



## The Importance of Sex in the Lives of Women Living with HIV: A Critical Quantitative Analysis

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### ABSTRACT

The authors explored the importance of sex for 1,289 women living with HIV in Canada. Approximately half of women viewed sex as “very” (19.6%) or “somewhat” important (32.3%) and the remaining reported “neither important or unimportant” (22.0%), “somewhat unimportant” (5.4%), or “not at all important” (20.1%). Women who had a regular sex partner, identified as African, Caribbean, or Black, were more educated, believed HIV treatment prevents transmission, or had better physical health-related quality-of-life reported greater importance of sex, whereas those who were older, used illicit drugs, or experienced violence in adulthood reported lesser importance. Findings underscore the diversity of women's perspectives within the context of their lives.

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### **Introduction**

Women living with HIV are often not seen as sexual beings (Welbourn, 2013). The narrative perpetuated by dominant culture and internalized by women is that they are “damaged goods” and ought not to be having or wanting sex (Lawless, Crawford, Kippax, & Spongberg, 1996; Robbins, 2016). Consequently, sexuality is often overlooked within health policies and programs (Stewart, Shipley, Spelman, & Giles, 2016), and, in some cases, clinicians even advise women to practice sexual abstinence (Seeley et al., 2009; Wamoyi, Mbonye, Seeley, Birungi, & Jaffar, 2011). This perpetuates the myth that if you are HIV-positive, sex—let alone sexual pleasure—is not important. At the same time, based on assumptions of they acquired HIV, women may be perceived as promiscuous (Lawless, Kippax, & Crawford, 1996). Researchers reinforce these myths by either not studying sexuality altogether, focusing on sexual risk and transmission as a synonymous way to address sexual health, or emphasizing women’s loss of interest in sex at the neglect of diversity of experience. Women living with HIV, however, are challenging these negative constructions of sex and HIV by developing an alternative discourse that reaffirms their sexual desires (Caballero, 2016; McClelland & Whitbread, 2016; Mitchell, Whitbread, & McClelland, 2011; Whitbread, 2017) and that demands recognition of their sexual rights within research, policy, and practice (International Community of Women Living with HIV/AIDS, 2015; Salmander Trust, 2014).

As more sex research among women living with HIV has emerged, additional assumptions about the value and importance of sex have taken hold—namely, that sex is normal and necessary for healthy sexuality, and, thus, not having sex is abnormal, or, at the very least, unfulfilling (for a comprehensive review and critique: ). This is evident in research accounts that problematize sexual abstinence, where sex is often conceptualized as penile-vaginal intercourse. Although specific sexual behaviors (including vaginal sex for cis women) may be important for some and is a common question/concern following an HIV diagnosis (Hoffman, 2009; Persson, 2005), it may not be important for

others. It is also not the only sexual concern women face after learning of their HIV-positive status, with many reporting struggles around the emotional aspects of sexuality and their identity as sexual beings (Gurevich, Mathieson, Bower, & Dhayanandhan, 2007; Keegan, Lambert, & Petrak, 2005; Lawless et al., 1996; Siegel, Schrimshaw, & Lekas, 2006; Squire, 2003). However, women’s broader needs around sexuality continue to be neglected in sexual health care, where public health priorities and heteronormative assumptions give rise to limited advice after diagnosis, with a near exclusive emphasis on how to use condoms (for penetrative sex; Gurevich et al., 2007; Lawless et al., 1996).

In this article, we sought to challenge both these assumptions (that sex is unimportant to women living with HIV but also that sex is necessary) by hearing from women themselves. The objective of this analysis was to measure the importance of sex in the lives of women living with HIV in Canada. Pursuant to critical feminist quantitative methodology (Harnois, 2013; Sprague, 2016), we aspired to document the diversity of women’s viewpoints taking into consideration the social context in which they take shape. We were particularly interested in how knowledge about the impact of antiretroviral treatment on HIV prevention (Montaner, 2011; Rodger et al., 2016) may influence sexual importance. We also remained attentive to the possible effects of violence (Logie et al., 2017), HIV stigma (Berger, 2010; International Community of Women Living with HIV/AIDS, 2015; Logie, James, Tharao, & Loutfy, 2011), and other social and structural forces (e.g., sexism, racism, trauma, education, substance use). This is the first national study to consider whether women living with HIV perceive sex as important in their own lives and the factors influencing their perceptions of importance. We see this as an essential precursor to further research around other domains of sexuality, such as sexual desire, satisfaction, and pleasure (McClelland, 2010).

### **Methods**

#### **Study design**

We used baseline questionnaire data from the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS, [www.chiwos.ca](http://www.chiwos.ca)). A detailed

description of the cohort its community-based research design and survey development process sampling and recruitment strategy and critical feminist and social determinants of women's health frameworks can be found elsewhere. Briefly, between August 2013 and May 2015, a total of 1,424 self-identified women living with HIV (trans inclusive) aged  $\geq 16$  years were recruited into CHIWOS from British Columbia ( $n = 356$ , 25%), Ontario ( $n = 713$ , 50%), and Québec ( $n = 355$ , 25%) using nonrandom sampling methods (e.g., peer word-of-mouth, clinic referrals, community-based agencies). Among recruited women, structured online questionnaires (FluidSurveys<sup>TM</sup>) were administered by peer research associates to collect information about various health outcomes and experiences. *Peer research associates* are women living with HIV (38 in total) who were hired, trained, and supported to engage as partners in all stages of the research process (from designing the survey to disseminating research findings). Questionnaires were completed in English or French either in person (at clinics, community sites, women's home) or by telephone/Skype, and lasted a median time of 120 min (interquartile range [IQR]: 90, 150). The research ethics boards approved all study procedures.

### Study variables

#### Primary outcome

Sex was defined for participants as "consensual partnered sexual activity, encompassing any type of sexual intercourse that you willingly engaged in, including getting or giving oral sex, vaginal sex, and/or anal sex with people of any gender." The importance of sex in women's lives (the primary outcome variable) was then measured by the following question: "Overall, how important a part of life is your sexual activity?" Possible responses were "very important," "somewhat important," "neither important nor unimportant," "somewhat unimportant," and "not at all important." We combined the latter two responses in analyses due to low sample size.

#### Explanatory variables

Consistent with the classification scheme proposed in critical reviews of women's sexuality Tiefer, 2001), explanatory variables were grouped into four categories (their exact derivations are shown in [Table 1](#)).

Firstly, at the individual level, physical health factors included history of combination antiretroviral therapy (cART), most recent viral load (VL), most recent CD4 cell count, and physical health-related quality-of-life, which was estimated using the SF-12 version 2 (score range = 0–100, Cronbach  $\alpha = .82$ ), with higher scores indicating higher overall physical health status (Carter et al., 2017).

