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Access and engagement in HIV care among a national cohort of women living with HIV in Canada

Nadine Kronfli^a*, Ashley Lacombe-Duncan^b*, Ying Wang^c, Alexandra de Pokomandy^{a,c}, Angela Kaida^d, Carmen Logie^{b,e}, Tracey Conway^{e,f}, V. Logan Kennedy^e, Ann Burchell^{g,h,i,j}, Wangari Tharao^k, Neora Pick^{l,m}, Mary Kestler^{l,m}, Paul Seredaⁿ, Mona Loutfy^{e,o} and on behalf of the CHIWOS Research Team#^a

^aChronic Viral Illness Services, McGill University Health Centre, Montreal, QC, Canada; ^bFactor-Inwentash Faculty of Social Work, University of Toronto, Toronto, ON, Canada; ^cDepartment of Family Medicine, McGill University, Montreal, QC Canada; ^dFaculty of Health Sciences, Simon Fraser University, Burnaby, BC, Canada; ^eWomen's College Research Institute, Women's College Hospital, Toronto, ON, Canada; ^fInternational Community of Women living with HIV, North America (ICWNA), New Brunswick, NJ, USA; ^gDivision of Epidemiology, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada; ^hDepartment of Family and Community Medicine, St. Michael's Hospital, Toronto, ON, Canada; ⁱDepartment of Family and Community Medicine, University of Toronto, Toronto, ON, Canada; ⁱDepartment of Family and Community Medicine, University of Toronto, Toronto, ON, Canada; ⁱDepartment of Family and Community Medicine, University of Toronto, Toronto, ON, Canada; ^lOak Tree Clinic, BC Women's Hospital and Health Centre, Vancouver, BC, Canada; ^mDepartment of Medicine, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada; ⁿEpidemiology & Population Health, British Columbia Centre for Excellence in HIV/AIDS, Vancouver, British Columbia, Canada; ^oDepartment of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto, ON, Canada

ABSTRACT

Attrition along the cascade of HIV care poses significant barriers to attaining the UNAIDS targets of 90-90-90 and achieving optimal treatment outcomes for people living with HIV. Understanding the correlates of attrition is critical and particularly for women living with HIV (WLWH) as gender disparities along the cascade have been found. We measured the proportion of the 1425 WLWH enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) who had never accessed HIV medical care, who reported delayed linkage into HIV care (>3 months between diagnosis and initial care linkage), and who were not engaged in HIV care at interview (<1 visit in prior year). Correlates of these cascade indicators were determined using univariate and multivariable logistic regression. We found that 2.8% of women had never accessed HIV care. Of women who had accessed HIV care, 28.7% reported delayed linkage and 3.7% were not engaged in HIV care. Indigenous women had higher adjusted odds of both a lack of access and delayed access to HIV care. Also, a younger age, unstable housing, history of recreational drug use, and experiences of everyday racism emerged as important barriers to ever accessing care. Programmatic efforts to support early linkage to and engagement in care for WLWH in Canada must address several social determinants of health, such as housing insecurity and social exclusion, and prioritize engagement of Indigenous women through culturally safe and competent practices.

ARTICLE HISTORY

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KEYWORDS

HIV; women; CHIWOS; access to HIV care; engagement in care; cascade of HIV care

Introduction

Providing optimal care to people living with HIV entails ensuring full engagement along the cascade of HIV care (Gardner, McLees, Steiner, Del Rio, & Burman, 2011). Given known gender disparities in HIV care and outcomes (Tapp et al., 2011), understanding the correlates of attrition at stages of the cascade for women living with HIV (WLWH) is essential.

Several barriers to entry and retention in care for WLWH exist. These include non-Caucasian ethnicity (Fleishman, Yehia, Moore, Korthuis, & Gebo, 2012), younger age (Blackstock, Blank, Fletcher, Verdecias, & Cunningham, 2015), unstable housing (Haley et al., 2014), food insecurity (Lo, MacGovern, & Bradford, 2002), depression (Pecoraro et al., 2013), substance use (Eastwood et al., 2015) and intersecting or occupational stigma and discrimination (Lazarus et al., 2012).

