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Housing Status and Health Outcomes in Aboriginal People Living with HIV/AIDS in Ontario: The Positive Spaces, Healthy Places Study

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ABSTRACT

Aboriginal people are vastly overrepresented in the HIV epidemic in Canada, but little is known about whether some Aboriginal groups are more at risk than others. The purpose of this paper is to highlight the differences in health and social determinants between First Nations, Métis and Inuit Aboriginal people living with HIV/AIDS in Ontario. Eighty Aboriginal people living with HIV/AIDS living off of reserve were recruited and interviewed by trained peer research assistants to collect information on socio-demographics, health status, housing, health care access, homelessness, discrimination, and health-related quality of life. Fifty (63%) participants were First Nations who would have lived at least part of their lives in reserve communities and 30 (37%) were Métis and Inuit who have lived most of their lives off of reserve settings.

Our findings indicate that all Aboriginal people are coping with severe health and social stresses that threaten their health. However, First Nations people were less likely than Métis and Inuit people to have completed high school, and they were more likely to have been incarcerated, to have been homeless, to not feel at home in their neighbourhood, to have harmful alcohol use, and to have experienced significant depression. First Nations people were also less likely than Métis and Inuit to be on antiretroviral treatment or to have seen an HIV specialist.

More research is required to determine to what extent conditions on reserve (e.g., little access to health care, AIDSphobia) and/or the loss of social support from leaving the reserve community contribute to the difference in health and social determinants between First Nations, Métis and Inuit people with HIV living off of reserve in order to develop more appropriate services in both reserve and non-reserve settings that will improve health of all Aboriginal peoples.

INTRODUCTION

Aboriginal peoples face particular challenges related to housing and its impact on their physical and mental health. While Aboriginal communities face the same common determinants of health as other Canadian communities, their history of colonization, along with its social, economic and political effects, add to the significance of access to appropriate and stable housing as a determinant of health (Walters & Simoni, 2002, cited in: Cedar Project Partnership, et al, 2008; Bailie & Wayte, 2006).

Canadian Aboriginal Peoples (First Nations, Inuit, Métis), who make up 3.8% of the total national population (Statistics Canada, 2006) and constitute a vibrant, growing segment of the population, are vastly overrepresented in the HIV epidemic in Canada. At the end of 2005, between 3,600 and 5,100 Aboriginal people were living with HIV (Boulos et al, 2006). In 1998, 18.8% of positive HIV test reports were estimated to be among Aboriginal peoples. This increased to 27.3% in 2006 (PHAC, HIV/AIDS Epi-Update, Nov. 2007).

The need for safe, affordable and appropriate housing is urgent among Aboriginal peoples in Canada and is critical for Aboriginal people living with HIV or AIDS. Aboriginal peoples, who share a common legacy of oppression and resilience, experience some of the worst housing conditions in Canada, and have an exceedingly difficult time locating affordable housing (Deschamps & Thoms, 1995).

Globally, Indigenous communities are forming a larger part of urban societies; in Canada, over 57% of Aboriginal peoples now live off reserve and approximately 50% live in large urban centres (Statistics Canada, 2003, cited in Walker, 2008; Cardinal, 2006; Statistics Canada, 2005; Siggner & Costa, 2005). In spite of the size of the First Nations off-reserve and Inuit and Métis population in Canada and the high rates of reciprocal movement among First Nations peoples between on- and off-reserve (urban-rural) locales, public policy discussions concerning Aboriginal peoples and housing tend to focus on on-reserve communities, perhaps because “the concepts of ‘urban’ and ‘Indigenous’ still seem an uneasy fit in policy and public consciousness.” (Walker, 2008, 185; Callaghan, 2007; Hanselmann, 2001) As Hanselmann (2001) points out, “this oversight is problematic as it ignores the urban realities of Canada’s Aboriginal population. An acute public policy need therefore exists for a broadening of perspectives to include not just on-reserve Aboriginal communities but also urban [and other off-reserve] Aboriginal communities.”

For First Nations peoples living on Canadian First Nations reserves, there exists an immediate housing and infrastructure crisis: shortages that lead to severe overcrowding, lack of plumbing, no electricity, poor insulation, toxic mould, and substandard construction (First Nations Housing Action Plan, 2005). The situation for First Nations peoples living off-reserve and Inuit and Métis peoples is not much better.

While there is a lack of data on the actual lived experiences of off-reserve First Nations and Inuit and Métis peoples, the information that is available indicates that the poor quality of life experienced by First Nations communities on-reserve is also present among Aboriginal peoples living in other areas (off reserves) (Cardinal, 2006). According to the Canada Mortgage and Housing Corporation (2001), in Ontario 35% of Aboriginal peoples living outside of reserves were unable to access or were not living in “acceptable” housing (Housing Conditions of Aboriginal Households Living outside Reserves, 2001). For example, Walker (2008) notes that “racial discrimination continues to be a complicating factor in [Aboriginal peoples’] search for adequate and affordable housing in Canada.” In 1992, fewer than 20% of the Aboriginal peoples living in urban centres in Canada were home-owners, lower than any other ethnocultural group (Balakrishnan & Wu, 1992). More recently, according to the BC Office of Housing and Construction Standards (2007), fewer than half of all Aboriginal peoples in Canada are home owners, with Métis peoples being the most likely to own a home (56%) and Inuit peoples being the least likely. Among the non-Aboriginal population, in Canada, nearly 66% are homeowners. (CMHC 2005 Housing Observer, cited in Palmer, et al, 2007)

A large part of the housing stock that is occupied by Aboriginal peoples is substandard and inappropriate—particularly for people living with HIV or AIDS (PHA)—because it is in poor condition, lacks basic amenities or is overcrowded (Palmer, et al, 2007; Deschamps & Thoms, 1995). There is no housing facility in Ontario that is designated specifically for Aboriginal people living with HIV or AIDS. Any such housing facility would need to be in adequate condition, encompass Aboriginal cultures and traditions, be integrated with Aboriginal health care services and practices, and be sensitive to the needs of Aboriginal people living with HIV/AIDS. The housing needs for Aboriginal people living with HIV have been recognized by the Royal Commission on Aboriginal Peoples in Urban Centres (1993), the Assembly of First Nations' First Nations Health Commission National Roundtable on HIV/AIDS (1994), the Canadian Aboriginal AIDS Network, and the Ontario Aboriginal HIV/AIDS Strategy (2008).

