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The Complexities of Accessing Care and Treatment: Understanding Alcohol Use by Aboriginal Persons Living with HIV and AIDS

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ACKNOWLEDGEMENTS: The funding for this study was provided by the Canadian Institutes of Health Research, Institute of Infection and Immunity through the HIV/AIDS Community-based Research Initiative.

Institutional support for this study was provided by: Canadian Aboriginal AIDS Network, CIHR Canadian HIV Trials Network, Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador (First Nations of Quebec and Labrador Health and Social Services Commission), University of British Columbia, and University of Saskatchewan.

The research sites and contacts involved in this study: 2-Spirited People of the First Nations, AIDS Saskatoon, AIDS Thunder Bay, AIDS Vancouver, All Nations Hope AIDS Network, Blood Ties Four Directions, Healing Our Nations, Healing Our Spirit, Nine Circles Community Health Centre, Positive Living North, Red Road HIV/AIDS Network, Sandy Hill Community Health Centre, Shining Mountains Community Living Services, The Canadian Association of Nurses in AIDS Care, The HAVEN/Hemophilia Program, Vancouver Native Health Society.

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ABSTRACT

The role of alcohol in the transmission of HIV and access to health services for persons living with HIV/AIDS is relatively unexamined across the globe. Our team's community-based, mixed methods study examined both of these questions from the perspectives of Aboriginal persons living in Canada with HIV/AIDS (APHA) and service providers (SP). A bilingual national survey was undertaken with APHAs and SPs and the findings were followed up on in peer interviews. A complex relationship was identified between alcohol use, perceptions of alcohol use and access to services. Nearly half of APHAs surveyed reported that alcohol played a role in their becoming HIV positive. APHAs and SPs differed in their assessment of the impact of alcohol in the lives of Aboriginal persons once diagnosed, with a far greater proportion of SPs identifying it as problematic. Both SPs and APHAs associated the misuse of alcohol with diminished health. Nearly half of the APHAs surveyed shared they had been told they were drinking by a SP when they were not, while over one-third reported ever being denied services because of drinking when in fact they were not. Both SPs and APHAs identified physical health and discrimination as key reasons. Notwithstanding these results that point to shortcomings in service provision, the data also reveal that most APHAs are receiving care in which their choices are respected and from providers they trust. The findings point to the need for a nuanced strategy to solidify the strengths and address the shortcomings in APHA's service provision.

The dogs in this image, that would represent us Aboriginal people, and not just for people living with HIV but for Aboriginal people that are dealing with addictions and that and how society sometimes just wants us to mush and get through all those years of history so fast and it took many, many years for all that stuff to happen and there's such a long line of stuff there that it's going to take many years of (pause) to be able to recover

from all that. And that's kind of where I feel they (pause) when I hear attitudes and feelings from other people who are not Aboriginal, that often they, you know, just push Aboriginal people, just "hurry up and get through all that stuff and start to be healthy.
-APHA Interview Respondent

INTRODUCTION

Aboriginal People and HIV

Aboriginal¹ persons in Canada are disproportionately represented in reported cases of HIV and AIDS. According to the 2006 census, Aboriginal persons comprise 3.8 percent of Canada's total population (Statistics Canada, 2008), however, an estimated 8.9 percent of all people living with HIV/AIDS and 12.2 percent of new HIV infections are among First Nations, Inuit and Métis (Public Health Agency of Canada, 2011). Furthermore, of known Aboriginal HIV cases, approximately half (48.8%) of all positive HIV test reports between 1998 and 2008 were for females and two-thirds (63.6%) of cases were attributable to injection drug use (Public Health Agency of Canada, 2010). In addition, one-third (32.6%) of known Aboriginal HIV reports in the same time period were under the age of 30, compared with only 20.5% for non-Aboriginal people (Public Health Agency of Canada, 2010). Aboriginal people, and youth specifically, in comparison to non-Aboriginal people are also more likely to have a late diagnosis, become acutely ill earlier, are less likely to receive optimal medical treatment and have shorter survival times (Mill et al., 2008, p. 133; Spittal et al., 2003).