In Canada, analysis of the cascade among WLWH has primarily focused on women who experience marginalization (Logie, James, Tharao, & Loutfy, 2012; Shannon, Bright, Duddy, & Tyndall, 2005); few studies have examined the broader demographic profiles and barriers of WLWH in accessing care across Canada. The purpose of this study was to determine the proportion of Canadian WLWH who have never accessed HIV care, who report delayed linkage into care, and who are not engaged in routine care, and to identify the correlates of lack of access to and non-engagement in care.

Check for updates

CONTACT Nadine Kronfli an adine.kronfli@mail.mcgill.ca *These authors contributed equally to this work

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Table 1. Socio-demographic and access characteristics of women living with HIV in Canad	a (<i>n</i> = 1313)	١.
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Age43.1 (10.4)Above 50 374 28.5 $41-50$ 425 32.4 $31-40$ 401 30.5 $16-30$ 113 8.6 Gender (% cisgender) 1250 95.4 Sexual orientation ($n = 1308$) (% heterosexual) 1146 87.6	
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Marined/Common-law/Relationship 425 32.4	
Single/Senzisted/Divorced/Widowed/Other \$888 676	
Jangle / Epianeta / Jangle / Andrea / Michael	
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Calidulari (fulzer) 1094 00.5	
Landed minigrant/Permahent resident 101 12.0	
Relugee/oner immigration status 60 4.6	
Ethnicity 520 to t	
White/Caucasian 530 40.4	
Indigenous 288 21.9	
African/Caribbean/Black 398 30.3	
Other ethnicity 97 7.4	
Education level ($n = 1306$) (% high school or higher) 1105 84.6	
Household gross yearly income ($n = 1273$)	
>\$40,000 per year 181 14.2	
\$20,000-\$40,000 per year 266 20.9	
<\$20,000/year 826 64.9	
Province	
Quebec 338 25.7	
British Columbia 334 25.4	
Ontario 641 48.8	
Geographic location (% large city vs. small/medium city) 1073 81.7	
Number of financial dependents living in Canada $(n = 578)$ 1.6 (1.4)	
Duration of years living with $HV (n = 1311)$ 10.7 (5.8–16.6)	
26 338 258	
6-14 533 406	
×14 440 23.6	
Nover accord HIV care 27 29	
Never accessed Tilv care (diagnosed 1903–2001) 2 0.4	
Never accessed HIV care (diagnosed 2002–2008) 2 0.4	
Never accessed HIV care (diagnosed 2009–2015) 31 2.7	
Duration of years living with Hiv among those who have never 2.0 (1.9–3.1)	
accessed HIV care (n = 35) (Median, IQR)	
Delayed linkage into HIV care 363 28.7	
Delayed linkage into HIV care (diagnosed 1983–2001) 192 35.4	
Delayed linkage into HIV care (diagnosed 2002–2008) 132 29.3	
Delayed linkage into HIV care (diagnosed 2009–2015) 39 14.6	
Time in months to linkage into HIV care for those with delayed linkage (Mean, SD)	
Diagnosed 1983–2001 47.2 (50.9)	
Diagnosed 2002–2008 30.0 (23.4)	
Diagnosed 2009–2015 10.9 (8.5)	
Not engaged in HIV care in the past year 47 3.7	
Past-year non-engagement (diagnosed 1983–2001) ^c 13 2.4	
Past-year non-engagement (diagnosed 2002–2008) 19 4.2	
Past-year non-engagement (diagnosed 2009–2015) 14 5.1	

IQR: interquartile range; SD: standard deviation

^aProportion is based on those who have year of diagnosis data: never accessed HIV care (n = 35); not retained in care (n = 46).

^bProportion is based on those who have time to access of care data (n = 1265).