In any attempt to reconcile the historical lack of attention to the housing and health needs of Aboriginal peoples, it is important to first acknowledge the inappropriateness of much of the inquiry related to Aboriginal groups in Canada to date (Smylie, 2004; Stout & Kipling, 1998). While Aboriginal communities are, in general, a highly researched group, much of the work that has been done has effectively reproduced the colonial relations experienced between Aboriginal peoples and other peoples living in Canada (Castellano, 2004; Cardinal, 2006; Schnarch, 2004). Aboriginal communities have been over-researched in inappropriate ways. Researchers have: gathered data on Aboriginal communities without their consent; selected academic subjects that are often not relevant to Aboriginal community needs; viewed Aboriginal persons as “subjects” only rather than as agents of power; pressured individuals and communities to participate in research; and excluded Aboriginal peoples from all but tokenistic decision-making (McPherson, Nelson & Rabb, 2004). Aboriginal self-determination has historically been unrecognized in research related to Aboriginal communities.

In response to this historical legacy, the Principles of Ownership, Control, Access and Possession (OCAP) were developed, and the methodology of community-based, peer-driven research (CBR) began to take hold within communities excluded from research-decision making. The OCAP Principles and CBR methodology operationalize the concept of Aboriginal self-determination in the context of research. Given the heightened awareness of physical and mental health issues facing Aboriginal communities, there has recently been increased interest in CBR about and for Aboriginal peoples in Canada (McPherson, Nelson & Rabb, 2004). A growing body of literature has started to focus on exploring Aboriginal lives and communities as a means of addressing these complex challenges (Stout & Kipling, 1998).

The Positive Spaces, Healthy Places (PSHP) team emerged within this context. PSHP, which was established to investigate the effects of housing on the health of all people living with HIV or AIDS in Ontario, recognized the importance of highlighting the unique needs of Aboriginal people living with HIV or AIDS off reserves in Ontario, within the framework and principles of CBR research and OCAP principles.

An annual retreat in 2002 of the Ontario AIDS Network Executive Directors was a key turning point in the development of the housing and health work in Ontario. At this meeting, housing was identified as one of the most urgent unmet needs of people living with HIV in Ontario. Without any research data for the Canadian context, a provincial sub-committee was formed to look at the issues facing people living with HIV directly related to housing. Through this work, Aboriginal and non-Aboriginal people living with HIV or AIDS, Executive Directors from AIDS service organizations (ASOs) in Ontario, and researchers from York and McMaster Universities began to develop a partnership to study the housing and related health needs of people living with HIV.

The collaborative efforts of the partnership resulted in a pilot, cross-sectional study¹ that examined the housing and health needs of people living with HIV and AIDS in Ontario. Shortly after the initiation of this study, the Canadian Institutes of Health Research (CIHR) launched its CBR program for HIV/AIDS. In the fall of 2004, the Ontario HIV Treatment Network (OHTN) provided support to the initial team to build a mixed method

¹ With project funding from the Ontario HIV Treatment Network (OHTN), the AIDS Bureau (MOHLTC), the Ontario AIDS Network and the Wellesley Institute.

prospective research study (i.e., with quantitative and qualitative components) and establish a larger team with more research breadth and experience to take advantage of this emerging opportunity. In April 2005, CIHR awarded three years of funding for this mixed method study and, with the bridging of the initial pilot study, the Positive Spaces, Healthy Places Study was formed².

The goals of Positive Spaces, Healthy Places are to: (1) Increase understanding and awareness about the housing needs and experiences of people living with HIV and to highlight the ways in which current social policy may impact the housing circumstance and stability of people living with HIV in Ontario; (2) Investigate the relationship of housing quality and security to the physical and mental health of people with HIV; (3) Investigate the relationship between housing quality and security to access to health care, treatment and social service utilization; and (4) Examine how housing characteristics may change for people with HIV from diagnosis through their life course, and identify possible areas for intervention. A major focus of PSHP has also been to determine possible variations in the housing and/or homelessness experiences of people living with HIV/AIDS from specific communities: Aboriginal communities, ethnocultural communities, women, families, sexual minorities, youth and ex-prisoners.

The principal aim of this report is to explore the housing status and experiences of Aboriginal people living with HIV/AIDS off reserves in Ontario and, more specifically, how the social determinants of health (i.e., socio-demographics, housing situation and geography, medical markers of HIV disease, social and psychological factors, health-related quality of life) and access to health and social services may vary between: 1) off-reserve First Nations people living with HIV/AIDS who have lived at least part of their lives on-reserve, and 2) Métis and Inuit people living with HIV and AIDS in Ontario.

METHODS

We recruited a sample of 605 people living in Ontario, who were principally affiliated with or connected to a community-based AIDS service organization in Ontario. This included youth, women, Aboriginal people, and people with HIV from endemic countries. To capture the full range of housing experiences, the team made specific efforts to include harder-to-reach populations such as those with HIV who engage in drug use and those who live in and out of hostels and homeless shelters. All participants were screened for eligibility, and informed consent was obtained prior to administering the questionnaire.³ For participants to be eligible for the PSHP study, they had to be HIV-positive, able to provide informed consent, and live in Ontario. To ensure a representative cross-section of people in Ontario, participants were sampled based on regional epidemiological data and through a range of access points, including: shelters and agencies serving women, families, and youth; Aboriginal organizations; transitional housing providers; and supportive housing agencies.

The PSHP study was conducted in three phases. Phase I involved the development of a 90-minute semi-structured quantitative questionnaire (with standardized survey instruments) by the PSHP Team, selection and training of research staff (Project Coordinator and peer research assistants), establishment of data-collection sites, and baseline data collection. To reflect the Principles of Ownership, Control, Access and Possession (OCAP), peer research assistants were trained by Aboriginal organizations on culturally appropriate ways to interview Aboriginal participants. Phase II involved the development of a short (15-20 minute) 6-month survey instrument, and qualitative questions and survey approach. Phase III involved the review and finalization of a 90-minute semi-structured quantitative one-year questionnaire (with survey instruments) similar to baseline.

The baseline questionnaire,⁴ developed in consultation with the entire PSHP team and pilot-tested with a sample

² As of May 2008, data collection for the one year study has been completed and the final analyses are underway; dissemination of research findings and action-outcome activities have also begun and are directed towards establishing relationships with relevant policy makers, community leaders and program providers in the areas of housing and supportive care.

³ Research ethics approval was obtained from McMaster University.

⁴ Complete survey instrument is available upon request.

of participants, was administered face-to-face by peer research assistants in approximately 60 to 90 minutes. A comprehensive spectrum of issues related to the housing experiences and health status of people living with HIV and AIDS was explored, including information on socio-demographics, markers of HIV disease, social and psychological factors such as presence of depression and harmful use of alcohol or other drugs, housing status, stability and experiences, health care access, experiences of discrimination, health outcomes and health-related quality of life. We made every attempt to design the survey in a way that would be engaging to the multiple cultural and racial groups we were recruiting. This included a few specific culturally-appropriate questions for Aboriginal communities (e.g., with respect to treatment options and modalities).

