics under study, however, may have lessened such biases. Other limitations of the study include the fact that data were collected from 2013 to 2015, the reliance on a one-item measure of sexual anxiety, the absence of questions aimed at understanding specific reasons for sexual anxiety, and dichotomous identity variables that fail to account for diversity within subgroups. Also, the small sample size of sexually active women meant we were restricted in the number of variables we could include within regression models. We chose to focus on aspects of relationships and social context that remain under-studied yet central to understanding sexual health (Carter et al., 2017b). As a result, several variables that were significant in bivariable analyses fell outside the broad findings discussed above. Their influence is

nonetheless important and should be further investigated in future studies.

Implications

Women living with HIV should be supported to have great sex, free from worry, by tackling unequal power in women's intimate relationships, lack of access to resources, and mental health difficulties. Clinicians could support sexual health by asking women if they are experiencing sexual difficulties and by making space for critically conscious sexuality education and support. This would move beyond safer sex messaging (e.g., understanding U=U, using condoms) to include broader, more nuanced contextual accounts of the issues that may influence sexual well-being, thereby supporting women living with HIV in understanding how their bodies and sexualities function in social, cultural, and political contexts. Sexual health educators and policy makers also have an important role to play in terms of creating enabling social environments for women's sexual health, well-being, and safety, including freedom from stigma and violence. With regard to research, studies might consider how we can make sexual experiences not only safer but also more enjoyable for women living with HIV. Ideally, such research might focus on the risks that women face (e.g., poverty, discrimination, criminalization) as well as protective factors—i.e., the strengths, resources, attributes, and conditions that can widen opportunities and possibilities for sexual happiness. Of central importance to future sex research is making this science accessible to women living with HIV through innovative knowledge translation activities such as lifeandlovewithhiv.ca (Life and Love with HIV, 2017).

Conclusions

The benefits of biomedicine are undisputable. However, as this study shows, these benefits do not eliminate the complex relational, social, and psychological realities in women's sexual lives. Thus, focusing solely on U=U, while useful in preventing sexual risk, is not sufficient for promoting sexual rights. If we are to truly advance sexual health equity for women living with HIV, a comprehensive understanding of the broader context of women's lives and therefore also their sexualities is needed. Policies can and should support sexuality for women living with HIV.

Acknowledgments The CHIWOS Research Team would like to thank women living with HIV for their contributions to this study. We also thank the national team of co-investigators, collaborators, and Peer Research Associates and acknowledge the national Steering Committee, our three provincial Community Advisory Boards, the national CHIWOS Aboriginal Advisory Board, the BC Centre for Excellence in HIV/AIDS for the data support and analysis, and all our partnering organizations for supporting the study.

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Authors' Contributions AC and AK conceived the idea for this analysis. All the authors contributed to the design and acquisition of data. Data preparation and statistical analysis were conducted by LW. Data interpretation was performed by AC and AK. AC drafted the initial manuscript; all the authors provided critical feedback. All the authors have critically reviewed and approved the final manuscript, gave approval for publication, and acted as guarantors of the work.

Funding CHIWOS is funded by the Canadian Institutes of Health Research (CIHR), the CIHR Canadian HIV Trials Network (CTN 262), the Ontario HIV Treatment Network (OHTN), and the Academic Health Science Centres (AHSC) Alternative Funding Plans (AFP) Innovation Fund. Title page listing all authors and affiliations Innovation Fund. AC received support from a CIHR Doctoral Award, SP received support in the form of a Study Abroad Studentship from the Leverhulme Trust, AdP received support from Fonds de Recherche du Québec – Santé (FRQS) (Chercheur-boursier clinicien – Junior 1 & 2), and AK received salary support through a Tier 2 Canada Research Chair in Global HIV and Sexual and Reproductive Health.

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