Aboriginal People and Alcohol Use

Conversely, Aboriginal people have among the highest rates of abstinence from alcohol; abstinence was reported by more than a third (35.3%) of First Nations adults in the 2008/10 First Nations Regional Health Survey (RHS) (The First Nations Information Governance Centre, 2012). However, harms from alcohol use for Aboriginal persons are particularly acute due to high levels of episodic drinking (Dell & Lyons, 2007, p. 6). The RHS reported that approximately two-thirds (63.6%) of adults who had consumed alcohol in the past 12 months met the criteria for binge drinking, defined as five or more drinks per sitting at least once a month (The First Nations Information Governance Centre, 2012). A higher proportion of males met heavy drinking criteria than females. It is well documented that alcohol contributes to a wide range of health-related harms, including injury, liver disease and cancer (Canadian Centre on Substance Abuse, 2006). In fact, according to the World Health Organization, alcohol use is the world's third largest risk factor for disease and disability (World Health Organization, 2011).

APHAs and Alcohol Use

There is a general paucity of literature specific to the use of alcohol by Aboriginal persons living with HIV/AIDS (APHA) in Canada. Of that available, one study reported that "almost all of the

¹ In this paper we use the term Aboriginal as an inclusive term that recognizes the First Nations, Inuit and Métis Peoples of Canada. We honour the diversity within our populations and use this terminology to be respectful of the broad range of participants who contributed to our study, to honour our peoples, and to respect confidentiality by writing about what we have learned from the study as a whole.

72 APHA participants [in the study] reported excessive drug or alcohol use in the past or present” (Jackson, Cain, & Prentice, 2008:15). A general population study by Petry (1999) in the United States concluded that alcohol use disorders may be two to four times more frequent among persons living with HIV/AIDS in comparison to the general population. Another US study concluded that there is no significant difference in alcohol and drug use between Aboriginal and non-Aboriginal people living with HIV/AIDS (Barman, 2005). Some studies have also suggested that the use of alcohol may be a way of coping with a recent diagnosis and the stress of living with HIV and being Aboriginal (Chander, Himelboch, & Moore, 2006; Mill, Kennan, & Lambert, 2004). Other studies have linked mental health with alcohol use, such as a study that associated depression in people with HIV/AIDS to frequent alcohol use (Chander, Himelboch, & Moore, 2006).

APHAs, Alcohol Use and HIV Transmission (drinking)

It is only in the past decade or so that alcohol’s role in the transmission of HIV has been recognized (Fritz, 2011, p. 1; Shield, Shuper, Gmel, & Rehm, 2013). Numerous studies have shown that drinking alcohol before sex or being intoxicated during sex is directly linked with HIV. In Rakai, Uganda, for example, the use of alcohol before sex increased HIV acquisition by 50 percent in a study of over 14,000 women and men (Zablotska et al., 2006). Similarly, among men who visited beer halls in Harare, Zimbabwe, having sex while intoxicated was strongly associated with having recently acquired HIV (Fritz, Woelk, Bassett, McFarland, Routh, Tiobaiwa, & Stall, 2002). And in a large study of male wine bar patrons in Chennai, India, unprotected sex was found to be significantly higher among those who used alcohol beforehand (Sivaram, Srikrishnan, Latkin, Iriondo-Perez, Solomon, & Celentano, 2008, p. 1).

A recent meta-analysis, however, cautions against making a causal link between using alcohol and sero-conversion, arguing instead that people who drink have a “generalized risk-taking personality (and) may be prone to both problematic drinking and risky sex” (Rehm, Shield, Joharchi, & Shuper, 2012, p. 10). Nonetheless, a qualitative study with Australian APHAs (Thompson, Bonar, Greville, Bessarab, Gilles, D'Antoine, & Maycock, 2009) found that respondents saw their use of alcohol as a dis-inhibitor that helped to create the conditions for vulnerability to HIV (e.g., unprotected sex). Further, in a recent US Agency for International Development update (Fritz, 2011) the link between alcohol and risky sexual behaviour was identified in sub-Saharan African countries and India.

APHAs, Alcohol Use and HIV Transmission (Injection Drug Use)

There is also some evidence that points to increased injection drug related HIV-risk from drinking. The National Institutes of Health in the United States released an Alcohol Alert in 2002 stating that: “Rates of injection drug use are high among alcoholics in treatment, and increasing levels of alcohol ingestion are associated with greater injection drug-related risk behaviors, including needle sharing,” (National Institute on Alcohol Abuse and Alcoholism, 2002, p. 2). A recent qualitative study of alcohol as a risk factor for HIV transmission among American Indian and Alaska Native drug users found “very high rates of alcohol use among...active crack and injection drug users” and that “those claiming more episodes of using alcohol before or during sex, reported significantly more events of unprotected sexual intercourse” (Baldwin, Maxwell,

Fenaughty, Trotter, & Stevens, retrieved September 16, 2014, p. 1). This is an area of increasing awareness in the HIV prevention field, and there is a need for further research and understanding.