The qualitative interviews complemented the quantitative research methodology by capturing the health and housing experiences of people living with HIV in Ontario; our approach was based on the view that it is important to include the 'voices' of people with HIV through in-depth interviews with a sub-sample of the research participants. These interviews provide additional knowledge about the connection between the health and housing experiences of people with HIV. Including excerpts of personal narratives and an analysis of the interviews in conjunction with statistical analyses will make the research accessible to all stakeholders.

A selected sub-group of 50 of the 605 participants participated (14% of whom were Aboriginal) in in-depth, semi-structured interviews (Phase II). As a main aim of this study is to explore subjective meanings, experiences, and interpretations and to facilitate the understanding of the essence of experience, a phenomenological orientation was incorporated (Creswell, 1998). Potential interview participants were identified based on an illustrative purposive sampling methodology, using specified sample stratification criteria relating to housing status, time between diagnosis and base line survey, gender, race, and risk category (MSM, heterosexual, IVDU), as well as the study's sampling strategy of ensuring the relevant and appropriate representation of Aboriginal communities and families affected by HIV/AIDS⁵ and the interviewer assessment of the face-to-face baseline questionnaire. To be eligible for the qualitative research, participants had to have completed the baseline survey in phase I and provided informed consent at the follow-up assessment. Peer research assistants were trained to conduct the qualitative interviews, and they recruited participants for the qualitative interviews when conducting the 6-month follow-up phone call.

In addition to our semi-structured interview with participants, we also administered several standardized psychometric instruments to capture key determinants of health that we expected would be related to housing status and stability and also included measures to capture health outcomes.

The primary outcome of the PSHP study was health-related quality of life (HRQOL) as measured by the Medical Outcomes Study HIV Health Survey (MOS-HIV) (Wu, 1996). The MOS-HIV is the most commonly used health-related quality of life measure in HIV research (Wu, 1997a). It is routinely incorporated as a secondary outcome measure in clinical trials and is increasingly being used as a primary outcome in observational studies (Wu, 1997a; Wu, 1997b). The psychometric properties of this instrument have been evaluated extensively, showing adequate content and construct validity (Wu, 1997a; Wu, 1997b), high internal consistency (Cronback's values above 0.75 across studies) (Wu, 1997b; Badia, 1999) and adequate test-retest reliability (Intraclass correlation coefficient of 0.72 for PHS and 0.53 for MHS over 4 months) (Revicki, 1998). The MOS-HIV is a 35-item instrument addressing 11 dimensions of health: General health perceptions, Physical functioning, Role functioning, Social functioning, Cognitive functioning, Pain, Mental health, Energy/fatigue, Health distress, Quality of life, and Health transition. To reduce the 11 dimensions into a smaller set of factors, the developers created through factor analysis two summary scores (Revicki, 1998): A physical health summary score (PHS) and a mental health summary score (MHS). Since these summary scores are recognized to be different components of health-related quality of life, separate analyses will be conducted on each.

We administered validated screening instruments for both alcohol and drug use: The Alcohol Use Disorders Identification Test (AUDIT) was developed by the World Health Organization (WHO) as a simple method

⁵ Families affected by HIV/AIDS include either couples or adults with children where at least one person in the family is infected with HIV, thereby affecting the whole family.

of screening for excessive drinking (i.e., identify persons with hazardous and harmful patterns of alcohol consumption) and to assist in brief assessment. It can help in identifying excessive drinking as the cause of the presenting illness. The first edition of this manual was published in 1989 (Document No. WHO/MNH/DAT/89.4) and was subsequently updated in 1992 (WHO/PSA/92.4). The Drug Abuse Screening Test (DAST-20) is a 20-item instrument that may be given in either a self-report or in a structured interview format; a “yes” or “no” response is requested from each of 20 questions. The purpose of the DAST is 1) to provide a brief, simple, practical, but valid method for identifying individuals who are abusing psychoactive drugs; and 2) to yield a quantitative index score of the degree of problems related to drug use and misuse. It obtains no information on the various types of drugs used, or on the frequency or duration of the drug use. An internal consistency coefficient of .92 was obtained for a sample of 256 drug/alcohol abuse clients. To assess depression and mental health status, we used the Center for Epidemiologic Studies Depression Scale - Revised (CESD-R); the CESD-R is a 20-item scale that evaluates symptoms of depression over the previous 2 weeks, including depressed affect, somatic complaints and suicidal ideation (Eaton, 2004; Gallo, 1999). The response options range from “Not at all or less than 1 day” to “Nearly everyday for 2 weeks”. The final scores range from 0-80, with higher scores indicating greater impairment. The scale is commonly used as a screening for depression with a cut-off of 16 or above as indicative of possible depression. The psychometric properties of the original CESD are well established with internal consistency values above 0.8 and test-retest reliability between 0.4 and 0.7 (Radloff, 1977; Devins, 1988), adequate concurrent and discriminant validity (Weissman, 1977) and high sensitivity and specificity for the cut-off score of 16 or above for depression (Devins, 1988). The CESD-R has not received the same psychometric attention as the original CESD, but a high correlation ($r = 0.88$) between both versions suggests similar psychometric properties (Eaton 2004).

COMMITMENT TO OCAP

To reflect the OCAP Principles, one of the study co-investigators is an Aboriginal person with long involvement in the HIV/AIDS movement, who was involved early in the research design and reviewed all aspects of the study related to Aboriginal peoples, including classifications (i.e., First Nations, Métis, Inuit) and developing strategies to recruit Aboriginal participants. Recruitment of Aboriginal participants was both general (i.e., through advertising, community-based AIDS organizations) and directed (i.e., through elders, traditional medicine people). The project tried unsuccessfully to recruit an Aboriginal peer research assistant who would conduct the interviews with the Aboriginal participants. To compensate for the lack of an Aboriginal peer research assistant, the Aboriginal co-investigator trained other peer research assistants on Aboriginal issues and how to interview Aboriginal people respectfully. Aboriginal workers from the Ontario Aboriginal HIV/AIDS Strategy worked with peer research assistants to schedule interviews, and were available before, during and after interviews to provide support. As a result, there was not a single complaint about the conduct of the interviews. The Aboriginal co-investigator was also involved in all analyses and conclusions, and presented the first outcomes to an Aboriginal audience at the first CAAN CBR Conference in Vancouver. Some of the individuals attending the CAAN conference had participated in the study, so they received the first report on research outcomes. The Aboriginal co-investigator also presented the research findings at the CAHR conference, and there is an ongoing commitment from the study to have the Aboriginal co-investigator present the Aboriginal findings at all conferences and events. All data, consent forms and confidential information from the PSHP study is stored in a locked cabinet in a locked office, and only the Project Coordinator and investigators from the study have access to this data. All PSHP study information and data will be retained for at least 10 years after the study is completed.

