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# Health-related quality-of-life and receipt of women-centered HIV care among women living with HIV in Canada

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**ABSTRACT**

We measured health-related quality of life (HRQOL) using the SF-12 among women living with HIV (WLWH) in Canada between August 2013 and May 2015. We investigated differences by perceived receipt of women-centered HIV care (WCHC), assessed using an evidence-based definition with a 5-point Likert item: "Overall, I think that the care I have received from my HIV clinic in the last year has been women-centered" (dichotomized into agree vs. disagree/neutral). Of 1308 participants, 26.3 percent were from British Columbia, 48.2 percent from Ontario, and 25.5 percent from Québec. The median age was 43 years (interquartile range = 36–51). Most (42.2 percent) were White, 29.4 percent African/Caribbean/Black, and 21.0 percent Indigenous. Overall, 53.4 percent perceived having received WCHC. Mean physical and mental HRQOL scores were 43.8 (standard deviation [*SD*] = 14.4) and 41.7 (*SD* = 14.2), respectively. Women perceiving having received WCHC had higher mean physical (44.7; *SD* = 14.0) and mental (43.7; *SD* = 14.1) HRQOL scores than those not perceiving having received WCHC (42.9; *SD* = 14.8 and 39.5; *SD* = 14.0, respectively; $p < .001$). In multivariable linear regression, perceived WCHC was associated with higher mental (β = 3.48; 95 percent confidence interval: 1.90, 5.06) but not physical HRQOL. Improving HRQOL among Canadian WLWH, which was lower than general population estimates, is needed, including examining the potential of WCHC as an effective model of clinical care.

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## Introduction

Over 17.5 million women globally, including 16,600 in Canada, are living with HIV (UNAIDS 2013), representing approximately one-quarter of all

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people with HIV (Public Health Agency of Canada 2012). Strong evidence now indicates that viral suppression through early and sustained use of combination antiretroviral therapy (cART) dramatically reduces HIV-related morbidity, mortality, and transmission (Cohen et al. 2011; Hogg et al. 1998; Montaner 2011; Montaner et al. 2014; Rodger 2016; Rodger et al. 2014). Yet significant gender gaps in HIV care and outcomes remain (Hankins 2008; Loutfy et al. 2013). Compared to men, women living with HIV (WLWH) are more likely to experience poorer quality care during the first year on treatment (Carter et al. 2014), worse adherence (Puskas et al. 2011), and suboptimal clinical outcomes including lack of viral suppression (Nicastri et al. 2007) and lower life expectancy (Patterson et al. 2015). These gaps are especially pronounced for Indigenous women and women who use illicit drugs (Carter et al. 2014; Patterson et al. 2015; Puskas et al. 2011). To address these inequities, greater emphasis must be placed on defining and measuring the impact of gendered person-centered HIV care models that consider the realities of women's entire lives, not just their infection, and adapt health services accordingly (Carter et al. 2013; Salmander Trust 2014). Such models of care, however, remain poorly understood.

Person-centered care models are multidimensional, involving several considerations such as understanding both the disease and illness experience, appreciating the whole person, promoting equity in decision-making, and enhancing the patient–doctor relationship (Kitson et al. 2013; McMillan et al. 2013). Further, individuals' perceptions of person-centered care have been associated with important health outcomes, more so than traditional approaches that measure doctors' verbal behavior. For instance, if patients receive what they perceive to be positive person-centered care, they are more satisfied, have fewer symptoms, and use system resources less (Little et al. 2001). Owing to these benefits, several instruments have been designed to measure distinct components of patients' perceptions of the clinical encounter such as communication, satisfaction, and trust (Hudon et al. 2011). Existing tools, however, have traditionally been developed to be gender neutral. One exception exists in the primary care literature (Scholle et al. 2004), wherein an instrument was gendered in several ways, including, for instance, modifying items to reflect women's framing of the issue (e.g., the health professional's ability to answer questions in a sensitive and caring way) and adding items specific to cis women (e.g., the ability to get obtain gynecologic and general health care at the same site).

In the context of HIV, research concerning gendered person-centered HIV care is still in its infancy. This emerging concept, termed women-centered HIV care (WCHC), was first conceptualized in a framework for cis, trans, and gender diverse women through a literature review conducted by our team in 2013 (Carter et al. 2013). The framework included twelve pillars of care for WLWH (e.g., care coordination and comprehensiveness, meeting women "where they are"), and drew attention to the women's unique opportunities and disadvantages in relation to health, owing to the intersections of sex (biology), gender (the socially constructed roles, identities, behaviors, expressions), race, class, sexual orientation, and other identities (Bowleg 2008; Wuest et al. 2002). The defining features of WCHC was further developed in a qualitative study among seventy-seven WLWH across Canada (O'Brien et al. submitted). Women's visions of WCHC reflected what was found in the literature with a particular emphasis on care that was not only coordinated, integrated, and comprehensive but also responsive to important social realities (e.g., stigma, violence, poverty, motherhood), community priorities (e.g., peer-driven support and leadership in care design and delivery), and cis women's specific health needs (contraception, pregnancy, cervical, and breast cancer screening). No empirical research, of which we are aware, has examined the potential relation of WCHC to health outcomes, despite calls for action from the global community of WLWH (Salmander Trust 2014).