APHA Access to Health Care Services

It is well established that the attitudes of individual service providers impact APHA's access to primary and emergency care. Canadian studies have found that health care providers need to practice increased cultural competence with their APHA clients (Jackson & Reimer, 2005; McCall, Talbot, & Lunny, 2006; CAAN, 2008). APHAs who have negative encounters with their health care providers also have significantly lower rates of returning for follow-up care and adhering to their prescribed medical regime (Benoit, Carroll, & Chaudhry, 2003; Gorman, 2006; Jackson et al., 2005; Jackson & Monette, 2005; Levin & Herbert, 2004; Meen et al., 2004; Mill, et al., 2006). A 2008 study of SPs highlighted the benefits of SPs acknowledging the unique, culturally-based needs of APHAs: "While the journey itself is not Aboriginal-specific, Service Providers generally agreed that there are cultural components to how APHAs balance positive and negative experiences and how they respond to diagnosis, adhere to treatment, access support, overcome obstacles and learn to live with HIV/AIDS" (Canadian Aboriginal AIDS Network, 2008, p. 9).

When our study commenced in 2007, a review of the empirical literature revealed little on the association between actual and perceived alcohol use by APHAs and access to services—a gap that largely remains today. Related publications that do exist emphasize research findings from the prairie and pacific regions of Canada and the majority take place in urban centres, even though nearly half of Canada's Aboriginal population lives in a rural or remote area or on-reserve. The existing research is also nearly exclusively based on Western academic approaches, which tend to silence the lived experiences and voices of Aboriginal persons. Our study attempted to address these significant gaps. Our team's community-based, mixed methodology approach combined a bilingual national survey with qualitative interviews conducted with APHAs and SPs. In this paper, the key findings are situated within the related literature. The paper concludes with suggestions for a nuanced strategy to solidify the strengths and address the shortcomings in service provision received by APHAs who may or may not be using alcohol.

METHODOLOGY

Approach – Aboriginal Ethics in Research

This study applied a community-based approach to research that challenges status quo assumptions in knowledge production, and was guided by the principles of Ownership, Control, Access and Possession (OCAP™) for research with First Nations communities (Schnarch, 2004; First Nations Information Governance Centre, 2014). These principles were originally developed in Canada within the context of "a large scale social movement of anti-colonialist discourse" (Lopez, as cited in Denzin & Lincoln, 2008, p. 3). Our adherence to the OCAP™ principles informed the development of our team's Principles of Research Collaboration Agreement and allowed us to engage in a research process that we intended to be respectful of and honour the diversity of participants and other involved partners (such as health care organizations) in the

research process. This understanding supports reference by the Canadian Institute of Health Research's to Elder Albert Marshall's concept of "two-eyed seeing" or "multiple-eyed seeing" (Institute for Integrative Science and Health, retrieved March 30, 2013, p. 1).

Research Framework

With Aboriginal Ethics guiding the study's development, it enabled our team to work from a community-based research (CBR) approach built upon decolonizing methodologies (Tuhiwai Smith, 1999) and a transformative-emancipatory paradigm (Mertens, 2003). A beginning point was acknowledging the diversity within our communities of interest—Aboriginal people living with HIV/AIDS and service providers who offer care to them. This necessarily required that attention be given to First Nations, Inuit and Métis heterogeneity, large and small urban and non-urban centres, socially complex and varied lived experiences, and gender diversity. Our team included academic and community-based peer researchers who are also: Aboriginal organizational representatives; Aboriginal people living with HIV/AIDS; of Aboriginal and non-Aboriginal descent; university based staff and students; and an Elder. Ethics approval for this study was granted by the University of Saskatchewan Behavioural Research Ethics Board.

(i) Community Based Research

Community Based Research (CBR) is a growing field of research in Canada and across the globe. CBR engages a range of research approaches, including participatory research, community-based participatory research, action research and social planning research (Walters, et al., 2009). Common among CBR is privileging critical-focused "bottom-up" approaches in which the research process mediates power differences among project members (Mendenhall & Doherty, 2007) and is both a "political and theoretical undertaking" (Cahill, 2007). CBR has been demonstrated to enhance wellness in Aboriginal and other communities and to result in more effective and sustainable policies and programs (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Henderson, Simmons, Bourke, & Muir, 2002). For example, an Australian study found that Indigenous-academic research partnerships contributed to individuals' recognition of factors important to their own well-being, such as spirituality (McLennan & Khavarpour, 2004).