Secondly, factors relating to emotional well-being and trauma included mental health-related quality-of-life (likewise estimated using the SF-12; Carter et al., 2017), any violence (i.e., physical, sexual, verbal, controlling) as an adult, child, or during war or violent conflict, depression, assessed via the 10-item Centre for Epidemiologic Studies Depression Scale which measures depressive symptoms (e.g., "I felt depressed") in the past week on a 3-point scale (score range = 0–30 and a cut-off of  $\geq 10$  suggesting probable depression, Cronbach  $\alpha = .74$ ; Radloff, 1977; Zhang et al., 2012), and posttraumatic stress disorder (PTSD), assessed using the six-item PTSD Checklist, which measures trauma symptoms (e.g., "repeated, disturbing memories, thoughts, or images of a stressful experience from the past") in the past month on a 5-point scale (score range = 6–30, a cut-off of  $\geq 14$  indicating likely PTSD, Cronbach  $\alpha = .91$ ; Lang & Stein, 2005; Lang et al., 2012).

Thirdly, at the interpersonal level, we examined women's current legal relationship status, their experience of love (assessed on a 5-point Likert, "How often do you have available someone to love and make you feel wanted;" Gjesfjeld, Greeno, & Kim, 2007), whether or not they engaged in consensual partnered sexual activity in the last six months (as defined above), and if they had casual and/or regular sex partner(s) (defined elsewhere, see Kaida et al., 2015).

Finally, we also considered several factors relating to social identity, economic status, and political context including age, sexual orientation, gender, ethnicity, gross annual personal income, education level, transactional sex in the past 6 months (i.e., exchanged sex for money, drugs, shelter, food, gifts, or other items), history of illicit drug use (i.e., street drugs or prescription medications taken in excess of the directions), presence of biological children in the home, time living with HIV, mode of HIV acquisition, discussion with a provider on how cART/VL changes HIV transmission risk and their perception of that change (i.e., "makes the risk a lot lower" vs. all other

responses), and three scales—sexism/genderism, racism, and HIV stigma.

Sexism/genderism (score range = 8–48, Cronbach  $\alpha$  = .94) and racism (score range = 8–48, Cronbach  $\alpha$  = .95) were both assessed by the Everyday Discrimination Scale, which measures on 6-point scale how often sexist or racist events occur because of their gender or race (e.g., “you are treated with less courtesy,” “you receive poorer service;” Williams, Yan, Jackson, & Anderson, 1997). HIV stigma was measured over one’s lifetime via the 10-item HIV Stigma Scale, with items scored on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*) and then summed and scaled to range from 0 to 100 (Cronbach  $\alpha$  = .84), with higher scores indicating higher stigma (Berger, Ferrans, & Lashley, 2001; Wright, Naar-King, Lam, Templin, & Frey, 2007). Subscales include personalized 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”).

## Analysis plan

### Final analytic sample

Of the 1,424 women living with HIV enrolled in the study, we excluded women who did not complete the sexual health section of the questionnaire ( $n = 85$ ) or chose not to respond to the questions about engaging in consensual sex ( $n = 16$ ) and the importance of sex in their life ( $n = 34$ ), resulting in a sample of 1,289 women (90.5% of cohort). Those excluded were more likely to identify as African, Caribbean, and Black, have experienced violence at war, and be living in Ontario ( $p < .05$ ; data not shown). An additional 198 women who responded “don’t know” or “prefer not to answer” to the variables selected for inclusion in the model were removed from regression analyses. Thus, the final analytic sample in multivariable analyses was 1,091.

### Descriptive, bivariable, and multivariable analyses

We calculated descriptive statistics to describe baseline characteristics and the patterns of sexual importance for the cohort overall, using frequencies ( $n$ ) and proportions (%) for categorical variables and medians

and IQRs for continuous measures. Bivariable analyses were conducted of the explanatory variables by the outcome measure, using the Pearson  $\chi^2$  test or Fisher’s exact test for categorical variables and the Kruskal Wallis test for continuous variables. Multinomial logistic regression was used to identify factors independently associated with increased odds of reporting sex as very important, somewhat important, or neither important nor unimportant in one’s life, using somewhat unimportant/not at all important as the referent. Both unadjusted and adjusted odds ratios (ORs and AORs, respectively) and 95% confidence intervals (95% CIs) were reported. To select variables and build the final model, we used a comprehensive approach involving objective tests and subjective decisions (Rentsch et al., 2014), following a review of the literature. Bivariable results were used to screen variables; candidates for model inclusion had a crude association  $p$  value of  $< .05$ . For variables that were highly correlated (i.e., age and time living with HIV; depression and mental health-related quality-of-life; having partnered sex and having a regular or casual sex partner; and perception of how cART/VL impacts HIV transmission risk and discussed this with a provider), we included the measure that had higher face validity (i.e., age; depression; type of sex partner; and perception of transmission risk). Following this, all candidate variables were entered into the model. We then conducted backward stepwise elimination, removing variables one by one until the final model had optimal fit (i.e., lowest Akaike information criterion) while maintaining covariates with Type III  $p$  values  $< .2$ . All analyses were conducted using SAS version 9.3 (SAS, North Carolina, United States).

## Results

### Participants

As noted in Table 1, the 1,189 women included in our analysis were diverse in gender, sexual orientation, ethnicity, and age and included communities historically marginalized from past research, such as trans and gender diverse women (4.2%), sexual minorities (12.6% lesbian, gay, bisexual, two-spirited, queer), racialized women (22.3% Indigenous women and 28.9% African, Caribbean, and Black women), and both younger and older women (9.8% under 30, 27.5% 50 and over). Most participants (84.4%) had at least high school education, with