Health-related quality of life (HRQOL), a multi-dimensional concept that includes the domains of physical, mental, emotional, and social functioning (Bakas et al. 2012), is an important health outcome that is widely used among the general population and HIV cohorts in Canada and globally. Studies of HRQOL in the HIV field have revealed gender differences in this outcome (Preau et al. 2004) and suggested that HRQOL is related to important aspects of person centeredness in care (Murri et al. 2003; Preau et al. 2004), along with several socioeconomic, psychological, and clinical and disease-related factors (Degroote, Vogelaers, and Vandijck 2014; Douab et al. 2014; Préau et al. 2007; Viswanathan, Anderson, and Thomas 2005). In this study, we measured HRQOL in a large, prospective cohort of WLWH in Canada, and assessed whether HRQOL differed by perceived receipt of WCHC.

## Methods

### The CHIWOS study

This analysis used data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a multi-site, longitudinal community-based research cohort study conducted by, with, and for WLWH in collaboration with researchers, health-care providers, policymakers, and other stakeholders (Loutfy et al. 2016, submitted).

### Study sample, recruitment, and procedures

Eligible participants included WLWH (self-identified) aged ≥16 years, including trans and gender-diverse women, from three Canadian provinces, including British Columbia (BC), Ontario (ON), and Québec (QC). Between August 27 2013 and May 1 2015, WLWH was recruited, mainly through peer word-of-mouth (35 percent), HIV clinics (34 percent), and AIDS Service Organizations (19 percent), as well as the networks of our national Steering Committee and three provincial Community Advisory Boards, and online methods, such as listservs for WLWH and our study's website (www.chiwos.ca), Facebook (www.facebook.com/CHIWOS), and Twitter (www.twitter.com/CHIWOSresearch) pages (Webster et al. submitted).

Participants completed structured questionnaires in English or French using online FluidSurveys$^{TM}$ software at baseline. Two follow-up interviews at approximately 18-month intervals are planned. Questionnaires are used to collect information about use of HIV clinical care, women's health outcomes, and various social determinants of health. Surveys were administered by Peer Research Associates, who were women living with HIV, recruited through an equity-oriented hiring process and trained in community-based research methodologies (e.g., confidentiality, survey design, interview skills, computer literacy) (Kaida et al. 2014). Study visits took 1.5–2.5 hours (median: 120 minutes, interquartile range [IQR]: 90–150) and were completed either in-person at collaborating HIV clinics, community-based organizations, or women's homes, or via telephone/Skype.

### Final analytic sample

A total of 1,425 WLWH enrolled in the CHIWOS study and completed the baseline visit. Baseline cross-sectional questionnaire data were used for this analysis. This analysis was restricted to participants who self-reported receipt of HIV care in the last year ($n$ = 1,335) and who provided valid responses to the primary explanatory variable (perceived WCHC; $n$ = 1,324) and the primary outcome measure (HRQOL; $n$ = 1,308). Thus, the final analytic sample for descriptive and bivariable analyses was 1,308. For the multivariable model, an additional 68 participants who had invalid responses to the covariates (such as *"don't know"* and *"prefer not to answer"*) were excluded from the final model ($n$ = 1,240).

### Primary outcome

The primary outcome was HRQOL estimated using the SF-12 (version 2), a measure for general health status (Ware, Kosinski, and Keller 1996), which has been validated among WLWH (Ion et al. 2011). The SF-12 contains 12 items that, when scored, yield eight subscales, which are then summarized into two summary scores: (1) a physical HRQOL score (subscales: physical functioning, role physical, bodily pain, and general health perceptions), and (2) a mental HRQOL score (subscales: vitality, social functioning, mental health and role emotional) (Ware, Kosinski, and Keller 1996). These two component scores provide a summary of the respondent's overall health status from both a broad physical and mental health perspective (Ware, Kosinski, and Keller 1996).

Data were scored by the Medical Outcomes Trust scoring method (Hays 2014; Ware et al. 2000; Ware, Kosinski, and Keller 1994). All 12 items were scored on a scale from 0 to 100, with higher scores indicating better health status. Items in the same subscale were then averaged together to create eight subscale scores, and each subscale score was standardized using a z-score transformation and normed to Canadian female population means and standard deviations (Hopman et al. 2000). Physical and mental HRQOL scores (Cronbach's alpha: 0.817 and 0.815, respectively) were calculated by adding the relevant subscale z-scores, each of which were multiplied by varimax-rotated factor scoring coefficients, and transforming to t-scores with a mean of 50 and a standard deviation of 10 (UCLA 2004). For those with one item missing, the missing value was replaced with the item sample mean. Participants missing more than one item were excluded from analyses. Higher scores for the SF-12 indicate better HRQOL.

### Primary explanatory variable

The primary explanatory variable was perceived WCHC, assessed using a 5-point Likert scale item measuring women's perceptions of the women-centeredness of HIV care received in the last year (i.e., whether from a clinic, health center, primary care office, or other care setting): "Overall, I think that the care that I have received from my HIV clinic has been women-centered." Responses were dichotomized into agree (*"strongly agree"*/*"agree"*) versus disagree (*"strongly disagree"*/*"disagree"*/*"neutral"*). Prior to responding to this question, all participants were provided with a standardized definition of WCHC which was developed based on a literature review (Carter et al. 2013), qualitative work with WLWH (Loutfy et al. submitted), and consultation with providers: "Women-centered care supports women living with HIV to achieve the best health and well-being as defined by women. This type of care recognizes, respects, and addresses women's unique health and social concerns and recognizes that they are connected. Because this care is driven by women's diverse experiences, women-centered care is flexible and takes the different needs of women into consideration."

Sub-analyses demonstrated the explanatory variable had construct validity, with agreement on this statement correlated with several features of WCHC, both overall and by each province, as expected from past research (Carter et al. 2013; O'Brien et al. submitted), including women's self-reports that their HIV clinic was a place where the care was gender-sensitive, had opportunities for peer support from other WLWH, and had multiple health services onsite to reduce the number of places women must visit for care (data not shown).