^cVariables with no "n" provided has data on the full data set of 1313.

Methods

We used baseline data from 1425 WLWH collected between August 2013 to May 2015 from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (Loutfy et al., in press). WLWH trained as peer research associates (PRAs) recruited self-identified WLWH aged 16 years or older using purposive and venue-based sampling methods (e.g., HIV clinics). All participants provided electronic informed consent, completed a structured, online questionnaire administered by PRAs, and received a \$50 honorarium. Ethics approval was obtained.

Outcomes

Participants who had non-missing access-to-care data were included in the analysis (n = 1313). "Ever accessing HIV care" was dichotomized to never versus ever. Among those who had ever accessed care, time to linkage to care was calculated in months between date of HIV

diagnosis and first accessing of HIV medical care, with "delayed linkage" defined >3 months between time of diagnosis and first access. Not receiving HIV medical care in the past year was considered "non-engagement" for those who had ever accessed care.

Correlates

Sociodemographic factors included age, gender, sexual orientation, legal relationship status, immigration status, ethnicity, education, income, size of geographic location of residence, years living with HIV, age at time of diagnosis, and age at time of HIV diagnosis squared to account for non-linear associations.

Psychosocial factors included recreational drug use (RDU), housing status, food security, mental health condition diagnoses, history of incarceration, and standardized measures for hazardous alcohol use (adapted 3item AUDIT-C) (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993), depression (10-item CES-D) (Zhang et al., 2012), health-related quality of life (HIV/AIDS Quality of Life Scale) (Holmes & Shea, 1998), resilience (10-item version of the Resilience Scale) (Wagnild, 2009), social support (4-item version of the Medical Outcomes Survey Social Support Survey) (Gjesfjeld, Greeno, & Kim, 2008), HIV stigma (HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001), racism and sexism (modified (8-item) versions of the 9-item Everyday Discrimination Scale) (Williams, Yan, Jackson, & Anderson, 1997).

Clinical factors measured included method of HIV acquisition, current CD4 count, self-reported viral load (VL), and hepatitis B and C status.

Analyses

Univariate and multivariable logistic regression analyses were conducted with each outcome, utilizing penalized maximum likelihood estimation to account for small outcome proportions (Williams, 2016). For the multivariable models of never accessing and not being engaged in HIV care, all correlates with a bivariate p < 0.05 were entered; sociodemographic factors p < 0.05 were controlled for (Cohen, Cohen, West, & Aiken, 2002). For the delayed linkage to care model, time invariant variables were entered. All statistical analyses were performed using STATA version 14 (College Station, TX) or SPSS, version 23 (Armonk, NY).

Results

Participants (n = 1313) were a mean age of 43.1 years (standard deviation: 10.4 years), primarily Canadian citizens (80.3%) and of white/Caucasian (40.4%) or African,

Caribbean, or Black (ACB) (30.3%) ethnicity (Table 1). Approximately 65% reported a gross yearly household income of less than \$20,000.

Overall, 2.8% of women had never accessed HIV care, 28.7% of those who had ever accessed care reported delayed linkage and 3.7% were not engaged in routine HIV care. Trends suggest that the proportion of those who have never accessed care is highest for those diagnosed most recently ($\chi^2(2) = 86.35$, p < 0.001) and that the proportion of those reporting delayed linkage to care has decreased over time ($\chi^2(2) = 38.2$, p < 0.001).

In multivariable analyses controlling for confounders (Table 2), Indigenous ethnicity, unstable housing and experiences of racism were associated with increased adjusted odds of never having accessed HIV care while RDU, and living with HIV for 6-14 years and >14 years were associated with decreased odds of never having accessed HIV care. In multivariable analysis with time invariant variables, factors associated with increased odds of delayed linkage to care included age at time of HIV diagnosis, age at time of HIV diagnosis squared, Indigenous, ACB or other ethnicity compared to white/Caucasian, years since diagnosis, and acquiring HIV through sharing/contaminated needles compared to through consensual intercourse. While the association between age at time of HIV diagnosis and delayed access to care implies that older age is associated with increased odds, the association between age at time of HIV diagnosis squared and the outcome suggests that both older women and younger women have increased odds of delayed access to care. In multivariable analyses controlling for confounders, a self-reported detectable VL was associated with increased odds of not being engaged in care in the past year; residency in British Columbia was associated with decreased odds of not being engaged in HIV care in the past year.