**Table 1.** Baseline characteristics of women living with HIV enrolled in [blinded] (N = 1,289).

Variables	n (%) or M (Q1, Q3)
Importance of sexual activity to life	
Very important	252 (19.6)
Somewhat important	416 (32.3)
Neither important nor unimportant	284 (22.0)
Somewhat unimportant	69 (5.3)
Not at all important	268 (20.8)
Correlates	
Social, cultural, political, and economic factors	
<i>Factors beyond HIV</i>	
Age (years), continuous	42.0 (35.0, 50.0)
Sexual orientation	
Heterosexual	1,122 (87.4)
Lesbian, gay, bisexual, two-spirited, queer (LGBTQ)	162 (12.6)
Gender identity	
Cis gendered women	1,235 (95.8)
Trans and gender diverse women	54 (4.2)
Genderism/Sexism, continuous	18.0 (10.0, 27.0)
Ethnicity	
White	540 (41.9)
Indigenous	291 (22.6)
African, Caribbean, Black	364 (28.2)
Other and multiple ethnicities	94 (7.3)
Racism, continuous	16.0 (8.0, 28.0)
Annual personal income (CAD)	
Less than \$20,000	900 (71.5)
\$20,000 to less than \$40,000	221 (17.5)
\$40,000 or more	138 (11.0)
Education	
Lower than high school	200 (15.6)
High school	552 (43.1)
Higher than high school	530 (41.3)
Transactional sex in the past 6 months	
No	1,197 (93.7)
Yes	80 (6.3)
Illicit drug use history	
Never	676 (53.1)
Previously	359 (28.2)
Currently (past 3 months)	237 (18.6)
Have biological children at home	
Yes	298 (23.1)
No	547 (42.4)
No biological children	395 (30.6)
Not biologically female	49 (3.8)
<i>Factors related to HIV</i>	
Time living with HIV (years), continuous	10.8 (6.1, 16.8)
Mode of HIV acquisition	
Consensual sex	625 (48.5)
Coercive sex	199 (15.4)
Sharing needles	254 (19.7)
Perinatal exposure	46 (3.6)
Blood transfusion or other	72 (5.6)
Don't know or prefer not to answer	93 (7.2)
Discussed with provider how viral load impacts HIV transmission risk	
Yes	872 (68.5)
No	402 (31.6)
Perception of how treatment changes HIV transmission risk	
Makes the risk a lot lower	845 (66.0)
All other responses (i.e., a little lower, no difference, higher, don't know)	435 (34.0)
HIV stigma scale (HSS), continuous	57.5 (42.5, 70.0)
Subscale 1 (personalized stigma), continuous	20.0 (12.5, 25.0)
Subscale 2 (disclosure), continuous	15.0 (12.5, 20.0)
Subscale 3 (internalized stigma), continuous	7.5 (2.5, 15.0)
Subscale 4 (public attitudes), continuous	15.0 (10.0, 17.5)

(Continued on next column)

**Table 1.** (Continued)

Variables	n (%) or M (Q1, Q3)
Mental health and violence factors	
Mental health-related quality of life, continuous	42.1 (31.4, 52.4)
Posttraumatic stress disorder, categorical	
Score < 14	668 (52.2)
Score ≥ 14 (likely PTSD)	612 (47.8)
Depression, categorical	
Score < 10	641 (51.4)
Score ≥ 10 (probable depression)	606 (48.6)
Any violence as an adult	
Never	235 (18.9)
Previously	737 (59.3)
Currently (past 3 months)	271 (21.8)
Any violence as a child	
No	382 (30.9)
Yes	852 (69.0)
Any violence at war, as an adult or child	
No	1,053 (85.1)
Yes	185 (14.9)
Physical health factors	
Physical health-related quality of life, continuous	47.9 (33.4, 55.3)
On combination antiretroviral therapy	
Never	161 (12.6)
Previously	59 (4.6)
Currently	1063 (82.9)
Most recent viral load	
Undetectable	1,000 (77.6)
Detectable	182 (14.1)
Never accessed medical care / Never received results	41 (3.2)
Don't know	66 (5.1)
Most recent CD4 cell count	
<200	69 (5.4)
200 to <500	350 (27.2)
500 or more	644 (50.0)
Never accessed medical care / Never received results	36 (2.8)
Don't know	188 (14.6)
Sex, love, and relationship factors	
Current legal relationship status	
Single	619 (48.3)
Separated/divorced/widowed	237 (18.5)
In a relationship, but not living together	117 (9.1)
Married/common-law	309 (24.1)
Frequency of experiencing love	
A little or none of the time	299 (23.6)
Some of the time	204 (16.1)
All or most of the time	766 (60.4)
Sexual activity with a partner in the past 6 months	
No	648 (50.3)
Yes	641 (49.7)
Casual sex partner in the past 6 months	
No	1,132 (89.3)
Yes	135 (10.7)
Regular sex partner in the past 6 months	
No	711 (55.7)
Yes	566 (44.3)

Note: [blinded].

incomes <\$20,000 CAD (71.4%). Some were using illicit drugs (18.6%) and involved in sex work (6.3%). The median time living with HIV was 10.8 years (IQR = 6.1, 16.8). Half of the cohort was sexually active, 88.2% of whom reported a regular sex partner. Depression (48.6%), PTSD

(47.8%), and violence as an adult (81.1%), child (69.0%), or during war (14.9%) were common. Most were on cART (82.9%) and had an undetectable VL (77.6%), with 66.0% believing it made the risk of HIV transmission a lot lower.

### **Perspectives on the importance of sex**

Approximately half of the women viewed sex as very (19.6%) or somewhat important (32.3%) and the remaining reported neither important or unimportant (22.0%), somewhat unimportant (5.4%), or not at all important (20.1%). In bivariable analyses (Table 2), perspectives on the importance of sex were not related to gender identity, sexism/genderism, sexual orientation, racism, sex work, PTSD, violence as a child or at war, or most recent VL or CD4 cell count. Women's views about sex were, however, associated at  $p < .05$  with several other social factors including age, ethnicity, income, education, illicit drug use, having children at home, time living with HIV, mode of HIV acquisition, discussions about and perceptions of how cART/VL changes transmission risk, and HIV stigma. For example, of women aware of antiretroviral therapy prevention benefits (i.e., it makes transmission risk a lot lower), 21.4% of women reported sex as very important, compared to 15.8% of women not aware ( $p < .0001$ ). Mental health-related quality-of-life, depression, and experiencing violence as an adult were also significantly related to the importance of sex in women's lives. For example, of women reporting previous or current violence as an adult, 29.7% and 25.8%, respectively, said sex was somewhat unimportant/not at all important, compared to 16.2% of women reporting no violence. Bivariable associations were additionally seen with cART use and physical health-related quality-of-life, with, for instance, those rating sex as very important having better overall physical health (47.7 [IQR = 34.4, 55.6]) versus those saying somewhat unimportant/not at all important (41.4 [IQR = 27.0, 53.9]). Finally, women's views about sex varied significantly by whether or not they were having sex. Of those reporting partnered sexual activity in the past 6 months, 30.1% viewed sex as very important and 42.1% as somewhat important, compared to 9.1% and 22.5%, respectively, of women not having partnered sex. Significant associations were also

observed by type of sex partner (i.e., regular, casual), current legal relationship status, and love.