## Covariates

Sociodemographic covariates known to be associated with HRQOL (Degroote, Vogelaers, and Vandijck 2014; Douab et al. 2014; Préau et al. 2007; Viswanathan, Anderson, and Thomas 2005) considered in analyses included the following: age at interview (16–29 *vs.* 30–39 *vs.* 40–49 *vs.* ≥50 years), self-reported race/ethnicity (Indigenous *vs.* White *vs.* African, Caribbean, or Black vs. other/multiple ethnicities), gender identity (cis gender vs. trans gender, two-spirited, or gender queer), sexual orientation (heterosexual vs. lesbian/gay/bisexual/two-spirited/queer), legal relationship status (married/common law/in a relationship vs. single vs. separated/divorced/widowed), annual household income (<\$20,000 vs. ≥\$20,000), and illicit drug use history (currently vs. previously vs. never).

Province of residence (BC vs. ON vs. QC) was also considered, given the varied women's HIV care landscapes across the country. All variables satisfied the criteria for confounding (i.e., were associated with the explanatory variable and the outcome) or were significantly related to the outcome and, thus, were considered for inclusion in multivariable analyses.

Lastly, several self-reported clinical factors thought to be associated with HRQOL were also considered (Degroote, Vogelaers, and Vandijck 2014; Viswanathan, Anderson, and Thomas 2005), including: years since HIV diagnosis (<6 years vs. 6–14 years vs. >14 years), currently on cART (yes vs. no), most recent CD4 cell count (<200 vs. 200–500 vs. >500 cells/mm$^3$ vs. unknown), and most recent viral load (undetectable (≤50 copies/mL) vs. detectable (>50 copies/mL). We compared self-reported viral load with laboratory confirmation and found high validity for self-report (Carter et al. submitted). Out of concern for potential over-adjustment, as well as collinearity between age and time living with HIV, most recent CD4 cell counts were the only clinical variable considered for inclusion in multivariable analyses. This decision was supported by bivariable data, showing that CD4 cell count was a strong confounder.

## Statistical analysis plan

Baseline characteristics of study participants were described for the cohort overall and by province, with differences by province tested using Pearson $\chi^2$ test or Fisher's exact test for categorical variables and Kruskal–Wallis test for continuous variables. Mean physical and mental HRQOL scores were then compared across socio-demographic and clinical groups, with the Wilcoxon rank-sum test or Kruskal–Wallis test used to assess for significant differences in mean scores. Unadjusted and adjusted multivariable linear regression was used to examine the relationship between perceived WCHC and HRQOL, controlling for potential confounders. Model selections were conducted using a backward stepwise elimination technique based on two criteria (Akaike Information Criterion (AIC) and Type III $p$ values), with the least significant variable dropped until the final model had the optimum (minimum) AIC (Lima et al. 2007). Analyses were conducted using SAS version 9.3 (SAS, North Carolina, United States).

### Ethical approval

Ethical approval was granted from all CHIWOS Principal Investigators' institutional Research Ethics Boards, including Women's College Hospital, Simon Fraser University, University of British Columbia/Providence Health, and McGill University Health Centre. Ethical approval was also granted from AIDS Service Organizations or hospitals if recruitment occurred on site. All participants provided written, signed informed consent if interviews were conducted in person; those who completed interview over the telephone/Skype provided oral consent, with a witness. Participants were provided with $50 (CAD) honorarium for the baseline study visit.

## Results

### Baseline characteristics overall and by province

Of 1,308 included participants, 26.3 percent were from BC, 48.2 percent ON, and 25.5 percent QC. Overall, median age was 43 years (IQR: 36–51) and 42.2 percent identified as White, 29.4 percent as African, Caribbean, or Black, and 21.0 percent as Indigenous (Table 1). About two-thirds (64.8 percent) reported an annual household income <$20,000 CAD, and 17 percent reported currently using illicit drugs. Most participants had been diagnosed with HIV more than a decade prior [median (interquartile range, IQR): 11.2 years (6.4–17.2)] and were on cART (86.7 percent), with an undetectable viral load (85.6 percent) and a CD4 count >500 cells/mm$^3$ (61.2 percent).

Sociodemographic and HIV-related clinical characteristics varied by province. Women in ON were younger (median [IQR]: 41 (35–49) years) than those in BC (44 (37–51) years) and QC (46 (38–53) years) ($p < .001$). Nearly, half (44.2 percent) of participants in BC identified as Indigenous compared to 18.2 percent in ON and 2.1 percent in QC, where a much larger proportion of women identified as African, Caribbean, or Black (BC: 7.9 percent *vs.* ON: 32.8 percent *vs.* QC: 45.1 percent, respectively) ($p < .001$). Women in BC were also more likely to be earning <$20,000 CAD annually (73.2 percent) and reported currently using illicit drugs (34.8 percent). Those in BC and QC were more likely to be currently on treatment with undetectable viral loads.

### Bivariable patterns in HRQOL, WCHC, and other covariates

Overall mean physical and mental HRQOL scores were 43.8 ($SD = 14.4$) and 41.8 ($SD = 14.2$), respectively (medians [IQR]: 47.5 [33.2–55.3] and 41.9 [31.2–52.4]).