Discussion

Our study utilized the cascade of care framework to identify sociodemographic, psychosocial and clinical care factors associated with attrition upon entry into and engagement in HIV care. In this study of Canadian WLWH, 2.8% of women had never accessed care, 28.8% reported delayed linkage and 3.7% were not engaged in routine care. These findings have important implications for individual WLWH, as well as for health care policies and practices.

Our study demonstrated that substance use was an important barrier to HIV care. RDU was associated with lower odds of never having accessed HIV care; conversely, RDU was associated with higher odds of delayed access to care. This implies that additional support

	Never accessed HIV care		Delaved linkage to HIV care		Not engaged in HIV care	
	Unadjusted OR (95% CI)	Adjusted OR ^a (95% CI)	Unadjusted OR (95% CI)	Adjusted OR ^b (95% CI)	Unadjusted OR (95% Cl)	Adjusted OR ^c (95% CI)
Socio-demographic factors						
Age						
Above 50 (ref)	1				1	
41-50	3.03				1.4/	
31_40	(0.74, 12.51)	NSb			(0.05, 3.34)	
51-40	(1 67 24 30)*	CN			(0.76, 3.85)	
16–30	16.72	NS			3.00	NS
	(4.18, 66.79)**				(1.12, 8.03)*	
Age at time of HIV diagnosis	Not included	0.98	1.08	Not included		
(continuous)		(0.97, 0.99)**	(1.01, 1.15)*			
Age at time of HIV diagnosis (squared)	Not included	1.00	0.99	Not included		
Gender (transgender or other gender	4.63	(1.00, 1.00) NS	1.18		2.42	
identity vs. cisgender)	(1.91, 11.24)**	115	(0.65, 2.21)		(0.88, 6.64)	
Sexual orientation (sexual minority vs.	2.43	NS	0.94		1.60	
heterosexual)	(1.14, 5.16)*		(0.64, 1.37)		(0.75, 3.42)	
Relationship status (single/separated/	0.62		0.90		0.99	
divorced/	(0.32, 1.18)		(0.70, 1.17)		(0.53, 1.83)	
widowed/Other						
Vs. married/common-law/						
relationship)						
Canadian citizen (ref)	1				1	
Landed immigrant/	0.31		1.72	Time variant	1.51	
Permanent resident	(0.06, 1.63)		(1.21, 2.43)**		(0.70, 3.25)	
Refugee/other	2.09		1.13		0.78	
immigration status	(0.82, 5.31)		(0.63, 2.03)		(0.21, 2.87)	
Ethnicity						
White/Caucasian (ref)	1		1		1	
Indigenous	7.68	4.30	1.88	2.04	0.95	
African/Caribbaan/Plack	(2.98,19.82)^^^	(1.31, 14.13)^	(1.36, 2.61)^^^	(1.42, 2.92)***	(0.43, 2.10)	
AITCall/Callbbeall/black	(0.81, 6.71)		(1 23 2 23)**	(1 95 3 98)***	(0.63, 2.36)	
Other ethnicity	2.50		1.46	1.76	0.69	
	(0.55, 11.33)		(0.90, 2.38)	(1.03, 3.00)*	(0.18, 2.64)	
Education level (less than high school	0.40		1.31		1.34	
vs. high school or higher)	(0.11, 1.46)		(0.95, 1.82)		(0.65, 2.77)	
Household gross yearly income					-	
>\$40,000 per year (ref)	1		1	T :	1	
\$20,000-\$40,000 per	3.96		1.28 (0.91 - 2.01)	lime variant	3.01	
<\$20.000/vear	(0.09, 22.08) 4 14		(0.81, 2.01)		(0.92, 9.02)	
<\$20,000, year	(0.79, 21,58)		(1.12, 2.41)**		(0.66, 6.15)	
Province	(,				(,,	
Quebec (ref)	1		1		1	
British Columbia	1.83		1.27		0.22	
0	(0.39, 8.66)		(0.92, 1.77)		(0.05, 0.85)*	
Ontario	6.94	NS	0.8/		1.69	
Geographic location (small/medium vs	(1.90, 25.35)""		(0.05, 1.17)		(0.86, 3.35)	
large)	(0.30, 1.87)		(0.52, 1.00)		(0.37, 1.79)	
Duration of years living with HIV	(0.00) 1107)		Not included		(0.07) (0.7)	
<6 (ref)	1				1	
6–14	0.05	0.06			0.83	
	(0.01, 0.17)***	(0.02, 0.24)***			(0.43, 1.62)	
>14	0.06	0.11			0.46	
Verse since diamonia (continuous)	(0.02, 0.20)***	(0.03, 0.42)***	1.00	1.07	(0.21, 1.03)	
rears since diagnosis (continuous)	Not included		(1.05, 1.08)***	(1.05, 1.10)***	Not included	
Psychosocial factors			(,	(,		
Housing status (unstable vs. stable)	6.61	4.06	1.36		2.14	
	(3.37, 12.97)***	(1.82, 9.06)***	(0.91, 2.03)		(0.99, 4.60)	
Food security (insecure vs. secure)	2.36	NS	1.09		3.24	NS
Incorporation (over the restor)	(1.05, 5.28)*		(0.85, 1.41)	Time verient	(1.48, 7.13)**	
incarceration (ever vs. never)	1.35		1.44 (1.12, 1.85)**	rime variant	1.44 (0.81 - 2.50)	
	(0.70, 2.39)		(1.12, 1.03)		(0.01, 2.39)	