### **Associations between sexual importance and covariates**

Table 3 presents the unadjusted ORs and AORs with 95% CIs of reporting increasing levels of sexual importance by differing levels of the covariates. The adjusted odds of viewing sex as very important, relative to somewhat unimportant/not at all important, were 13 times greater among women with a regular sex partner than women without (AOR: 13.46 [95% CI: 8.36, 21.66]). The AOR decreased across the remaining outcome levels (i.e., somewhat important, neither important nor unimportant) but remained significant (i.e., excluded the null value of 1) with a wide range of possible effects. While those with casual sex partners had elevated unadjusted odds of reporting higher levels of sexual importance (i.e., OR = 2.37 [95% CI: 1.28, 4.39]), this variable was not selected for during model fitting procedures. Love and relationship status were similarly unselected, signifying that other covariates more strongly explain variation in the outcome. Still, their unadjusted effects were notable. For example, relative to single women, women who were married/common-law (OR: 3.78 [95% CI = 2.35, 6.06]) or in a non-cohabiting relationship (OR = 4.18 [95% CI: 2.04, 8.57]) had increased odds of reporting sex as very important while women who were separated, divorced, or widowed had reduced odds (OR = 0.83 [95% CI: 0.51, 1.36]).

With respect to social factors, the adjusted odds of viewing sex as very important, relative to somewhat unimportant/not at all important, were 2 to 2.5 times greater for those with a high school education (AOR = 2.07 [95% CI: 1.12, 3.83]) or more (AOR = 2.47 [95% CI: 1.31, 4.66]), relative to those with less than high school education. A similar effect and variance around the estimate was seen among those believing that treatment makes the risk of HIV transmission a lot lower (AOR = 1.88 [95% CI: 1.21, 2.92]). African, Caribbean, and Black women also exhibited higher odds of rating sex as very important, relative to White women (AOR = 2.07 [95% CI: 1.13, 3.80]). In contrast, older age and substance use were associated with lower AORs. For example, for each 10-year increase in age, the odds of rating sex as very (AOR = 0.68 [95% CI: 0.54, 0.85]) or somewhat (AOR =

**Table 2.** Bivariable associations with sexual importance among women living with HIV enrolled in [blinded] ( $N = 1,289$ ), with row percentages shown.

Variables	Importance of sexual activity to life				p-value
	Very important $n$ (%) or $M$ (Q1, Q3)	Somewhat important $n$ (%) or $M$ (Q1, Q3)	Neither important nor unimportant $n$ (%) or $M$ (Q1, Q3)	Somewhat unimportant/not at all important $n$ (%) or $M$ (Q1, Q3)	
<b>Social, cultural, political, and economic factors</b>					
<i>Factors beyond HIV</i>					
Age (years), continuous	40.0 (34.0, 46.5)	41.0 (33.0, 48.0)	40.0 (34.0, 48.5)	49.0 (40.0, 55.0)	< .0001 .4673
Sexual orientation					
Heterosexual	212 (18.9)	364 (32.4)	251 (22.4)	295 (26.3)	
Lesbian, gay, bisexual, two-spirited, queer (LGBTQ)	39 (24.1)	50 (30.9)	32 (19.7)	41 (25.3)	3541
Gender identity					
Cis gendered women	237 (19.2)	403 (32.6)	273 (22.1)	322 (26.1)	
Trans and gender diverse women	15 (27.8)	13 (24.1)	11 (20.4)	15 (27.8)	
Genderism/sexism, continuous	20.0 (11.0, 29.0)	18.0 (10.0, 27.0)	17.0 (10.0, 27.0)	17.0 (8.0, 26.5)	.3401 .0005
Ethnicity					
White	86 (15.9)	187 (34.6)	111 (20.6)	156 (28.9)	
Indigenous	45 (15.5)	92 (31.6)	80 (27.5)	74 (25.4)	
African, Caribbean, Black	96 (26.4)	113 (31.0)	76 (20.9)	79 (21.7)	
Other and multiple ethnicity	25 (26.6)	24 (25.5)	17 (18.1)	28 (29.8)	
Racism, continuous	17.0 (8.0, 30.0)	16.0 (8.0, 29.0)	16.0 (8.0, 28.0)	14.0 (8.0, 26.0)	.1350
Annual personal income (CAD)					
<\$20,000	157 (17.4)	284 (31.6)	197 (21.9)	262 (29.1)	.0034
\$20,000 to <\$40,000	53 (24.0)	72 (32.6)	51 (23.1)	45 (20.4)	
≥\$40,000	38 (27.5)	46 (33.3)	31 (22.5)	23 (16.7)	< .0001
Education					
Less than high school	29 (14.5)	51 (25.5)	35 (17.5)	85 (42.5)	
High school	98 (17.7)	181 (32.8)	142 (25.7)	131 (23.7)	
More than high school	124 (23.4)	183 (34.5)	105 (19.8)	118 (22.3)	.3578
Transactional sex in the past 6 months					
No	234 (19.5)	385 (32.2)	270 (22.6)	308 (25.7)	
Yes	15 (18.7)	25 (31.2)	13 (16.2)	27 (33.7)	< .0001
Illicit drug use history					
Never	135 (20.0)	218 (32.2)	181 (26.8)	142 (21.0)	
Previously	75 (20.9)	117 (32.6)	55 (15.3)	112 (31.2)	< .0001
Currently (past 3 months)	40 (16.9)	77 (32.5)	41 (17.3)	79 (33.3)	
Have biological children living at home					
Yes	97 (17.7)	183 (33.5)	93 (17.0)	174 (31.8)	
No	67 (22.5)	100 (33.6)	63 (21.1)	68 (22.8)	< .0001
No biological children	75 (19.0)	122 (30.9)	118 (29.9)	80 (20.2)	
Not biologically female	13 (26.5)	11 (22.4)	10 (20.4)	15 (30.6)	
<i>Factors related to HIV</i>					
Time living with HIV (years), continuous	10.7 (5.9, 16.7)	9.8 (5.8, 16.6)	9.5 (4.9, 15.1)	13.1 (8.0, 18.1)	< .0001
Mode of HIV acquisition					
Consensual sex	125 (20.0)	194 (31.0)	168 (26.9)	138 (22.1)	< .0001
Non-consensual sex	40 (20.1)	72 (36.2)	34 (17.1)	53 (26.63)	
Sharing needles	38 (15.0)	77 (30.3)	38 (15.0)	101 (39.8)	
Perinatal exposure	13 (28.3)	20 (43.5)	7 (15.2)	6 (13.0)	
Blood transfusion or other	16 (22.2)	23 (31.9)	13 (18.1)	20 (27.8)	
Don't know or prefer not to answer	20 (21.5)	30 (32.3)	24 (25.8)	19 (20.4)	

(Continued on next column)



Table 2. (Continued)