**Table 1.** Baseline characteristics of women living with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study, overall and by province ($N$ = 1308).

| Variables | Overall ($N$ = 1308) $n$ (%) | BC ($N$ = 344) $n$ (%) | ON ($N$ = 631) $n$ (%) | QC ($N$ = 333) $n$ (%) | $p$ value |
|---|---|---|---|---|---|
| **Primary explanatory variable** | | | | | |
| Receipt of perceived WCHC from HIV clinic in last year | | | | | |
| Strongly agree/agree | 698 (53.4) | 210 (61.1) | 375 (59.4) | 113 (33.9) | < .001 |
| Strongly disagree/ disagree/neutral | 610 (46.6) | 134 (38.9) | 256 (40.6) | 220 (66.1) | |
| **Sociodemographic variables** | | | | | |
| Age at interview (in years), median (IQR): | 43 (36–51) | 44 (37–51) | 41 (35–49) | 46 (38–53) | < .001 |
| Age at interview (in years), categorized | | | | | |
| 16–29 | 113 (8.6) | 24 (7.0) | 66 (10.5) | 23 (6.9) | < .001 |
| 30–39 | 389 (29.7) | 96 (27.9) | 221 (35.0) | 72 (21.6) | |
| 40–49 | 424 (32.4) | 120 (34.9) | 191 (30.3) | 113 (33.9) | |
| ≥ 50 | 382 (29.2) | 104 (30.2) | 153 (24.2) | 125 (37.5) | |
| Gender identity | | | | | |
| Cis-gender | 1257 (96.1) | 331 (96.2) | 608 (96.2) | 319 (95.8) | .946 |
| Trans-gender, two-spirited or gender queer | 51 (3.9) | 13 (3.8) | 24 (3.8) | 14 (4.2) | |
| Sexual orientation | | | | | |
| Heterosexual | 1145 (87.9) | 286 (83.1) | 552 (87.9) | 308 (92.5) | .001 |
| Lesbian/gay/bisexual/ trans/queer/other | 158 (12.1) | 57 (16.6) | 76 (12.1) | 25 (7.5) | |
| DK/PNTA[1] | 5 | < 5 | < 5 | < 5 | |
| Legal relationship status | | | | | |
| Married/common law/ in relationship | 420 (32.3) | 124 (36.4) | 195 (31.1) | 101 (30.3) | < .001 |
| Single | 627 (48.2) | 160 (46.9) | 334 (53.2) | 133 (39.) | |
| Separated/divorced/ widowed | 255 (19.6) | 57 (16.7) | 99 (15.8) | 99 (29.7) | |
| DK/PNTA[1] | 6 | < 5 | < 5 | < 5 | |
| Annual household income (Canadian dollars) | | | | | |
| < $20,000 | 822 (64.8) | 252 (73.2) | 365 (60.1) | 205 (62.9) | < .001 |
| ≥ $20,000 | 446 (35.2) | 83 (24.8) | 243 (39.9) | 121 (37.1) | |
| DK/PNTA[1] | 40 | 9 | 24 | 7 | |
| Race/ethnicity | | | | | |
| Indigenous | 274 (20.9) | 152 (44.2) | 115 (18.2) | 7 (2.1) | < .001 |
| Caucasian | 552 (42.2) | 137 (39.8) | 257 (40.7) | 158 (47.4) | |
| African, Caribbean, or Black | 384 (29.4) | 27 (7.9) | 207 (32.8) | 150 (45.1) | |
| Other | 98 (7.5) | 28 (8.1) | 52 (8.2) | 18 (5.4) | |
| Illicit drug use | | | | | |
| Currently (within the past 3 months) | 229 (17.8) | 120 (34.8) | 66 (10.7) | 43 (12.9) | < .001 |
| Previously | 375 (29.0) | 157 (45.6) | 128 (20.7) | 90 (27.2) | |
| Never | 685 (53.2) | 67 (19.5) | 420 (68.5) | 198 (59.8) | |
| DK/PNTA[1] | 20 | 0 | 18 | 2 | |

(*Continued*)

**Table 1.** (Continued).

| Variables | Overall (*N* = 1308) *n* (%) | BC (*N* = 344) *n* (%) | ON (*N* = 631) *n* (%) | QC (*N* = 333) *n* (%) | *p* value |
|---|---|---|---|---|---|
| **HIV-related clinical variables** | | | | | |
| Years since HIV diagnosis, median (IQR): | 11.2 (6.4–17.2) | 12.0 (6.6–17.8) | 10.2 (5.5–16.0) | 12.8 (7.6–18.3) | < .001 |
| Years since HIV diagnosis, categorized | | | | | |
| < 6 | 293 (23.1) | 73 (21.7) | 170 (27.8) | 50 (15.4) | < .001 |
| 6–14 | 516 (40.7) | 131 (39.0) | 250 (40.9) | 135 (41.9) | |
| > 14 | 460 (36.3) | 132 (38.3) | 191 (31.3) | 137 (42.6) | |
| DK/PNTA[1] | 39 | 8 | 20 | 11 | |
| Currently on antiretroviral therapy | | | | | |
| Yes | 1128 (86.7) | 311 (90.6) | 505 (80.6) | 312 (94.0) | < .001 |
| No | 173 (13.3) | 32 (9.3) | 121 (19.3) | 20 (6.0) | |
| DK/PNTA[1] | 7 | < 5 | 5 | < 5 | |
| Most recent CD4 cell count | | | | | |
| < 200 cells/mm3 | 68 (6.1) | 27 (8.9) | 21 (3.9) | 20 (7.1) | .003 |
| 200–500 cells/mm3 | 363 (32.7) | 112 (37.0) | 158 (29.9) | 93 (33.2) | |
| > 500 cells/mm3 | 680 (61.2) | 164 (54.1) | 349 (66.1) | 167 (59.6) | |
| DK/PNTA[1] | 197 | 41 | 103 | 53 | |
| Most recent viral load | | | | | |
| Undetectable (<50 copies/mL) | 1055 (85.6) | 281 (85.7) | 474 (81.7) | 300 (92.6) | < .001 |
| Detectable (≥50 copies/mL) | 177 (14.4) | 47 (14.3) | 106 (18.2) | 24 (7.4) | |
| DK/PNTA[1] | 76 | 16 | 51 | 9 | |
| **Outcome** | | | | | |
| Physical HRQOL score | | | | | |
| Mean (std): | 43.8 (14.4) | 39.6 (15.6) | 45.4 (13.1) | 45.3 (14.6) | < .001 |
| Median (IQR): | 47.5 (33.2–55.3) | 41.5 (27.3–53.1) | 50.0 (36.6–54.9) | 49.8 (33.3–57.7) | |
| Mental HRQOL score | | | | | |
| Mean (std): | 41.7 (14.2) | 39.8 (13.8) | 43.1 (14.4) | 41.3 (14.0) | .001 |
| Median (IQR): | 41.9 (31.2–52.4) | 40.3 (29.8–50.4) | 43.9 (32.2–53.8) | 41.9 (32.3–52.2) | |