(ii) Decolonizing methodologies

Decolonizing methodologies specifically challenge the dominant, Western academic research paradigm of non-Indigenous researchers doing research on 'others' (Tuhiwai Smith, 1999). It encourages the use of research approaches where inquiry comes from Indigenous communities, and with the communities thereafter involved in every stage of the research process.

Decolonizing research likewise emphasizes that the strengths of Indigenous knowledge be considered alongside Western methodological approaches. Tuhiwai Smith (1999) refers to this as telling the untold story (4). Indigenous approaches in research—and specifically a decolonizing orientation—"can be defined as research by and for Indigenous people, using techniques and methods drawn from the traditions and knowledges of those people" (p. 894). This required the inclusion of Aboriginal persons directly affected and living with HIV/AIDS in this study. As Tuhiwai Smith (1999) shares: "When Indigenous peoples become the researchers and not merely the researched, the activity of research is transformed. Questions are framed differently,

priorities are ranked differently, problems are defined differently, people participate on different terms" (p. 193).

(iii) Transformative-emancipatory paradigm

This study also draws upon a transformative-emancipatory paradigm, which is acknowledged for bridging Indigenous and Western worldviews and uses research as a strategy to achieve social justice, and specifically by marginalized groups (Mertens, 2003, p. 136). The transformative-emancipatory paradigm invites scholars to consciously collaborate with diverse marginalized individuals, groups and communities as a foundation to the research process (Denzin & Lincoln, 2008). Transformative scholars assume that knowledge is not neutral but is influenced by human interests, that all knowledge reflects power and social relationships within society, and that an important purpose of knowledge construction is to help people improve society (Banks, 1993, 1995). This corresponds with the underlying philosophies of community-based research, Indigenous methodologies and Aboriginal research ethics. This study's partnerships explored Indigenous ways of knowing and integrated traditional knowledge with modern scientific methods of inquiry (Reading, 2006). This approach contributed toward avoiding the risks of incorporating a strong bias from the dominant Western culture that could in turn lead to results that misinform next steps in policy and programming.

Data Collection

Reviewing existing community consultations and the empirical literature, our data collection was designed using a mixed methods approach over a 16 month period: APHA and SP self-administered cross-sectional bilingual surveys and follow-up in-depth bilingual interviews. The quantitative APHA survey was designed to collect information on alcohol use patterns and experiences accessing care and treatment. The SP survey was designed to collect information on experiences of providing care and treatment to APHAs who are using or are perceived to be using alcohol. The surveys were pilot-tested with an equal number of APHAs and SPs (N=20) and subsequently revised to change the phrasing of several questions and add an introductory statement to emphasize the personal nature of the questions. A prospective power calculation was undertaken to determine the number of completed surveys required for a representative sample, and a minimum of 94 completed surveys was identified to achieve a confidence interval of 10 percent. A total sample of 116 APHAs and 109 SPs from across Canada engaged in the survey. This renders the quantitative results of the survey statistically significant, meaning that the results are unlikely to be attributable to chance.

Informed by the data gathered through the surveys, qualitative, open-ended interview guides were developed for APHAs and SPs to contextualize the survey results. Two peer researchers conducted the majority of the interviews. Both were APHAs and worked as SPs in the past. Each interview began with the respondent selecting an image that symbolized their experiences with accessing care and treatment and drinking, and SPs selected an image representing their provision of care and treatment to someone they perceived to be drinking. This technique was used to facilitate a two-way, open dialogue. On average, the interviews were 45 minutes in duration and a total of 25 APHAs and 23 SPs were interviewed.

Our two study samples represent APHAs and SPs from across Canada. Of the 116 APHAs who participated in this study, over three-quarters were First Nations (primarily Status), 15 percent Métis and 6 percent Inuit. Forty-three percent identified as male, 34 percent as female and the remaining as two-spirited, trans-gendered and intersexed (16%, 5% and 2% respectively). The average age of APHA respondents was 43 years. On average, they had been living with HIV or AIDS for 12 years at the time of the survey, with approximately one-third reporting AIDS status. Fifty-eight percent reported to be on a treatment regimen from a physician that included anti-retroviral medication and 43 percent reported to have changed their lifestyle to improve their health. The primary language spoken by APHAs is English (97%) with 18 percent also speaking French, and 27 percent reported to speak at least one Aboriginal language. Just over half of APHA respondents identified their sexual orientation as straight. The vast majority reported to live in an urban centre and in a private residence (81% and 78% respectively) and approximately half (51%) felt they had treatment and care in their home city; an additional 19 percent had moved to access treatment and care, and 10 percent reported that they were considering moving. Most of the APHAs reported being impacted by residential schooling themselves (16% attended) or through their parents and/or grandparents (54% and 36% attended respectively). Just over a quarter of respondents identified as the primary caregiver in their family.