For the purposes of this paper, we are focusing exclusively on the baseline data for the 80 Aboriginal participants who were enrolled.⁶ Other manuscripts in development will address findings from the larger PSHP study, including the qualitative analyses.

⁶ The target enrolment of Aboriginal participants for the study was 10% of sample, and we were able to recruit 13%.

RESULTS

All three phases of the PSHP research study are now complete. Data from Phase I have been analyzed and are the focus of this report.

I. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Of the 605 participants enrolled in PSHP across Ontario, a convenience sample of 80 participants (13% of total sample) identified as being from an Aboriginal group:⁷ 63% of whom identified as being First Nations, 29% as Métis, and 4% as Inuit⁸ [5% of sample did not specify that they belong to a specific Aboriginal group, and 3% reported belonging to an African ethnic and cultural group].

While all participants were living off-reserve at the time of the study, First Nations peoples who are also defined as “status Indians” under the Indian Act⁹ are the only Aboriginal peoples who are legally entitled to live on reserves, and 100% of First Nations participants had lived on-reserve at some point in their lives. Our PSHP research team hypothesized that Aboriginal people who had lived on-reserve where they would be among the majority and have a strong sense of belonging might be less comfortable or familiar with urban housing and support services than those who had never lived on-reserve – and therefore feel less supported when they leave their home communities. To assess whether the health and housing experience might be different for those who had lived at least part of their lives on-reserve, our research team analyzed the data on the 50 First Nations participants (“First Nations”) separately from the 30 participants who identified themselves as Métis and Inuit or did not specify an Aboriginal group (“Métis and Inuit”). See Table 1 below for the breakdown of these participants by their Aboriginal group, gender, age, sexual orientation, and geographical region.

Gender and Sexual Orientation: As indicated in Table 1, about 65% of the participants were male, 29% female and 6% identified as Transgender. All five Transgender participants were First Nations; they accounted for 71% of the total Transgender sample in the PSHP study. In terms of sexual orientation, 46% identified as being heterosexual (23 First Nations, and 14 Métis and Inuit), and 38% identified themselves as Gay, Lesbian, or Bisexual (22 First Nations, and 16 Métis and Inuit). Five per cent identified their sexual orientation as “other” (4 First Nations), while one person refused to answer this question.

Age: The average age¹⁰ of participants was 41.8 years, with a range of 26 to 65 years. Almost 63% were 40 years or older and 10% were younger than 30 years at the time of the interview. First Nations participants were somewhat younger (average age 40.3 years) than the Métis and Inuit participants (average age 44.2 years). There was a significantly higher proportion of First Nations participants who were younger than 40 years than Métis and Inuit participants in that age group (42% versus 20%, respectively).

Geography: 50% of the Aboriginal sample lived in the Greater Toronto Area, while one-fourth lived in Eastern Ontario (Ottawa and Kingston areas), 16% in Northern areas (Thunder Bay, Sudbury, and Kenora areas) and 9% in Southwestern Ontario (Hamilton, Guelph, Kitchener, and Windsor areas). The distribution of First Nations and Métis and Inuit participants is similar in GTA and Eastern Ontario; 75% of First Nations and Métis and Inuit participants live in these two regions. A relatively higher proportion (20% versus 10%) and lower proportion (4% versus 17%) of First Nations participants than Métis and Inuit participants reside in Northern Ontario and Southwestern Ontario, respectively.

⁷ Of the 80 enrolled, 19 were lost to follow-up at one year (24%) – this will be part of our 1-year analysis.

⁸ Despite our efforts and direct recruitment, we were able to recruit only a small number of Inuit participants. As the study was conducted with a small number of Aboriginal people, it represents a convenience and exploratory sample of Aboriginal people living with HIV/AIDS.

⁹ The Indian Act, R.S., 1985 C. 1-5

¹⁰ Data on age were available for 77 of the 80 participants

Table 1. Gender, Sexual Orientation, Age, Place of Residence, Education, Employment, Income, and Incarceration

Demographic Characteristics	First Nations (N=50)	Métis and Inuit (N=30)	Total Sample (N=80)
	%	%	%
Gender			
Female	28	30	29
Male	62	70	65
Transgender	10	0	6
Sexual Orientation			
Heterosexual	46	47	46
Gay, Lesbian, Bisexual	44	53	48
Other	8	0	5
Age			
Mean (SD)	40.3 (7.4)	44.2 (8.0)	41.8 (7.8)
Age Categories			
20-29 years	6	10	8
30-39 years	36	10	26
40-49 years	42	60	49
50 years or older	12	17	14
Region of residence			
Greater Toronto Area-GTA	56	40	50
Eastern Ontario	20	33	25
South Western Ontario	4	17	9
Northern Ontario	20	10	16
Highest level of education			
Less than Grade 12	46	30	40
Completed high school	18	17	18
Trades/technical/college	22	40	29
University	14	13	14
Employment			
Working for pay	12	10	11
Gross Monthly Income *			
Mean (\$)	\$ 1,094	\$ 1,271	\$ 1,129
Median (\$)	\$ 1,006	\$ 1,170	\$ 1,100
Incarceration †			
Have been in Jail or Prison	56	47	53

*Data is missing for 3 participants. †Data is missing for 21 participants

Table 2. HIV Disease, Addiction and Depression, Housing, Mobility, Homelessness, and Discrimination

Health-related characteristics	First Nations (N=50)	Métis and Inuit (N=30)	Total Sample (N=80)
	%	%	%
Time of HIV Diagnosis			
1978-1990	20	23	21
1990-2000	54	57	55
2001-2006	26	20	24
Highest CD4 count (last 6 months)*			
<200	28	0	16
200-499	32	37	34
>=500	40	63	50
AIDS defining illnesses & HCV co-infection			
Diagnosed with AIDS	46	50	48
Diagnosed with Hepatitis C †	35	30	33
On ARV treatment	60	70	64
Prevalence of Addiction and Depression			
Harmful Alcohol Use ‡	60	17	46
Harmful Substance use §	74	63	70
Depressed ¶	58	37	49
Housing Situation			
Housed with supportive services	22	23	22
Housed without supportive services	66	77	70
Unstable housing	12	0	8
Number of times moved			
Moved 3 or more times since HIV Diagnosis	70	70	70
Moved in the last 12 months	36	23	31
Homelessness			
At least once	64	57	61
Three to five times	16	13	15
More than 5 times	20	13	18
Discrimination accessing housing services			
Experienced discrimination	52	43	49
Basis of discrimination (Top 6)			
Source of Income	24	30	26
Race	20	28	25
Employment status	18	26	21
Sexual orientation	12	13	13
HIV Status	12	10	11
Gender	6	10	8

*Data is available for 44 participants; † Data was collected 12 months later from 61 participants; ‡ Data is available for 55 participants; § Data is available for 50 participants; ¶ Data is available for 75 participants.