*Note*: IQR, interquartile range; DK, don't know; PNTA, prefer not to answer; HRQOL, health-related quality of life; WCHC, women-centered HIV care; std, standard deviation. DK/PNTA[1] not included in the denominator for %.

Women in BC had significantly lower mean physical (39.6 [*SD* = 15.6]) and mental (39.8 [*SD* = 13.8]) HRQOL scores compared to women in ON (45.4 [*SD* = 13.1] and 43.1 [*SD* = 14.4], respectively) and QC (45.3 [*SD* = 14.6] and 41.3 [*SD* = 14.0], respectively). Regarding WCHC, 53.4 percent of women perceived the care that they received from their HIV clinic to be women centered, with significant variation observed by province (61.1 percent in BC vs. 59.4 percent in Ontario, and 33.9 percent in Québec; $p < .001$).

Women who perceived their HIV care to be women-centered were more likely to have higher unadjusted mean mental HRQOL scores (43.7 [*SD* = 14.1]) compared to those who did not (39.5 [*SD* = 14.0]. $p < .001$) (Table 2). A crude

**Table 2.** Bivariable associations between women-centered HIV care, socio-demographic and clinical variables, and health-related quality of life among women living with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study ($N = 1308$).

| | Physical health summary score | | | Mental health summary score | | |
|---|---|---|---|---|---|---|
| Variables | Mean | Std | *p* value | Mean | Std | *p* value |
| **Primary explanatory variable** | | | | | | |
| Receipt of perceived WCHC from HIV clinic in last year | | | | | | |
| Strongly agree/agree | 44.7 | 14.0 | .035 | 43.7 | 14.1 | < .001 |
| Strongly disagree/disagree/neutral | 42.9 | 14.8 | | 39.5 | 14.0 | |
| **Sociodemographic variables** | | | | | | |
| Province of residence | | | | | | |
| BC | 39.6 | 15.6 | < .001 | 39.8 | 13.8 | .001 |
| ON | 45.4 | 13.0 | | 43.1 | 14.4 | |
| QC | 45.3 | 14.6 | | 41.3 | 14.0 | |
| Age at interview (in years), categorized | | | | | | |
| 16–29 | 50.6 | 1.3 | < .001 | 43.9 | 14.0 | .007 |
| 30–39 | 48.3 | 12.0 | | 42.4 | 15.2 | |
| 40–49 | 42.5 | 14.2 | | 4.0 | 13.3 | |
| 50+ | 38.7 | 15.7 | | 42.4 | 14.1 | |
| Gender identity | | | | | | |
| Cis-gender | 43.8 | 14.5 | .977 | 41.8 | 14.2 | .963 |
| Trans-gender, two-spirited or gender queer | 44.6 | 12.2 | | 41.4 | 14.9 | |
| Sexual orientation | | | | | | |
| Heterosexual | 43.9 | 14.6 | .877 | 42.4 | 13.9 | < .001 |
| Lesbian/gay/bisexual/trans/queer/other | 43.8 | 13.1 | | 36.9 | 15.5 | |
| Legal relationship status | | | | | | |
| Married/common law/in relationship | 44.6 | 14.4 | .011 | 42.8 | 13.9 | .034 |
| Single | 44.3 | 14.1 | | 41.8 | 14.7 | |
| Separated/divorced/widowed | 41.3 | 14.8 | | 39.9 | 13.0 | |
| Annual household income (Canadian dollars) | | | | | | |
| < $20,000 | 42.2 | 14.4 | < .001 | 4.7 | 14.2 | < .001 |
| ≥ $20,000 | 46.7 | 13.8 | | 43.8 | 13.9 | |
| Race/Ethnicity | | | | | | |
| Indigenous | 42.7 | 13.8 | < .001 | 42.0 | 14.7 | .436 |
| White | 43.2 | 15.2 | | 42.1 | 14.7 | |
| African, Caribbean, or Black | 46.3 | 13.2 | | 4.9 | 13.1 | |
| Other | 41.1 | 14.9 | | 42.6 | 14.1 | |
| Illicit drug use | | | | | | |
| Currently (within the past 3 months) | 40.7 | 14.8 | < .001 | 4.9 | 13.5 | < .001 |
| Previously | 40.3 | 14.4 | | 32.7 | 14.0 | |
| Never | 45.6 | 13.9 | | 43.0 | 14.0 | |
| **HIV-relate clinical variables** | | | | | | |
| Years since HIV diagnosis, categorized | | | | | | |
| < 6 | 46.4 | 13.8 | < .001 | 41.9 | 14.6 | .807 |
| 6–14 | 44.6 | 13.9 | | 41.7 | 14.4 | |
| > 14 | 41.2 | 14.9 | | 41.6 | 13.7 | |
| Currently on antiretroviral therapy | | | | | | |