Table 2. Sociodemographic, psychosocial, and clinical characteristics associated with never accessing HIV care (n = 1313), delayed linkage to HIV care (n = 1265), and not being engaged in HIV care in the past year (n = 1276).

Table 2. Continued.

	Never access	ed HIV care	Delayed linkage to HIV care		Not engaged in HIV care	
	Unadjusted OR (95% CI)	Adjusted OR ^a (95% CI)	Unadjusted OR (95% CI)	Adjusted OR ^b (95% CI)	Unadjusted OR (95% CI)	Adjusted OR ^c (95% CI)
Hazardous alcohol use	0.74		1.01		1.52	
	(0.04, 12.43)		(0.96, 1.06)		(0.29, 8.12)	
History of injection drug use (ever vs.	0.54		1.96	Time variant	0.93	
never)	(0.24, 1.20)		(1.52, 2.53)***		(0.50, 1.76)	
History of recreational drug use (yes vs.	0.43	0.23	1.30	Time variant	0.76	
no)	(0.21, 0.88)*	(0.09, 0.57)***	(1.02, 1.66)*		(0.42, 1.37)	
Depression	0.96		1.01		0.95	NS
	(0.92, 1.01)		(1.00, 1.03)		(0.91, 0.99)*	
Ever diagnosed with a mental health	0.65		0.89		0.57	
issue (ves vs. no)	(0.32, 1.32)		(0.69, 1.14)		(0.30, 1.09)	
HIV-related quality of life	1.11	NS	1.00		0.96	
	(1.03, 1.20)**		(0.97, 1.02)		(0.91, 1.02)	
Resilience	0.98		1.00		1.05	NS
	(0.94, 1.01)		(0.99, 1.01)		(1.00, 1.11)*	
Social support	1.02		0.97		1.03	
	(0.95, 1.11)		(0.95, 1.00)		(0.96, 1.10)	
Personalized HIV stigma	1 06	NS	1 00		1 02	
r cisonalizea niv stigina	(1 02 1 11)**	115	(0.98, 1.01)		(0.98, 1.06)	
Disclosure HIV stigma	1 04		0.98	Time variant	1 01	
	(0.07 1.12)		(0.96, 1.00)*	Time variant	(0.05 1.07)	
Negative self-image HIV stigma	(0.57, 1.12)	NIS	(0.90, 1.00)		(0.95, 1.07)	
	(1.01 1.02)*	CN	(0.09 1.01)		(0.03 1.00)	
Public attitudos HIV stigma	(1.01, 1.00)	NC	(0.90, 1.01)		(0.95, 1.00)	
Fublic attitudes filv stigilla	1.14 (1 OF 1 34)***	CNI	(0.07, 1.01)		(0.05, 1.07)	
Paciem	(1.05, 1.24)	1.04	(0.97, 1.01)		(0.95, 1.07)	
Racism	1.00	1.04	(1.00, 1.02)		(0.00, 1.04)	