II. SOCIOECONOMIC CHARACTERISTICS

Aboriginal participants' socioeconomic characteristics such as level of education, rate of employment, monthly income, and history of incarceration are presented in Table 1.

Education: Overall, 40% of Aboriginal participants in our sample reported not completing high school; this proportion is higher among First Nations groups (46%) than Métis and Inuit groups (30%). Métis and Inuit participants were twice as likely to have received Trade, Technical or College level training compared to First Nations participants (40% versus 22%, respectively), while 14% (similar to the proportion among First Nations participants) had University level training.

Employment and Income: At the time of the baseline interview, only 11% of Aboriginal participants were working for pay or employment; the employment rate was the lowest among Aboriginal women living with HIV (employment rate of 4%). A slightly higher proportion of First Nations participants reported being employed than Métis and Inuit participants (12% vs. 10%, respectively). Employment rate varied by region, with the highest rate in Southwestern Ontario (33%) and the lowest in Eastern Ontario (33% and 5%, respectively). Despite the slightly higher employment rate, the average monthly income for First Nations participants was 14% lower than that of Métis and Inuit participants (\$1,094 and \$1,271, respectively). Aboriginal transgender participants earned an average of \$800, 29% less than the average income. For the entire sample, those participants in Southwestern Ontario reported the highest average monthly income (\$1,666), while people living in Eastern Ontario reported the lowest monthly income (\$1,085).

Incarceration: Overall, 74% of participants provided information on their history of incarceration. Of those who provided information, 48% reported a history of being in prison or jail at least once. Of those who reported being incarcerated in the past, 61% lived in the Greater Toronto Area and Eastern Ontario. A slightly higher percent of First Nations participants (56%) than Métis and Inuit participants (47%) were incarcerated.

III. HEALTH STATUS OF ABORIGINAL PARTICIPANTS

Selected measures indicating the health status of Aboriginal participants is presented in Table 2.

Time of HIV Diagnosis: Approximately 55% of the 80 Aboriginal participants were diagnosed between 1991 and 2000, 21% were diagnosed before 1991, and the remaining 24% were diagnosed between 2001 and 2006. The time of diagnosis is similar for both First Nations and Métis and Inuit, with a slightly higher proportion of HIV diagnosis among First Nations since 2001 than among Métis and Inuit (26% vs. 20%, respectively).

CD4 T Lymphocyte Cell Counts: CD4 (T-cell) count is used to assess the status and progression of HIV infection into AIDS and to determine treatment types required. Information on participants' highest level of CD4 (T-cell) count in the 6 months prior to the baseline interview was collected. A lower CD4 (T-cell) count indicates higher susceptibility of an HIV-infected person for opportunistic infections. Approximately 55% of participants provided information on their highest CD4 count in the 6 months period prior to the baseline interview. Approximately 50% of participants had a CD4 count of 500/mm³ or higher, while 34% reported that their highest CD4 count was between 200 and 499. The remaining 16% of participants had a CD4 count of less than 200/mm³ and all of them were First Nations participants. Overall, about 63% of Métis and Inuit participants reported having a CD4 count greater than or equal to 500 while only 40% of First Nations participants had a similar level of CD4 count.

AIDS-defining Illnesses: Nearly half (48%) were diagnosed with AIDS-defining illnesses. The gender breakdown indicates that 50% of female, 48% of male, and 40% of transgender Aboriginal participants were diagnosed with at least one AIDS-defining condition. A slightly higher percent of First Nations (50%) than Métis and Inuit (46%) – and Gay, Lesbian, and Bisexuals (50%) than Heterosexuals (44%) – are diagnosed with AIDS.

Antiretroviral Treatment: About 64% of participants reported receiving antiretroviral treatment at the time of the baseline interview. A higher proportion of Métis and Inuit participants than First Nations participants (70% versus 60%) were represented in this group. Seventy percent of all gay, lesbian, and bisexual participants were receiving treatment, compared to 60% of heterosexuals, and a higher percentages of males than females reported being on antiretroviral treatment at baseline (70% versus 61%, respectively).

Addiction and Mental Health (Depression): Standardized population measures were administered to determine the level of harmful alcohol and substance use and depression among the participants. Of the 80 Aboriginal participants, 69% provided information on their alcohol use while 63% and 94% provided information on substance use and status of their mental health, respectively. With respect to alcohol use, nearly half of the 50 Aboriginal participants reported use above an established threshold considered “harmful use” of alcohol, while 70% reported harmful substance use. Half (49%) of the 75 Aboriginal participants who provided information on their mental health had a level of depression consistent with a clinically significant level of depression. A significantly higher proportion of First Nations participants reported harmful alcohol use than Métis and Inuit participants (60% vs. 17%). First Nations participants also reported a higher prevalence of harmful substance use (74% versus 63%) and depression (58% versus 37%) than Métis and Inuit participants.

Co-Infection with Hepatitis C: During our follow-up interview conducted at one year, 76% of Aboriginal participants (61) were able to be re-interviewed and were asked if they had ever been diagnosed with Hepatitis C. Of the 61 interviewed, 57 provided a response: 33% reported being diagnosed with Hepatitis C virus infection. Higher proportions of participants who were First Nations than Métis and Inuit (35% versus 30%) and females than males (41% versus 28%) were diagnosed with HIV-HCV. The prevalence among those participants identified as being heterosexual was 2.5 times higher than those participants who identified as being gay, lesbian, or bisexuals (54% versus 21%).

Access to Health Services: More than 70% of Aboriginal participants (77% of Métis and Inuit versus 74% of First Nations) reported receiving services of a family doctor at least once; 79% and 25% (respectively) reported receiving services of HIV specialists and other specialists (excluding mental health specialists). A higher percentage of Métis and Inuit than First Nations participants (87% versus 76%) reported accessing HIV specialists, while a slightly higher proportion of First Nations participants (26% versus 23%) received services of other specialists. A higher proportion of First Nations participants accessed culturally appropriate services than Métis and Inuit participants (50% versus 23%).