(*Continued*)

**Table 2.** (Continued).

| Variables | Physical health summary score |  |  | Mental health summary score |  |  |
|---|---|---|---|---|---|---|
|  | Mean | Std | *p* value | Mean | Std | *p* value |
| Yes | 43.3 | 14.4 | < .001 | 41.3 | 13.8 | .003 |
| No | 47.2 | 13.5 |  | 44.3 | 16.5 |  |
| Most recent CD4 cell count |  |  |  |  |  |  |
| < 200 cells/mm3 | 37.9 | 15.2 | .005 | 35.4 | 13.7 | < .001 |
| 200–500 cells/mm3 | 43.4 | 14.3 |  | 42.9 | 13.5 |  |
| > 500 cells/mm3 | 44.3 | 14.6 |  | 42.1 | 14.3 |  |
| Most recent viral load |  |  |  |  |  |  |
| Undetectable (< 50 copies/mL) | 43.7 | 14.4 | .777 | 42.1 | 13.7 | .692 |
| Detectable (≥ 50 copies/mL) | 44.2 | 14.1 |  | 41.1 | 16.2 |  |

*Note*: WCHC, women-centered HIV care; std, standard deviation.

association with WCHC was also seen for mean physical HRQOL scores ($p = .035$). Physical and mental HRQOL scores also varied considerably along key socio-demographic and HIV-related clinical characteristics. Women had *higher* physical HRQOL scores if they identified as African, Caribbean, or Black, had never used illicit drugs (*vs*. current and previous users, who had comparable scores), were not currently on cART, and had a current CD4 cell count > 200 cells/mm3, whereas women had *lower* physical HRQOL scores if they were older, had been diagnosed and living with HIV for longer, were separated/divorced/widowed, had an annual household income < $20,000, and were living in BC. No significant differences in physical HRQOL scores were seen by gender, sexual orientation, or most recent viral load. In terms of mental HRQOL, similar associations were seen overall with a three differences observed: First, previous drug users had scores that were more comparable to never users (rather than current users, as was the case for physical health); second, scores did not vary significantly by ethnicity or years since diagnosed with HIV; and, lastly, lower scores were seen among women identifying as LGBTQ.

### *Unadjusted and adjusted associations between WCHC and HRQOL*

In unadjusted bivariable linear regression, a significant association between perceived receipt of WCHC and better mental HRQOL was observed ($\beta = 4.26$ [95 percent CI: 2.74–5.79]), indicating that on average, mental HRQOL scores increased by 4.26 points among women who received care they perceived to be women centered, compared to women who received care they perceived to not be women centered (Table 3). A smaller effect estimate was observed for physical HRQOL, although the confidence interval included the null value of “1” ($\beta = 1.75$ [95 percent CI: 0.18–3.31]). In the adjusted multivariable linear regression model, perceived receipt of WCHC remained independently associated with mental HRQOL ($\beta = 3.48$ [95 percent CI: 1.90–5.06]) but not physical HRQOL ($\beta = 1.12$ [95 percent CI: −0.45–2.69]), compared with women who did not perceive having received WCHC. For mental HRQOL, the

**Table 3.** Unadjusted and adjusted linear regression results of the relationship between perceived women-centered HIV care and physical and mental health-related quality of life, controlling for covariates, among women living with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (*N* = 1240).