Caviana	(1.05, 1.09)	(1.01, 1.06)"	(1.00, 1.02)		(0.99, 1.04)	
Sexism	1.00	IND	1.00		1.01	
Clinical factory	(1.03, 1.09)****		(0.99, 1.01)		(0.98, 1.04)	
Hiv acquisition method						
Consensual intercourse (ref)	I		1		I	
Non-consensual	0 71		1 43	Not selected	1 32	
(forced) intercourse	(0.28, 1.81)		(1.02, 2.03)	Not selected	(0.58, 3.01)	
Sharing needles/	0.20, 1.01)		1 90	1 88	1 29	
contaminated peodles	(0.18, 1.40)		(1 38 2 50)	(1 33 267)***	(0.50, 2.85)	
Blood transfusion/other	(0.10, 1.40)		(1.30, 2.39)	Not selected	(0.39, 2.03)	
medical peripatal	(0.08 2.12)		(0.60, 1.65)	NUL SEIECLEU	(0.21 3.03)	
Most recent viral load (detectable vs	(0.00, 2.12) Not included		(0.00, 1.05)	Timo variant	(0.21, 5.05)	2.00
undetectable)	Not included		(0.00).15 (2 71 0 70)***	3.00 (1 22 6 70)**
Most recent CD4 count (<200, 500	Not included		(0.47, 0.99)		(2./1, 9./9)	(1.52-0.79)"" NC
$\frac{1}{2} \frac{1}{2} \frac{1}$	Not included		1.01 (0.70, 1.22)		Z.3Z /1 13 / 01*	IND
$\frac{1}{1} \frac{1}{1} \frac{1}$	0.75		(0.70, 1.33)	Time verient	(1.12, 4.01)"	
nepaulus C (yes vs. no)	0.75		1.89 (1.46 - 2.44)***	nme variant	1.03	
Hanatitic P (was was no)	(0.37, 1.04)		(1.40, 2.44)***	Time variant	(0.30, 1.91)	
nepatitis B (yes vs. no)	0.45		2.U/	nme variant	1.39	
	(0.09, 2.33)		(1.38, 3.10)***		(0.56, 3.46)	

OR, odds ratio; NS, non-statistically significant (i.e., p > 0.05).

^aAdjusted for age, gender identity, sexual orientation, ethnicity, province, and duration living with HIV.

^bAll time invariant variables entered in one step. Analyzed using backwards stepwise regression, final step shown.

^cAdjusted for age and province.

p* < 0.05, *p* < 0.01, ****p* < 0.001.

services and ongoing efforts in reducing substance use stigma and increasing treatment services for women who use drugs remain essential (Krusi, Wood, Montaner, & Kerr, 2010).