IV. HOUSING CHARACTERISTICS, MOBILITY, HOMELESSNESS, AND DISCRIMINATION

Our semi-structured interview included questions on type of housing, experience of homelessness, number of times people moved, experience of discrimination in accessing housing services, and perceived basis of discrimination. Results are presented in Table 2.

A total of 22% of Aboriginal participants were housed with support services to assist with their physical or mental health, physical ability and rehabilitation on site. The vast majority of Aboriginal participants (70%) were living in apartments or houses with no on-site supportive services. The remaining 8% of the Aboriginal sample were living in unstable housing conditions including shelters, outdoors, streets, and parks. Equal proportions of First Nations and Métis and Inuit participants were housed with supportive services, while all those with unstable housing conditions were First Nations participants. Higher proportions of Métis and Inuit than First Nations participants (77% versus 66%); gay, lesbian, and bisexual than heterosexuals (29% versus 16%); and male participants than female / transgender participants (25% versus 18%) were receiving on-site supportive services.

Homelessness: There were 61% of participants who reported experiencing homelessness at least once, with

a higher percentage among First Nations compared to Métis and Inuit participants (64% versus 57%), among females compared to males (70% versus 54%), and among those participants who identified as heterosexual compared to those who identified as gay, lesbian, or bisexuals (68% versus 53%). There is a high prevalence of homelessness in the overall sample of participants: 65% in the greater Toronto area (GTA) area, followed by 60% in Eastern Ontario, 57% in Southwest Ontario, and 54% in Northern Ontario.

Twenty-two per cent of those who experienced homelessness had been homeless 3 to 5 times, and another 30% reported being homeless more than 5 times. A higher percentage of female participants compared to male participants (39% versus 29%) and those who identified as heterosexuals compared to those who identified as gay, lesbian, or bisexuals (38% versus 26%) reported experiencing frequent homelessness (i.e., being homeless 3 or more times). Aboriginal participants reported that inability to pay rent; eviction; release from jail, prison or hospital; social issues due to HIV; and concern for personal safety were the five (5) most common factors for their recent past episode of homelessness.

Participant Mobility: People move frequently in search of better health care or a living environment that minimizes social and psychological stressors associated with HIV infection. Participants of the study were asked if they had moved since they were diagnosed with HIV and the number of times they had moved. Almost all Aboriginal participants (96%) had moved at least once and 70% had moved 3 or more times since they were diagnosed with HIV. The number of times moved is similar between First Nations and Métis and Inuit participants. However, a higher percentage of participants who identified as gay, lesbian, or bisexual (84%) had moved frequently (i.e. 3 or more times) than those who identified as heterosexual. About 30% reported moving in the 12 months prior to the time of the interview. A significantly higher proportion of First Nations participants reported moving during this period than Métis and Inuit participants. (36% versus 23%).

Experiences of Discrimination Accessing Housing Services: Overall, half (49%) of the 80 Aboriginal participants reported experiencing discrimination when trying to get housing services, with a higher percentage of First Nations participants reporting discrimination than Métis and Inuit participants (52% versus 43%). A higher proportion of female and transgender participants than male participants (60% versus 42%) and those who identified as heterosexual rather than gay, lesbian, or bisexual (54% versus 39%) reported experiencing discrimination when trying to get housing. Aboriginal participants reported their source of income, race, employment status, sexual orientation, HIV status, and gender as the most common reasons for discrimination when trying to access housing services. These reasons were similar among both First Nations and Métis and Inuit participants.

Feeling of Belonging in Their Neighbourhood: First Nations participants were much less likely than Métis and Inuit participants to feel they belonged in their neighbourhood (54% compared to 77%) or to report that their home provided a good location for them (56% compared to 70%).

V. HEALTH OUTCOMES: HEALTH-RELATED QUALITY OF LIFE

MOS-HIV health outcome measures: Health-related quality of life among Aboriginal participants was assessed with the Medical Outcomes Study (MOS)-HIV instrument. The items of this instrument (n=35) can be scored and summarized into 10 dimensions: General Health Perceptions, Physical Functioning, Pain, Role Functioning, Social Functioning, Cognitive Functioning, Mental Health, Energy, Health Distress, and Quality of Life, and 2 summary measures: Physical Health and Mental Health (summary scores range from 0 to 100 with an average of 50, lower scores indicating poor health status and higher scores indicating better health status). Results of these two summary measures (Physical Health and Mental Health) are presented in Figures 1-3 below to illustrate the health-related quality of life outcomes of participants.