Variables	Importance of sexual activity to life				p-value
	Very important n (%) or M (Q1, Q3)	Somewhat important n (%) or M (Q1, Q3)	Neither important nor unimportant n (%) or M (Q1, Q3)	Somewhat unimportant/not at all important n (%) or M (Q1, Q3)	
Discussed with provider how viral load impacts HIV transmission risk					
Yes	191 (21.9)	311 (35.7)	189 (21.7)	181 (20.8)	< .0001
No	59 (14.7)	104 (25.9)	87 (21.6)	152 (37.8)	< .0001
Perception of how treatment changes HIV transmission risk					
Makes the risk a lot lower	181 (21.4)	288 (34.1)	200 (23.7)	176 (20.8)	
All other responses (i.e., a little lower, no difference, higher, don't know)	69 (15.8)	125 (28.7)	82 (28.9)	159 (36.6)	
HIV stigma scale, continuous	57.5 (42.5, 72.5)	55.0 (40.0, 67.5)	62.5 (50.0, 75.0)	55.0 (42.5, 70.0)	.0002
Subscale 1 (personalized stigma), continuous	20.0 (12.5, 27.5)	17.5 (12.5, 25.0)	22.5 (15.0, 27.5)	17.5 (12.5, 27.5)	.0270
Subscale 2 (disclosure), continuous	17.5 (12.5, 20.0)	17.5 (12.5, 20.0)	15.0 (13.8, 20.0)	15.0 (10.0, 20.0)	.0294
Subscale 3 (internalized stigma), continuous	7.5 (0.0, 15.0)	7.5 (0.0, 15.0)	7.5 (7.5, 17.5)	7.5 (2.5, 15.0)	.0006
Subscale 4 (public attitudes), continuous	15.0 (10.0, 17.5)	15.0 (10.0, 15.0)	15.0 (10.0, 17.5)	15.0 (10.0, 17.5)	.0056
Mental health and violence factors					
Mental health-related quality of life, continuous	44.0 (33.9, 54.4)	42.7 (31.6, 52.3)	45.0 (32.7, 53.8)	38.1 (29.1, 50.7)	.0019
Posttraumatic stress disorder, categorical	128 (19.2)	224 (33.5)	157 (23.5)	159 (23.8)	.1641
Score < 14	122 (19.9)	188 (30.7)	126 (20.6)	176 (28.8)	
Score ≥ 14 (likely PTSD)	141 (22.0)	215 (33.5)	145 (22.6)	140 (21.8)	.0025
Score < 10	103 (17.0)	185 (30.5)	132 (21.8)	186 (30.7)	
Score ≥ 10 (depressive symptoms)	45 (19.1)	74 (31.5)	78 (33.2)	38 (16.2)	
Any violence as an adult	141 (19.1)	229 (31.1)	148 (20.1)	219 (29.7)	< .0001
Never	55 (20.3)	97 (35.8)	49 (18.1)	70 (25.8)	
Previously	73 (19.1)	119 (31.1)	101 (26.4)	89 (23.3)	.0918
Currently (past 3 months)	166 (19.5)	279 (32.7)	173 (20.3)	234 (27.5)	
Any violence as a child	201 (19.1)	338 (32.1)	236 (22.4)	278 (26.4)	.8141
No	40 (21.6)	61 (32.97)	38 (20.5)	46 (24.9)	
Yes	47.7 (34.4, 55.6)	51.4 (36.3, 56.5)	49.4 (36.6, 54.9)	41.4 (27.0, 53.9)	< .0001
Any violence at war, as an adult or child	25 (15.5)	56 (34.8)	56 (34.8)	24 (14.9)	.0002
Physical health factors	14 (23.7)	18 (30.5)	14 (23.7)	13 (22.0)	
Physical health-related quality of life, continuous	212 (19.9)	338 (31.8)	214 (20.1)	299 (28.1)	.5255
On combination antiretroviral therapy	201 (20.1)	319 (31.9)	212 (21.2)	268 (26.8)	
Never	34 (18.7)	54 (29.7)	48 (26.4)	46 (25.3)	
Previously	7 (17.1)	18 (43.9)	10 (24.4)	6 (14.6)	
Currently	10 (15.1)	25 (37.9)	14 (21.2)	17 (25.8)	.4896
Most recent viral load	13 (18.8)	26 (37.7)	12 (17.4)	18 (26.1)	
Undetectable	65 (18.6)	104 (29.7)	80 (22.9)	101 (28.9)	
Detectable					
Never accessed medical care / Never received results					
Don't know					
Most recent CD4 cell count					
<200					
200 to <500					

Table 2. (Continued)

Variables	Importance of sexual activity to life				p-value
	Very important n (%) or M (Q1, Q3)	Somewhat important n (%) or M (Q1, Q3)	Neither important nor unimportant n (%) or M (Q1, Q3)	Somewhat unimportant/not at all important n (%) or M (Q1, Q3)	
500 or more	135 (21.0)	210 (32.6)	134 (20.8)	165 (25.6)	
Never accessed medical care / Never received results	6 (16.7)	16 (44.4)	10 (27.8)	4 (11.1)	
Don't know	33 (17.5)	60 (31.9)	48 (25.5)	47 (25.0)	
Sexuality and relationship factors					
Current legal relationship status					
Single	93 (15.0)	181 (29.2)	160 (25.8)	185 (29.9)	< .0001
Separated/divorced/widowed	35 (14.8)	66 (27.8)	42 (17.7)	94 (39.7)	
In a relationship, but not living together	32 (27.3)	43 (36.7)	28 (23.9)	14 (12.0)	
Married/common-law	87 (28.2)	125 (40.4)	53 (17.1)	44 (14.2)	.0006
Frequency of experiencing love					
A little or none of the time	41 (16.5)	83 (20.1)	72 (25.7)	103 (31.4)	
Some of the time	38 (18.6)	73 (35.8)	40 (19.6)	53 (26.0)	
All or most of the time	169 (22.1)	257 (33.5)	168 (21.9)	172 (22.4)	< .0001
Sexual activity in the past 6 months					
No	59 (9.1)	146 (22.5)	180 (27.8)	263 (40.6)	
Yes	193 (30.1)	270 (42.1)	104 (16.2)	74 (11.5)	< .0001
Casual sex partner in the past 6 months					
No	205 (18.1)	353 (31.2)	262 (23.1)	312 (27.6)	< .0001
Yes	41 (30.4)	55 (40.7)	19 (14.1)	20 (14.8)	< .0001
Regular sex partner in the past 6 months					
No	67 (9.4)	166 (23.3)	197 (27.7)	281 (39.5)	< .0001
Yes	181 (32.0)	245 (43.3)	87 (15.4)	53 (9.36)	

Note: [blinded]

**Table 3.** Multinomial logistic regression results of reporting sex as ‘very important’, ‘somewhat important’, or 3, in reference to ‘somewhat unimportant/not at all important’ among women living with HIV enrolled in [blinded] ( $N = 1,091$ ).