Access to HIV care for WLWH in Canada has improved. Among women diagnosed between 2009 and 2015, 14.6% reported delayed access to care, compared with 35.4% diagnosed between 1983 and 2001. Furthermore, time to first access has improved from a mean of 47.2 months to 10.9 months. This finding has important implications on the integration of test-andtreat strategies. However, given that both older and younger women had higher odds of delayed access to care, future studies should attend to non-linear associations between continuous variables (e.g., age) and access.

WLWH who reported detectable VLs were three-fold more likely to not be engaged in routine HIV care, suggesting that barriers exist to achieving good virological outcomes in the absence of clinical care. Future research may seek to understand women's HIV knowledge, explore social supports, and determine whether specific program components can mediate engagement. Our study demonstrated that Indigenous ethnicity was a risk factor for suboptimal access to HIV care. Future studies should explore barriers for Indigenous WLWH, such as injection drug use (Public Health Agency of Canada, 2014), engagement in survival sex work (Lemstra, Rogers, Thompson, Moraros, & Buckingham, 2012), and a history of sexual abuse (Mehrabadi et al., 2008). These findings reinforce the need for decolonizing research methods to understand the health care priorities for Indigenous WLWH and for culturallycompetent HIV care created for and by Indigenous women.

Our study confirmed existing evidence that unstable housing is associated with decreased retention in HIV care (Haley et al., 2014). Research focusing on marginally-housed women may consider developing partnerships with organizations that address housing, and identifying alternative contact methods (Haley et al., 2014).

Our study has limitations. Our purposive, non-random sampling strategy may have introduced selection bias. To mitigate this, we recruited many women who experience multiple forms of social and structural marginalization (Loutfy et al., in press). Data were selfreported and subject to recall and social desirability bias. To overcome these biases, we engaged PRAs as interviewers, and we found a high degree of correlation between self-reported and laboratory VLs (Carter et al., 2017).

In conclusion, our study highlights several important factors associated with lack of entry into and engagement in HIV care in a large cohort of Canadian WLWH. Programmatic efforts for WLWH in Canada should focus on the social determinants of health.

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#The CHIWOS Research Team

British Columbia: Aranka Anema (University of British Columbia), Denise Becker (Positive Living Society of British Columbia), Lori Brotto (University of British Columbia), Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Claudette Cardinal (Simon Fraser University), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Erin Ding (British Columbia Centre for Excellence), Janice Duddy (Pacific AIDS Network), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Robert S. Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Terry Howard (Positive Living Society of British Columbia), Shahab Jabbari (British Columbia Centre for Excellence), Evin Jones (Pacific AIDS Network), Mary Kestler (Oak Tree Clinic, BC Women's Hospital and Health Centre), Andrea Langlois (Pacific AIDS Network), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS), Elisa Lloyd-Smith (Providence Health Care), Melissa Medjuck (Positive Women's Network), Cari Miller (Simon Fraser University), Deborah Money (Women's Health Research Institute), Valerie Nicholson (Simon Fraser University), Gina Ogilvie (British Columbia Centre for Disease Control), Sophie Patterson (Simon Fraser University), Neora Pick (Oak Tree Clinic, BC Women's Hospital and Health Centre), Eric Roth (University of Victoria), Kate Salters (Simon Fraser University), Margarite Sanchez (ViVA, Positive Living Society of British Columbia), Jacquie Sas (CIHR Canadian HIV Trials Network), Paul Sereda (British Columbia Centre for Excellence in HIV/AIDS), Marcie Summers (Positive Women's Network), Christina Tom (Simon Fraser University, BC), Lu Wang (British Columbia Centre for Excellence), Kath Webster (Simon Fraser University), Wendy Zhang (British Columbia Centre for Excellence in HIV/AIDS). Ontario: Rahma Abdul-Noor (Women's College Research Institute), Jonathan Angel (Ottawa Hospital Research Institute), Fatimatou Barry (Women's College Research Institute), Greta Bauer (University of Western Ontario), Kerrigan Beaver (Women's College Research Institute), Anita Benoit (Women's College Research Institute), Breklyn Bertozzi (Women's College Research Institute), Sheila Borton (Women's College Research Institute), Tammy Bourque (Women's College Research Institute), Jason Brophy (Children's Hospital of Eastern Ontario), Ann Burchell (Ontario HIV Treatment