| | Unadjusted β (95% CI) | Adjusted β (95% CI) |
|---|---|---|
| **Model 1: Physical HRQOL** | | |
| ***Primary explanatory variable*** | | |
| Receipt of perceived WCHC from HIV clinic in last year [Strongly agree/agree vs. strongly disagree/disagree/neutral] | 1.75 (0.18, 3.31) | 1.12 (-0.45, 2.69) |
| ***Other covariates*** | | |
| Province | | |
| ON vs. BC | 5.75 (3.88, 7.62) | 2.65 (0.65, 4.66) |
| QC vs. BC | 5.66 (3.52, 7.80) | 4.73 (2.51, 6.96) |
| Age category (in years) | | |
| 16–29 vs. ≥ 50 | 11.94 (9.04, 14.83) | 10.63 (7.64, 13.62) |
| 30–39 vs. ≥ 50 | 9.65 (7.70, 11.59) | 8.92 (6.94, 10.90) |
| 40–49 vs. ≥ 50 | 3.84 (1.94, 5.75) | 3.25 (1.33, 5.16) |
| Gender identity | | |
| Trans-gender, two-spirited, gender queer vs. cis gender | 0.78 (-3.25, 4.81) | Not selected |
| Sexual orientation | | |
| Lesbian/gay/bisexual/trans/queer/other vs. heterosexual | 1.22 (-2.45, 2.35) | Not selected |
| Legal relationship status | | |
| Married/common law/in relationship vs. single | 0.15 (-1.63, 1.93) | Not selected |
| Separated/divorced/widowed vs. single | -2.85 (-5.00, -0.69) | |
| Annual household income (Canadian dollars) | | |
| ≥ $20,000 vs. < $20,000 | 4.44 (2.80, 6.08) | 3.35 (1.75, 4.96) |
| Race/Ethnicity | | |
| White vs. Indigenous | 0.41 (-1.67, 2.49) | Not selected |
| Black vs. Indigenous | 3.53 (1.30, 5.75) | |
| Other vs. Indigenous | 2.08 (-5.38, 1.21) | |
| Illicit drug use | | |
| Currently (within past 3 months) vs. never | -5.97 (-7.75, -4.18) | -3.54 (-5.83, -1.25) |
| Previously vs. never | -6.09 (-8.21, -3.97) | -3.46 (-5.31, -1.61) |
| Most recent CD4 cell count | | |
| 200-500 cells/mm3 vs. < 200 cells/mm3 | 5.42 (1.65, 9.19) | 3.87 (0.31, 7.42) |
| > 500 cells/mm3 vs. < 200 cells/mm3 | 6.36 (2.73, 9.99) | 4.05 (0.61, 7.50) |
| Unknown vs. < 200 cells/mm3 | 7.34 (3.39, 11.29) | 5.12 (1.31, 8.92) |
| **Model 2: Mental HRQOL** | | |
| ***Primary explanatory variable*** | | |
| Receipt of perceived WCHC from HIV clinic in last year [agree vs. disagree (ref)] | 4.26 (2.74, 5.79) | 3.48 (1.90, 5.06) |
| ***Other covariates*** | | |
| Province | | |
| ON vs. BC | 3.35 (1.49, 5.21) | 1.19 (-0.87, 3.24) |
| QC vs. BC | 1.50 (-0.63, 3.63) | 1.59 (-0.78, 3.97) |
| Age category (in years) | | |
| 16–29 vs. ≥ 50 | 1.45 (-1.52, 4.42) | Not selected |
| 30–39 vs. ≥ 50 | -0.06 (-2.05, 1.94) | |
| 40–49 vs. ≥ 50 | -2.47 (-4.42, -0.51) | |
| Gender identity | | |
| Trans-gender, two-spirited, gender queer vs. cis gender | -0.42 (-4.40, 3.56) | Not selected |
| Sexual orientation | | |
| Lesbian/gay/bisexual/trans/queer/other vs. heterosexual | 1.19 (-7.90, -3.21) | Not selected |
| Legal relationship status | | |
| Married/common law/in relationship vs. single | 1.06 (-0.69, 2.81) | Not selected |
| Separated/divorced/widowed vs. single | -1.84 (-3.90, 0.22) | |

(*Continued*)

**Table 3.** (Continued).

| | Unadjusted β (95% CI) | Adjusted β (95% CI) |
|---|---|---|
| Annual household income (Canadian dollars) | | |
| ≥ $20,000 vs. < $20,000 | 3.15 (1.52, 4.77) | Not selected |
| Race/ethnicity | | |
| White vs. Indigenous | 0.09 (-1.97, 2.15) | -1.14 (-3.28, 1.01) |
| Black vs. Indigenous | -1.09 (-3.29, 1.12) | -7.04 (-9.71, -4.37) |
| Other vs. Indigenous | -0.58 (-2.69, 3.86) | -2.32 (-5.64, 1.02) |
| Illicit drug use | | |
| Currently (within past 3 months) vs. never | -8.09 (-10.17, -6.02) | -10.05 (-12.55, -7.54) |
| Previously vs. never | -3.12 (-4.86, -1.38) | -6.01 (-8.16, -3.85) |
| Most recent CD4 cell count | | |
| 200-500 cells/mm3 vs. < 200 cells/mm3 | 7.48 (3.85, 11.15) | Not selected |
| > 500 cells/mm3 vs. < 200 cells/mm3 | 6.67 (3.17, 10.16) | |
| Unknown vs. < 200 cells/mm3 | 5.06 (1.17, 8.96) | |

*Note*: WCHC, women-centered HIV care; HRQOL, health-related quality of life; CI, confidence interval.

95 percent CI excluded the null value of '1′ and reflected a range of effects, from a 2-point (β = 1.90) to a 5-point increase in scores with receipt of perceived WCHC versus no receipt of such care. This was after adjusting for province, age, gender identity, sexual orientation, legal relationship status, annual household income, ethnicity, illicit drug use, and most recent CD4 cell count.

## Discussion

In this large Canadian cohort study of WLWH, we found that mean physical and mental HRQOL scores were 43.8 (*SD* = 14.4) and 41.8 (*SD* = 14.2), respectively, with lower scores among women from BC and differences observed across several other key socio-demographic and HIV-related clinical characteristics. We also found that 53 percent of women overall perceived that the care they received from their HIV clinic in the last year was women centered, with BC and ON participants more likely than QC participants to report receipt of WCHC. We found that perceived receipt of WCHC was associated with higher HRQOL scores, although, in adjusted analyses, this association was only significant for mental HRQOL. However, our results cannot indicate the direction of the causality; while WCHC may lead to higher QOL, it is also possible that WCHC might attract a clientele with higher QOL, or women followed at WCHC clinics might have higher QOL for different reasons.