Figure 1: Physical and Mental Health Status by Aboriginal Group

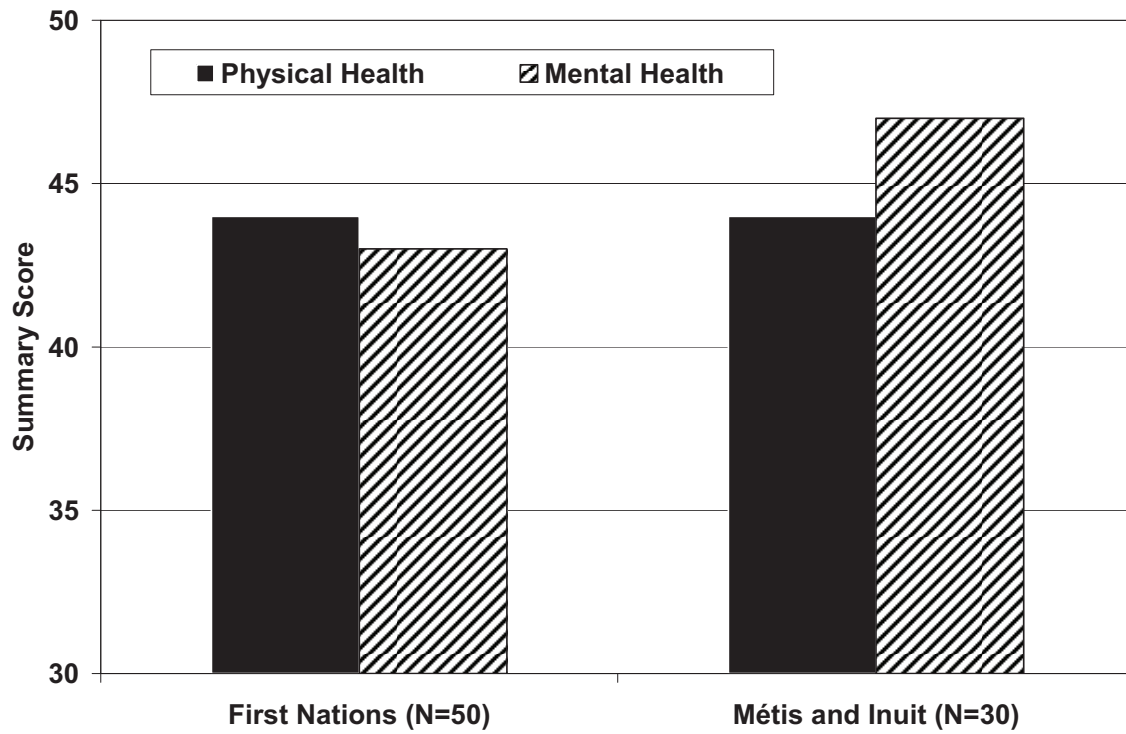


Figure 2: Physical and Mental Health Status by Housing Situation

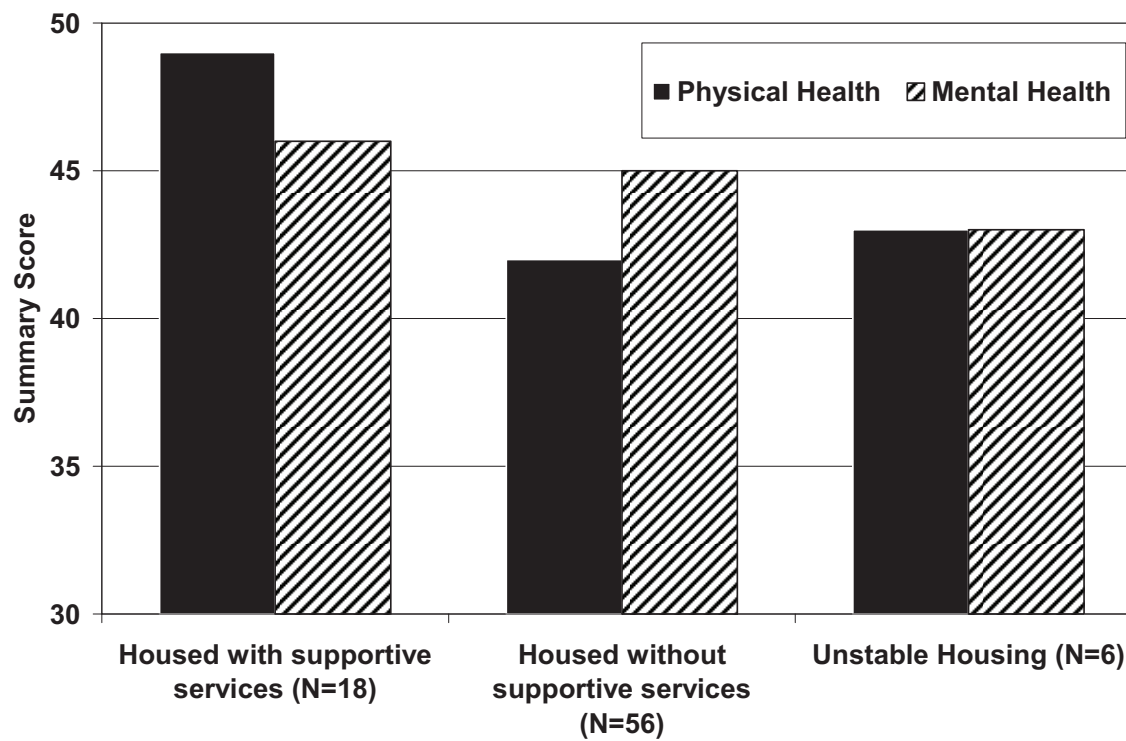
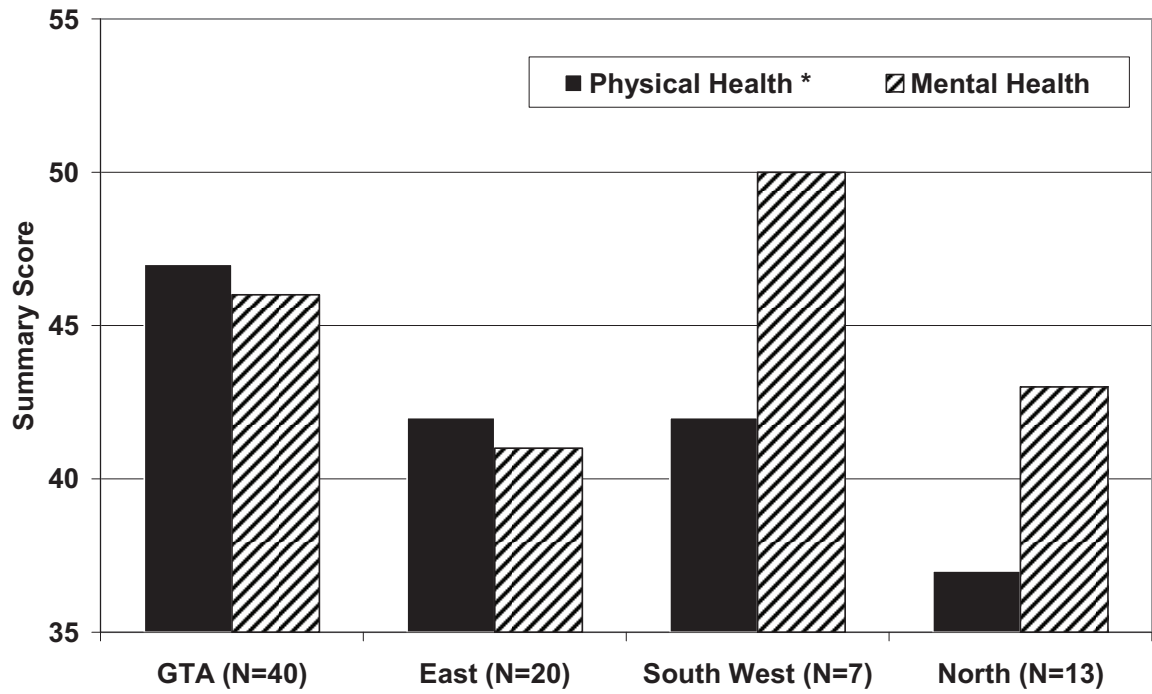


Figure 3: Physical and Mental Health Status by Region



* denotes $p < 0.05$

HEALTH OUTCOMES

By Gender: Overall, Aboriginal participants had below-average physical and mental health scores (average score is 50), indicating that their health status is worse than that of a person living with HIV with average health. While First Nations participants had a similar physical health status to that of Métis and Inuit participants, they had a poorer mental health status compared to that of Métis and Inuit participants¹¹.

By Housing Situation: As can be seen in Figure 2, health-related quality of life outcomes also varied by housing situation of Aboriginal participants, with those housed in places with supportive services having better physical and mental health than those housed without supportive services or with an unstable housing situation.