Network), Allison Carlson (Women's College Research Institute), Lynne Cioppa (Women's College Research Institute), Jeffrey Cohen (Windsor Regional Hospital), Tracey Conway (Women's College Research Institute), Curtis Cooper (Ottawa Hospital Research Institute), Jasmine Cotnam (Women's College Research Institute), Janette Cousineau (Women's College Research Institute), Annette Fraleigh (Women's College Research Institute), Brenda Gagnier (Women's College Research Institute), Claudine Gasingirwa (Women's College Research Institute), Saara Greene (McMaster University), Trevor Hart (Ryerson University), Shazia Islam (Women's College Research Institute), Charu Kaushic (McMaster University), Logan Kennedy (Women's College Research Institute), Desiree Kerr (Women's College Research Institute), Maxime Kiboyogo (McGill University Health Centre), Gladys Kwaramba (Women's College Research Institute), Lynne Leonard (University of Ottawa), Johanna Lewis (Women's College Research Institute), Carmen Logie (University of Toronto), Shari Margolese (Women's College Research Institute), Marvelous Muchenje (Women's Health in Women's Hands), Mary (Muthoni) Ndung'u (Women's College Research Institute), Kelly O'Brien (University of Toronto), Charlene Ouellette (Women's College Research Institute), Jeff Powis (Toronto East General Hospital), Corinna Quan (Windsor Regional Hospital), Janet Raboud (Ontario HIV Treatment Network), Anita Rachlis (Sunnybrook Health Science Centre), Edward Ralph (St. Joseph's Health Care), Sean Rourke (Ontario HIV Treatment Network), Sergio Rueda (Centre for Addiction and Mental Health [CAMH]), Roger Sandre (Haven Clinic), Fiona Smaill (McMaster University), Stephanie Smith (Women's College Research Institute), Tsitsi Tigere (Women's College Research Institute), Wangari Tharao (Women's Health in Women's Hands), Sharon Walmsley (Toronto General Research Institute), Wendy Wobeser (Kingston University), Jessica Yee (Native Youth Sexual Health Network), Mark Yudin (St-Michael's Hospital). Quebec: Dada Mamvula Bakombo (McGill University Health Centre), Jean-Guy Baril (Université de Montréal), Nora Butler Burke (University Concordia), Pierrette Clément (McGill University Health Center), Janice Dayle, (McGill University Health Centre), Danièle Dubuc, (McGill University Health Centre), Mylène Fernet (Université du Québec à Montréal), Danielle Groleau (McGill University), Aurélie Hot (COCQ-SIDA), Marina Klein (McGill University Health Centre), Carrie Martin (Native Women's Shelter of Montreal), Lyne Massie, (Université de Québec à Montréal), Brigitte Ménard, (McGill University Health Centre), Nadia O'Brien (McGill University Health Centre and Université de Montréal), Joanne Otis

(Université du Québec à Montréal), Doris Peltier (Canadian Aboriginal AIDS Network), Alie Pierre, (McGill University Health Centre), Karène Proulx-Boucher (McGill University Health Centre), Danielle Rouleau (Centre Hospitalier de l'Université de Montréal), Édénia Savoie (McGill University Health Centre), Cécile Tremblay (Centre Hospitalier de l'Université de Montréal), Benoit Trottier (Clinique l'Actuel), Sylvie Trottier (Centre Hospitalier Universitaire de Québec), Christos Tsoukas (McGill University Health Centre). Other Canadian provinces or international jurisdictions: Jacqueline Gahagan (Dalhousie University), Catherine Hankins (University of Amsterdam), Renee Masching (Canadian Aboriginal AIDS Network), Susanna Ogunnaike-Cooke (Public Health Agency of Canada).

All other CHIWOS Research Team Members wish to remain anonymous.

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