Of the 109 SPs who were reached through the study, 71 percent were female, 21 percent male and 8 percent two-spirited. Half identified as non-Aboriginal and 17 percent reported to speak at least one Aboriginal language with their clients. The SPs worked for an average of eight years in their field. Forty-three percent worked at an Aboriginal service organization and another 28 percent worked at an agency that served both Aboriginal and non-Aboriginal clients. Approximately 70 percent of the SPs offered targeted services for APHAs, however, the number of APHA cases managed by their agencies over the past two years varied widely (ranging from between 1 and 10 to over 30).

(i) Sampling Strategy

(a) Quantitative

Given our team's recognition of the long-standing absence of data collection with APHAs and APHA SPs outside of large, urban centres and English-speaking Canada, data collection in smaller urban centres and the province of Quebec was prioritized. Our national quantitative data collection with APHAs had highest concentration in Ontario (31%), followed by British Columbia (20%), Saskatchewan (18%), both Manitoba and Quebec (8%), Alberta (5%), the Atlantic provinces (2%), and Yukon (1%). Seven percent did not identify their location. Quantitative data collection with SPs was also distributed across Canada and once again responses were concentrated in Ontario (33%), followed by British Columbia (19%), Saskatchewan (17%), Quebec (12%), the Atlantic provinces (10%), Manitoba (4%), Alberta (2%), Yukon (2%) and 1 % did not answer. A limitation of the sample was that it was outside of the scope of this project to travel widely and negotiate the intricacies of research partnerships with multiple First Nations, and so no data was collected in First Nations communities.

Both APHAs and SPs were sampled by contacting AIDS service organizations, health centres and professional organizations such as the National Native Partnership Foundation, National

Native Alcohol and Drug Abuse Program and Canadian Nurses in AIDS Care. Cities were chosen based upon existing contacts of research team members and snowball sampling within a city. Contact was first made via email and then a follow up phone call reviewed the project, expectations, procedures and contributions back to the organization for participation. Surveys were mailed to the organizational contacts with honoraria for participants provided in separate envelopes (both SP and APHAs received \$20 to complete the quantitative survey & \$40 to participate in a qualitative interview). Respondents completed the survey as well as a separate form to acknowledge receipt of the honorarium. Complete and incomplete surveys and unused honoraria were returned to the research coordinators. Surveys were also distributed at one national and one sizeable provincial Aboriginal health conference (with high attendance from across the country) and an HIV/AIDS health care provider national conference. The same participation process was followed as above, with the additional specification that individuals do not complete a survey if they have already done so through their organization. Team members, and primarily peer researchers and project coordinators, issued the surveys at a display table at the conferences. An online version of the survey was also developed to help reach a network of SPs who are broadly distributed geographically through a national service provider organization, including on-reserve, however a small number of people completed it.

(b) Qualitative

The concluding question on the quantitative survey asked if respondents were interested in doing a qualitative interview. For those who indicated interest, the research coordinators followed-up and interviews were offered. A total of 25 interviews were conducted with APHAs and 23 with SPs. Qualitative data collection with APHAs similarly took place across the country, with concentration highest in Ontario (52%), followed by British Columbia (16%), Quebec, Manitoba and the Atlantic provinces (8%), Saskatchewan (4%) and Alberta (4%). Data collection was similarly distributed with APHA SPs and concentrated in Ontario (31%), Manitoba (17%), British Columbia and Quebec (13%), Saskatchewan and Atlantic provinces (9%), Alberta (4%) and Yukon (4%).

(ii) Limitations

A key limitation of this study is that the data was collected from AIDS service organizations and conferences. It follows that the study's respondents are likely to be connected with AIDS-related resources in their communities and work places. Therefore, the sample likely does not capture APHAs who are not accessing services. Similarly, it is plausible that the sample of SPs in this study are more aware of issues related to HIV than the overall population of SPs that APHAs encounter. Given this, the findings may be more troubling in areas of concern for those who are less engaged than those in our sample population. Similarly, areas of positive findings in this study may be inflated as they may represent services and/or approaches that are more frequently offered within HIV/AIDS care. Also, given our team's recognition of the long-standing absence of data collection with APHAs and SPs outside of large, urban centres, our prioritization of smaller urban centres may skew the results in that services tend to be less functional in these locations. In this case, areas of positive findings in the study may be slightly deflated, and negative findings moderately inflated.