By Gender and Sexual Orientation: A considerable variation of health-related quality of life outcomes by gender was reported¹². Overall, Aboriginal male participants reported having better physical and mental health than female and transgender Aboriginal people. Transgender participants had the highest physical health, but the lowest mental health score. However, this result should be interpreted cautiously, as only 8% of participants identified as being transgendered. Gay, lesbian, and bisexual participants had better health-related quality of life at the time of the interview than participants who reported their sexual orientation as heterosexual or “other”.

By Age: An age-associated mental health gradient was observed¹³. Participants in the 20-29 years of age category had the lowest level of mental health, and a significant increase in mental health outcomes was observed with an increase in age. A different pattern was observed for physical health-related quality of life: Younger participants (20-29 years old) had the highest level of physical health, followed by those 50 years or older. Participants between the ages of 30 to 39 years had the lowest level of physical health outcomes score.

By Geography: Health-related quality of life also varied by geography (see Figure 3). Overall, Aboriginal participants in the Greater Toronto Area reported having the best physical and mental health outcomes, followed by those in Southwestern Ontario and Eastern Ontario. Participants in Northern Ontario had the lowest level of physical health outcomes.

DISCUSSION

The innovative community-based research study Positive Spaces, Healthy Places has broken new ground in its ability to engage Aboriginal peoples living off reserve in a longitudinal study in Ontario. The success of the study is due to a number of factors. The research team identified an issue that was highly relevant to Aboriginal peoples, included an Aboriginal researcher on the team, and engaged the Aboriginal community early in the design of the study, in decisions about survey instruments, in the training of peer research assistants, and in the recruitment of Aboriginal participants. The Aboriginal community has also been directly involved in the analysis and interpretation of the data, in presenting findings, and in knowledge translation strategies. Aboriginal self-determination was essential to build trust with participants. The study has effectively used CBR methodology, OCAP principles and best practices in knowledge translation and exchange (KTE) to engage a traditionally hard-to-reach and under-represented population in research. It has also managed to complete a culturally sensitive survey of Aboriginal peoples within the context of a larger study of people living with HIV. The advantages to Aboriginal peoples living with HIV are the opportunity both to understand their own lived experience with housing and health, and to compare their experience to other populations and ethnoracial groups living with HIV. The Aboriginal participants living with HIV can assist in resulting advocacy and community development efforts to improve the programs and services available to them.

Our current findings provide interesting insights into the different experiences of those who have likely lived at least part of their lives on-reserve (First Nations), compared to those who will have lived mainly in non-

¹¹ Figure not shown – available from authors

¹² Figure not shown – available from authors

¹³ Figure not shown – available from authors

reserve settings (Métis and Inuit). On average, Aboriginal persons living with HIV in our study have poor health outcomes. However, compared to Métis and Inuit peoples, First Nations people living with HIV are younger, less educated, have lower incomes and are more likely to have harmful substance use and suffer depression. They are more likely to have been incarcerated and to have experienced discrimination when trying to get housing. They are also more likely to be homeless or unstably housed, to feel not-at-home in their neighbourhoods, to be dissatisfied with their housing situation, and to feel that they do not belong. They have lower CD4 counts (a marker of more advanced HIV disease), are more likely to be co-infected with hepatitis C, and are less likely to be on treatment or to have seen an HIV specialist.

The Aboriginal front-line workers and researchers involved in this study believe that the experience of First Nations people with HIV is related to having lived for at least some time on-reserve, where there is little access to adequate health care – particularly specialized HIV care and treatment. This view is supported by evidence that variation in health status and risk-taking behaviour within/among First Nations communities may be related to varying colonial histories. (Jacklin, 2009). Although First Nations people with HIV living on-reserve are likely to have better family support and a social support network, many also experience either homophobia or AIDS-phobia, which drives them away from the reserve and their support networks. This loss of community can be associated with depression, mental health issues and substance use. Once in urban settings, these people may not know how to access supports such as social assistance, community-based AIDS organizations, or housing. Many will not have the health card they need to access services. Because First Nations people living with HIV off-reserve are younger, they will have less schooling and be less employable, which will affect their ability to find housing and may lead them into survival sex or sex work – which, in turn, is associated with high rates of substance use, depression, incarceration and housing loss.

These findings have implications for both policy and services. To meet the needs of all Aboriginal people with HIV who live off-reserve, it will be important to develop and enhance culturally sensitive services that will improve housing and access to health services in urban centres, as well as help these people cope with a wide range of other health and social issues – including the need for social support networks that will help build a sense of community, particularly for First Nations people with HIV. However, action off-reserve will not be enough. Many of the experiences that affect the housing and health of First Nations people with HIV – such as substance use, depression, lack of access to adequate or HIV-specific health care and lack of adequate or appropriate education – were experienced in their home communities, and First Nations communities must be part of the solution. It will be important to provide more information and education for First Nations communities about the quality of life issues faced by First Nations people living with HIV who leave their home communities to obtain specialized care and other services, including housing. More attention should also be given to combating homophobia/AIDS-phobia in all Aboriginal communities and to improving the health and social services available to First Nations Aboriginal peoples living with HIV who are living on-reserve.

This paper looks at the differences between two distinct groups of off-reserve Aboriginal peoples: those who have lived at least part of their lives on-reserve (First Nations) and those who have not lived on-reserve (Métis and Inuit). When reviewing these findings, readers should be aware that the proportion of all people living with HIV who are experiencing housing and related health problems is extremely high. However, the situation for all Aboriginal peoples – First Nations, Métis and Inuit – is much worse than for others living with HIV. Other work underway by our group will help to quantify the magnitude of differences in health outcomes in key vulnerable populations affected by HIV.

Our PSHP study is the first systematic community-based study in Canada to explore how housing status and stability affect the health and well-being of people living with HIV in Ontario. The results presented in this paper represent only a first cross-sectional examination of how the social determinants of health are having a negative impact on the health and well-being of Aboriginal people living with HIV and AIDS. While we had a broad and engaging recruitment strategy that was developed and supported by the Ontario Aboriginal HIV/AIDS Strategy, our findings are limited by the fact that we had a relatively small and “convenient” sample which may not be not representative of all Aboriginal people living with HIV in Ontario, especially for those who

identify as Inuit. These limitations notwithstanding, with our prospective analyses underway, we will be able to begin to explore and understand how housing instability and other social determinants of health are more tightly linked to health outcomes and health-related quality of life for our current sample of Aboriginal people living with HIV/AIDS in Ontario. Through these explorations, we will begin to shed light on the types of interventions and strategies that may be helpful to explore and evaluate, to influence better housing and health policy and care decisions that will improve the health of all Aboriginal people living with HIV and AIDS.

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