Variables	Sexual importance					
	Very important		Somewhat important		Neither important or unimportant	
	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)
Social, cultural, political, and economic factors						
<i>Factors beyond HIV</i>						
Age (years), continuous (per 10-unit increase)						
Ethnicity						
White	1	1	1	1	1	1
Indigenous	1.17 (0.71, 1.92)	1.30 (0.73, 2.31)	1.05 (0.69, 1.57)	1.12 (0.69, 1.81)	1.66 (1.08, 2.54)	1.55 (0.95, 2.53)
African, Caribbean, Black	<b>2.37 (1.53, 3.68)</b>	<b>2.07 (1.13, 3.80)</b>	1.38 (0.93, 2.04)	0.96 (0.57, 1.63)	1.38 (0.89, 2.14)	0.76 (0.44, 1.30)
Other and multiple ethnicities	1.71 (0.89, 3.30)	2.05 (0.97, 4.33)	0.84 (0.45, 1.57)	0.94 (0.45, 1.81)	0.98 (0.49, 1.94)	0.86 (0.41, 1.79)
Annual personal income (CAD)						
<\$20,000	1	Not selected	1	Not selected	1	Not selected
\$20,000 to <\$40,000	<b>2.02 (1.25, 3.26)</b>		1.42 (0.92, 2.21)		1.37 (0.85, 2.22)	
≥\$40,000	<b>2.88 (1.57, 5.29)</b>		<b>1.97 (1.11, 3.49)</b>		<b>1.88 (1.02, 3.48)</b>	
Education						
Less than high school	1	1	1	1	1	1
High school	2.05 (1.20, 3.52)	2.07 (1.12, 3.83)	1.76 (1.13, 2.74)	1.77 (1.07, 2.94)	2.60 (1.58, 4.27)	2.00 (1.17, 3.43)
More than high school	2.92 (1.72, 4.98)	2.47 (1.31, 4.66)	2.37 (1.52, 3.68)	2.06 (1.21, 3.49)	2.20 (1.32, 3.67)	1.62 (0.91, 2.89)
Illicit drug use history						
Never	1	1	1	1	1	1
Previously	0.64 (0.43, 0.96)	0.99 (0.55, 1.79)	0.67 (0.47, 0.96)	0.72 (0.44, 1.19)	0.38 (0.25, 0.57)	0.46 (0.27, 0.78)
Currently (past 3 months)	<b>0.48 (0.29, 0.79)</b>	0.57 (0.28, 1.16)	<b>0.56 (0.37, 0.85)</b>	<b>0.46 (0.26, 0.83)</b>	<b>0.40 (0.25, 0.64)</b>	<b>0.38 (0.21, 0.71)</b>
Have biological children at home						
Yes	1	Not selected	1	Not selected	1	Not selected
No	<b>0.52 (0.33, 0.83)</b>		<b>0.64 (0.43, 0.96)</b>		<b>0.58 (0.37, 0.92)</b>	
No biological children	0.90 (0.54, 1.48)		0.90 (0.57, 1.41)		1.48 (0.92, 2.39)	
Not biologically female	0.64 (0.25, 1.69)		<b>0.26 (0.09, 0.77)</b>		0.59 (0.22, 1.62)	
<i>Factors related to HIV</i>						
Mode of HIV acquisition						
Consensual sex	1	Not selected	1	Not selected	1	Not selected
Non-consensual sex	0.84 (0.50, 1.41)		1.08 (0.69, 1.70)		<b>0.57 (0.34, 0.96)</b>	
Sharing needles	<b>0.41 (0.25, 0.67)</b>		<b>0.58 (0.39, 0.86)</b>		<b>0.34 (0.21, 0.54)</b>	
Perinatal exposure	3.08 (0.95, 9.96)		2.57 (0.82, 7.99)		1.46 (0.42, 5.11)	
Blood transfusion or other	0.86 (0.40, 1.72)		0.82 (0.41, 1.64)		0.49 (0.21, 1.11)	
Don't know or prefer not to answer	1.12 (0.511, 2.46)		1.10 (0.54, 2.25)		1.25 (0.61, 2.57)	
Perception of how treatment changes HIV transmission risk						
All other responses	1	1	1	1	1	1
Makes the risk a lot lower	<b>2.50 (1.71, 3.67)</b>	1.88 (1.21, 2.92)	2.00 (1.45, 2.77)	1.46 (1.01, 2.11)	2.26 (1.58, 3.25)	1.72 (1.16, 2.55)
HIV stigma scale (HSS), continuous	1.05 (0.96, 1.15)	1.04 (0.94, 1.16)	1.00 (0.92, 1.08)	0.99 (0.90, 1.08)	1.15 (1.06, 1.26)	1.09 (0.99, 1.20)
Mental health and violence factors						

Table 3. (Continued)

Variables	Sexual importance					
	Very important		Somewhat important		Neither important or unimportant	
	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)
Depression, categorical						
Score < 10	1	Not selected	1	Not selected	1	Not selected
Score ≥ 10 (depressive symptoms)	<b>0.58 (0.40, 0.83)</b>		<b>0.70 (0.51, 0.96)</b>		<b>0.67 (0.48, 0.95)</b>	
Any violence as an adult						
Never	1	1	1	1	1	1
Previously	0.61 (0.36, 1.02)	0.57 (0.31, 1.05)	0.59 (0.37, 0.94)	0.68 (0.40, 1.16)	0.34 (0.21, 0.54)	<b>0.51 (0.30, 0.87)</b>
Currently (past 3 months)	0.72 (0.39, 1.31)	0.60 (0.29, 1.26)	0.82 (0.48, 1.39)	0.93 (0.49, 1.76)	<b>0.36 (0.20, 0.63)</b>	0.55 (0.28, 1.07)
Physical health factors						
Physical health-related quality of life, continuous (per 10-unit increase)	<b>1.23 (1.09, 1.39)</b>	1.02 (0.88, 1.19)	<b>1.31 (1.18, 1.46)</b>	<b>1.14 (1.00, 1.29)</b>	<b>1.27 (1.13, 1.43)</b>	1.06 (0.93, 1.22)
On combination antiretroviral therapy						
Never	1	Not selected	1	Not selected	1	Not selected
Previously	0.75 (0.27, 2.10)		0.50 (0.20, 1.27)		<b>0.37 (0.14, 0.99)</b>	
Currently	0.57 (0.30, 1.10)		<b>0.46 (0.26, 0.81)</b>		<b>0.28 (0.16, 0.49)</b>	
Sexuality and relationship factors						
Current legal relationship status						
Single	1	Not selected	1	Not selected	1	Not selected
Separated/divorced/widowed	0.83 (0.51, 1.36)		0.68 (0.45, 1.03)		<b>0.50 (0.32, 0.79)</b>	
In a relationship, but not living together	<b>4.18 (2.04, 8.57)</b>		<b>2.86 (1.46, 5.60)</b>		<b>2.09 (1.03, 4.24)</b>	
Married/common-law	<b>3.78 (2.35, 6.06)</b>		<b>2.74 (1.19, 4.20)</b>		1.24 (0.77, 2.02)	
Frequency of experiencing love						
A little or none of the time	1	Not selected	1	Not selected	1	Not selected
Some of the time	<b>2.36 (1.29, 4.35)</b>		<b>2.43 (1.48, 4.01)</b>		1.42 (0.82, 2.48)	
All or most of the time	<b>2.86 (1.80, 4.54)</b>		<b>2.10 (1.43, 3.06)</b>		<b>1.66 (1.12, 2.48)</b>	
Casual sex partner in the past 6 months						
No	1	Not selected	1	Not selected	1	Not selected
Yes	<b>2.37 (1.28, 4.39)</b>		<b>2.01 (1.13, 3.58)</b>		1.16 (0.59, 2.28)	
Regular sex partner in the past 6 months						
No	1	1	1	1	1	1
Yes	<b>13.63 (8.79, 21.15)</b>	<b>13.46 (8.36, 21.66)</b>	<b>7.99 (5.43, 11.74)</b>	<b>7.48 (4.94, 11.34)</b>	<b>2.47 (1.62, 3.76)</b>	<b>2.62 (1.67, 4.13)</b>