The mental and physical HRQOL scores for WLWH enrolled in this study were significantly lower than estimates for the general population of Canadian women (Hopman et al. 2000) and for other international HIV cohorts (Burgoyne and Renwick 2004; Douab et al. 2014; Mannheimer et al. 2005; Murri et al. 2003). For instance, a prospective cohort study of 9,423 women and men aged 25 years or older from nine Canadian cities produced Canadian normative data for the SF-12 (Hopman et al. 2000), reporting that the mean age- and sex-standardized physical and mental HRQOL scores for Canadian women were 49.7 (*SD* = 9.4) and 50.9 (*SD* = 9.6), respectively, which are 5.9 and 9.10 points higher than the mean scores in our cohort. Previous studies of HRQOL in people living with HIV have reported mean scores that were 3–5 points higher (better) than our estimates (Burgoyne and Renwick 2004; Douab et al. 2014; Mannheimer et al. 2005; Murri et al. 2003), but WLWH represented only 13–20 percent of their participants and the data were not disaggregated by gender, although male gender was associated with higher scores (Preau et al. 2004). Thus, the lower observed scores in our women only cohort adds to the literature documenting important gender inequities in health and clinical outcomes for people with HIV (Carter et al. 2014; Nicastri et al. 2007; Patterson et al. 2015; Puskas et al. 2011). Further, our population had a higher mean age than most cohorts and a much larger proportion of participants with a current or previous history of illicit drug use. Previous research has identified age (Douab et al. 2014) and drug use (Aden et al. 2015; Préau et al. 2007) as significantly independently related to lower HRQOL, and this was observed in our own bivariable analyses as well as adjusted modeling estimates.

In relation to the primary explanatory variable, over half of our cohort reported perceived receipt of WCHC. The higher proportion (60 percent) seen in ON and BC may reflect the presence of women's speciality HIV clinics in those provinces such as Vancouver's Oak Tree Clinic, which offers multiple health and social services onsite, addressing a range of reproductive, sexual, mental, social, and HIV needs for women, and their family members, affected by HIV (Oak Tree Clinic 2014). In ON, Women's Health in Women's Hands, among others, also offers a multidisciplinary holistic approach to HIV care for women. Whereas the lower proportion (34 percent) of perceived receipt of WCHC in QC may reflect the absence of clinics with this explicit gendered model or clinics that are specifically advertised as serving women's needs, regardless of what care they actually receive. The observed differences may also be due to varying communities of women or sociocultural differences women's engagement in HIV care across regions. We re-ran the model among QC participants only. The adjusted estimate for the main relationship between WCHC and mental HRQOL reduced from 3.48 (95 percent CI: 1.90, 5.06) in the full model to 0.59 (95 percent CI: −2.65 to 3.83) in the QC-only model and the CI included the null value. The direction of effect was the same, however. Further research, including qualitative investigations, of the differences in the landscape of HIV care across jurisdictions is needed.

In the adjusted multivariable analyses, perceived receipt of WCHC was associated with better mental HRQOL. Specifically, women who perceived the HIV care they received in the last year to be women-centered had HRQOL scores that were 3.48 points higher (95 percent CI: 1.90, 5.06) than women who did not report receiving such care. The smallest clinically important difference (CID) for both sub-scales of the SF-12 is often considered to be between three and five points (Samsa et al. 1999; Shulman et al. 2010), suggesting that the magnitude of the difference between these groups is clinically meaningful.

This study built on previous research that has identified factors associated with HRQOL that are related to the clinic environment and the patient–provider relationship experience (Bankoff, McCullough, and Pantalone 2013; Murri et al. 2003; Preau et al. 2004). Trust, communication, and satisfaction with the information provided has previously been reported to be associated with higher levels of HRQOL, while experiencing rejection by medical staff, often due to stigma against drug use, has been correlated with lower HRQOL (Murri et al. 2003; Preau et al. 2004). A recent study also highlighted the important role of both quality of information offered and provider interaction style (Bankoff, McCullough, and Pantalone 2013). Several other factors, including socio-demographic (e.g., age, education, income, drug use history) and clinical and disease-related factors (e.g., comorbidity, time since diagnosis, antiretroviral therapy, adherence), have been found to be associated with HRQOL among people with HIV (Aden et al. 2015; Degroote, Vogelaers, and Vandijck 2014; Douab et al. 2014; Préau et al. 2007; Viswanathan, Anderson, and Thomas 2005). We identified similar covariates in our study, though two findings (i.e., newly diagnosed women and those not on cART had better HRQOL) differed from past research (Tomita et al. 2014), perhaps reflecting earlier diagnosis rates in Canada (Hall et al. 2013) and the impact of aging with HIV. We also added to the literature by investigating associations between HRQOL and perceptions of WCHC, an emerging concept in the HIV field (Carter et al. 2013).

This study had several limitations. First, the explanatory variable lacked specificity, though bivariable associations demonstrated construct validity, and research has shown that perceptions of person-centered care are related to outcomes (Little et al. 2001). We are currently developing a validated, multi-item scale that measures perceived WCHC in a more holistic way. Also, while we adjusted for several confounders in our study, the observed association between perceived receipt of WCHC and HRQOL may be partly explained by other variables not included in this analysis. Additionally, the data were derived from a cross-sectional questionnaire; therefore, it is impossible to determine the temporal direction of the associations. Lastly, self-reporting of WCHC and HRQOL may be influenced by social desirability bias given that questionnaires were administered by WLWH, many of whom were peers of the participants enrolled and/or accessing the same clinics. However, other HIV community-based research studies suggest that the involvement of Peer Research Associates increases trust and rapport with participants, thereby supporting more accurate data collection (Brizay et al. 2015).

In conclusion, for WLWH in this study, mental and physical HRQOL was significantly lower than estimates for the general population of Canadian women and other international HIV cohorts. Receipt of perceived WCHC was associated with higher mental HRQOL. Given these findings and those of other studies showing that WLWH face significant gender inequities and gaps in HIV clinical care designed for their unique needs, further research is needed to develop and examine WCHC as an effective model of clinical care for improving HIV and HRQOL outcomes for diverse communities of WLWH.

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