Note: [blinded]. OR = odds ratio; AOR = adjusted odds ratio. Effect estimates with 95% confidence intervals that do not cross the null value of 1 are in bold.

0.72 [95% CI: 0.59, 0.87]) important were reduced by 28–34%. Other social factors were not selected for (i.e., income, children at home, mode of HIV acquisition) or not significant (i.e., HIV stigma) in the final multiple-adjusted model.

Although depression and violence as an adult showed unadjusted associations with the outcome, only violence was maintained in the model after backward selection and negatively associated with sexual importance (although the 95% CI excluded the null value for only one comparison: neither important or unimportant, in reference to somewhat unimportant/not at all important, for those experiencing previous violence compared to those never reporting any violence). Regarding physical health factors, use of cART was not selected for, and, after adjusting for all factors, higher physical health-related quality-of-life scores were associated with increased odds of feeling that sex was somewhat important, relative to somewhat unimportant/not at all important (AOR = 1.14 [95% CI: 1.00, 1.29]).

## Discussion

In this study of women living with HIV in Canada, we found that the importance of sex in women's lives was highly diverse. In contrast to cultural myths about sex being irrelevant once diagnosed with HIV, we found that one in two women living with HIV viewed sex as a very (19.6%) or somewhat (32.3%) important part of their lives. The remaining women felt sex (defined narrowly in our survey as consensual vaginal, anal, or oral sexual activity with another person) was neither important nor unimportant (22.0%), somewhat unimportant (5.4%), or not at all important (20.1%), challenging heteronormative and risk-based assumptions in research that tend to position these specific sexual acts as the most important sexual experiences and concerns for women (Fahs & McClelland, 2016). We also observed in this study that perspectives on sex varied markedly depending on what is happening in women's lives, from their experiences with sex and relationships through to complex personal and social factors such as age, education level, substance use, cultural background, mental and physical health, various forms of violence, and awareness of cART prevention benefits. These results suggest that as we work toward improving women's health and reducing social inequality in the context of HIV, sex may become an

important part of more women's lives. Findings also point to a need for HIV research to extend beyond sexual behaviors, however, because sex is not a universal priority.

The proportion of women in our study who rated sex as very or somewhat important was lower than estimates for general population studies (Avis et al., 2005; Laumann et al., 2006; Mulhall, King, Glina, & Hvidsten, 2008). For example, a global study of 27,500 individuals aged 40–80 years in 29 countries found that 33.8% of Canadian women felt that sex was an extremely or very important part of their life (Laumann et al., 2006). Different study measures and disparate social conditions may account for some of the observed differences. Our findings are consistent with other research using qualitative methods (Grodensky et al., 2015; Keegan et al., 2005; Nevedal & Sankar, 2015; Taylor et al., 2016) and women's own writings (Caballero, 2016; Iacono, 2016; Mitchell et al., 2011), which reveal that sex and more specifically sexual pleasure continue to be important in the lives of many women living with HIV. Although sexuality is often constructed as dangerous and more constraining with HIV owing to numerous social and structural forces (e.g., fear of transmission, external and internalized stigma, HIV non-disclosure laws; Gurevich et al., 2007; International Community of Women Living with HIV/AIDS, 2015; Nevedal & Sankar, 2015; Salamander Trust, 2014), these collective findings offer an alternative, more positive narrative regarding sex for women to examine.

At the same time, our findings confirm prior research showing that specific sexual behaviors are of little to no importance to some women living with HIV (Bernier et al., 2016; Nevedal & Sankar, 2015; Siegel & Schrimshaw, 2003). Within qualitative literature in particular, some women report a sense of apathy toward sex, especially if sex is how they contracted HIV (Grodensky et al., 2015; Gurevich et al., 2007). For various reasons, many make a deliberate choice to not to be sexually active and are happy with that decision (Psaros et al., 2012; Siegel & Schrimshaw, 2003), demonstrating resistance to the social construction of sex as necessary to life fulfillment. Our study adds to these nuanced understandings by also showing how other women (about one-quarter) continue to have sex despite feeling indifferent toward it. This may relate to particular social contexts or sexual expectations in relationships (e.g., sex to maintain a

relationship, sex to satisfy an aroused partner), as reported in literature among women without HIV (Braun, Gavey, & McPhillips, 2003; Hayfield & Clarke, 2012; Impett & Peplau, 2002). For some women, it may also relate to sex as work rather than pleasure (Hankins, Gendron, Tran, Lamping, & Lapointe, 1997). Rather than pathologize women's sexual feelings (or lack thereof), these findings highlight how women's views about sex are extremely diverse and reflect the unique context of women's lives.

Despite a common focus in sex research on factors relating to HIV infection, use of cART, VL level, and CD4 cell counts were not independently associated with how sex was prioritized for women living with HIV in our analysis. We did, however, find an association between better physical health-related quality-of-life and higher sexual importance, consistent with limited previous findings (Negin et al., 2016), though our results were only significant at the neutral level of the outcome (i.e., neither important nor unimportant, relative to somewhat unimportant/not at all important). Prior research has suggested that poorer physical health can create barriers to sexual activity (Bogart et al., 2006; Courtenay-Quirk, Zhang, & Wolitski, 2009). This can, in turn, result in sex assuming a lower priority, particularly among older people (Gott & Hinchliff, 2003), although it is unclear whether this is related to poorer physical functioning itself or other related factors (e.g., emotional stress, lack of a partner). Furthermore, our analysis points to factors beyond physical health, with relational and social variables showing the greatest associations with whether women placed more or less importance on sex.

One of the clearest findings from this analysis was that engaging in sexual activities with a partner was strongly correlated with sexual importance, as shown in a study of midlife women (HIV status unknown) (Thomas, Chang, Dillon, & Hess, 2014) and qualitative research with women living with HIV (Grodensky et al., 2015). Importantly, however, this does not mean that sex was altogether unimportant in the lives of women who were sexually inactive; in fact, sex assumed no importance at all for only one-third of this group. In addition, although we found women value sex more in both casual and committed relationships, the effects were most pronounced for those with regular sex partners. Previous work in this field has revealed that the frequency of sex and orgasms is higher in regular partnerships (Hankins et al., 1997),

which may explain this finding and underscore the importance of women's enjoyment of sex to its positioning in their life. A more multidimensional view of relationships is needed, however, as there may be meaningful differences in these couples' sexual attitudes and experiences based on other intersecting dynamics, such as power equity, emotional closeness, love, and marital status. For example, in our analysis, women who were separated, divorced, or widowed rated sex as less important. Although past HIV studies tend to cluster these women into an indiscriminate "single" category, the emotions accompanying these life transitions (e.g., sadness, anger, exhaustion, frustration) can, understandably, affect women's desire for sex (Hamilton & Meston, 2013), and, thus, may influence the role of sex in their life.

In terms of social context, our findings suggest HIV stigma does not influence (at least at a population level) the overall importance of sex in women's lives, though previous studies have shown links between stigma and different aspects of sexuality, including sexual activity (Kaida et al., 2015; Kaida et al., 2017) and sexual satisfaction (Castro, Le Gall, Andreo, & Spire, 2010). We also found no independent association with other structural systems (e.g., genderism/sexism, racism) and social identities (e.g., gender, sexual orientation). Instead, in our analysis, women who identified as African, Caribbean, Black women, reported higher levels of education, and were aware that HIV treatment reduces HIV transmission risk were more likely to say that sex was important to them. These findings underscore the influence of culture and education on sexuality (Heinemann, Atallah, & Rosenbaum, 2016) and may also signify the potential of the medical normalization of HIV as a chronic condition to de-stigmatize sex and sexuality for some women (Persson, 2016). Our analysis also found that older age, substance use, and violence lead some women to deprioritize the role of sex in their lives. Previous studies outside the HIV field have reported similar results regarding age and socioeconomic status as predictors of sexual importance (Avis et al., 2005; Cain et al., 2003). Importantly, however, in an ad-hoc analysis of sexually active women in our cohort, aging did not negatively impact sexual importance, whereas markers of social status, including current sex work, remained significant (data not shown). This finding refutes the stereotype that sex is altogether unimportant to women later in life, consistent with past

research outside the HIV field (Watson, Stelle, & Bell, 2017). Taken together, these results reveal how the importance of sex for women changes with context, life events, their status in society, and is not solely dependent on HIV-related factors.

### **Limitations and future research directions**

This analysis used secondary data. Although sexual health was a key objective of CHIWOS and our survey was driven by women's priorities, we were restricted to available measures. In particular, sex was defined in terms of oral, anal, and vaginal sexual behaviors with a partner. This is problematic because sex and sexuality can include a variety of elements (Fahs & McClelland, 2016; Peterson & Muehlenhard, 2007) that may matter as much to women as specific partnered sexual acts (Hayfield & Clarke, 2012; Taylor et al., 2016) such as kissing, cuddling, touching, feeling sexual attraction, being aroused, flirting and seduction, and masturbation. Future research should measure a wider range of sexual experiences, examining the importance of each.

In addition, the construct of "sexual importance" has not been well explored in previous literature and we are limited in our understanding of how women interpret this aspect of sexuality in the socially stigmatized context of HIV (McClelland, 2010). For some women, it is possible that the risks of pursuing sex may be so high (e.g., rejection, humiliation, disappointment) that even imagining this aspect of life as important isn't worthwhile. We recommend that this be considered in qualitative research. We also advocate for prospective cohort studies to evaluate changes in sexual importance over time.

Issues of self-reporting must also be considered in evaluating findings given the sensitive nature of the topic. Eighty-five participants skipped the sexual health section. This could indicate more negative experiences with sex or discomfort with answering questions about sexuality, which may have biased the results. The data may also be subject to social desirability bias, as prior research suggests self-reports of sexuality-related information are influenced by age (Wiederman, 1993), gender norms (Alexander & Fisher, 2003), and mode of data collection (McCallum & Peterson, 2012). However, having women living with HIV facilitate the interviews may have helped in building trust

and improving accuracy of reporting (Brizay et al., 2015).

It is also critical to stress that although our sample was diverse, further studies, including in-depth qualitative explorations, would be helpful in better understanding the meaning and importance of sex among under-represented groups, particularly trans and queer/lesbian women. Further, this study has focused on single identities and women's views about sex are likely influenced by multiple intersecting social categories and systems of privilege and oppression. Although qualitative methods are particularly well suited for this kind of inquiry, quantitative techniques, such as interaction terms (Harnois, 2013) and latent class analysis (Lanza, Bray, & Collins, 2013), may also be useful. Future studies could also model intimate relationships with an intersectional approach.

Major strengths of this analysis are that the idea for this work came from community, it was framed within a sex-positive feminist lens, and data were drawn from a large, multi-site cohort of women living with HIV, an underresearched population in the field of sexual science. Further critical work devoted to understanding and enhancing the sexual well-being and rights of women living with HIV is needed.

### **Implications**

Our grounding in feminist values means that our recommendations for women living with HIV are not intended to be prescriptive. We are not advocating that women prioritize sex in their lives, nor if, when, how, with whom, or how frequently they should have sex. Instead, we hope these findings help make women's voices and perspectives around sex heard in research and the larger world. For women living with HIV who place great importance on sex, they should be supported to construct more positive, rewarding, and confident sexual experiences. Those who feel sex is unimportant and prefer not to have it must also be supported—and their sexuality needs beyond sexual activity should not be neglected. Promoting positive sexuality also requires developing awareness of the links between society, culture, politics and how women come to think about and enact their sexuality. Helping women understand for themselves if and how larger social and structural forces may affect private intimate matters through access to nonjudgmental

information about sexuality (Life and Love with HIV, 2017) is key to building resilience—and resistance.

### Conclusions

This is the first large-scale cohort study to explore the importance of sex in the lives of women with HIV from their perspective, and the social factors that shape these views. This analysis provides empirical evidence to counter desexualizing stereotypes of women with HIV, while at the same time underscoring the need for sex research in the HIV field to move beyond a focus on prescriptive and risk-centered sexual behaviors. Future research on relational and psychosocial aspects of sexuality could help us more fully understand women's experiences. The social and political contexts that frame these experiences also need more attention. In studying the sexual lives of women living with HIV in this way, feminist research (Harnois, 2013; Sprague, 2016) is not about women per se but about what sexuality fully looks like from their perspective and what may need to change in the world around them so that they can have the sexual life they want.

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