Another limitation of the study is the minimal engagement of French speaking respondents; in fact, 96% of surveys and all of the interviews were completed in English despite French translations and translators/French speaking team members. The importance of our approach though is that it highlights centres that have been less likely included in HIV/AIDS research in Canada. And last, given the wealth of knowledge collected in this study, this paper combines responses, for example, for in-patient and community-based care; data collected on drugs other than alcohol are not presented; and multivariate statistical analyses are not presented.

(iii) Data analysis

Our team applied a constant comparative approach to data analysis, also known as a concurrent triangulation design – comparing qualitative and quantitative data analysis results throughout the data analysis phase (Creswell, 2011; Denzin & Lincoln, 2000). Drawing on the work of Kovach (2009), we brought both Indigenous and conventional Western knowledge systems and methods to our analysis. Once again, with the principles of OCAP guiding our study's development, this enabled our team to work from a community-based research approach built upon decolonizing methodologies (Tuhivai Smith, 1999) and a transformative-emancipatory paradigm (Mertens, 2003). This framework guided our work with the data.

(a) Quantitative Data Analysis Process

Survey responses for each sample were collected in a Predictive Analytics SoftWare (PASW) 18 database from which both descriptive and inferential statistical analyses were calculated. Unlike some quantitative or mixed methods studies, no participants were 'scrubbed' from the data set in order to achieve a statistically significant result: all participants' voices were treated as equally important. Analyses of the data were brought to the research team, discussed in plain language and then directly applied to inform the second stage of the data collection – the interviews.

(b) Qualitative Data Analysis Process

All interviews were transcribed verbatim and cleaned to remove any identifying information. These transcripts were loaded into Atlas.ti, a qualitative data analysis software package. An inductive approach to coding the data was adopted. At an in-person team meeting, our members divided into small groups with APHA and Aboriginal and Western worldviews represented in each. The groups reviewed a sample of transcripts together to agree upon thematic codes. The small groups then merged into a whole, in which our team reviewed the coded transcripts together and a coding framework was agreed upon. Applying the framework, each interview was coded by at least two people. The initial code list included 78 themes and was eventually collapsed to 42. From this, 9 central themes emerged. Next, our team met in person to review the coded data. Three small groups worked together to analyze a central theme each. Two team members volunteered to analyze three additional themes, and the remainder of the analysis was completed by the research coordinators with the guidance of the team. A final team meeting resulted in a team plan for reporting our key findings, all the while ensuring peer researcher and Elder participation.

RESULTS

All results draw upon analysis of the quantitative survey data and incorporate the qualitative interview data, except for demographic information about the 'impact of alcohol' which are primarily drawn from the quantitative survey data.

(i) Role of alcohol in becoming positive

Forty-seven percent of APHAs surveyed agreed that alcohol played a role in their sero-conversion. In the qualitative interviews, APHAs identified multiple ways in which they saw drinking related to their becoming HIV positive, the most prominent being a loss of inhibition or control and engaging in unprotected consensual or nonconsensual sex and intravenous drug use. One respondent shared: "I was definitely more 'influencable' when I was drinkin'. I would be more easy to say, "Yeah, okay, sure I'll go try that". Another recounted: "I'd get to the point where I'd just overdo it and drinking and something and I'd wake up and you know, sometimes I wouldn't even know where I was and I'd be in somebody else's place and that's how I contracted HIV". A respondent specifically shared how he became HIV positive when he was drunk by choosing to re-use someone's needle: "I was drunk and...he left a syringe full and it was bloody and he said 'don't touch that'... so I sat there and went 'Oh fuck', I took it and shoved it in my arm and I got high."

(ii) Alcohol Use

Alcohol use patterns varied among APHAs, from not consuming alcohol at all to drinking in excess. APHAs and SPs differed in their assessment of the impact of alcohol in APHAs' lives, with some APHAs identifying problems associated with their use and a much greater proportion of SPs identifying it. At the time of the survey, 33 percent of APHAs reported that they did not consume alcohol. Of those that did, 25 percent were not worried about negative impacts of alcohol use in their lives and 10 percent claimed it made their lives easier, such as providing emotional relief and social connection. Conversely, 22 percent reported to sometimes worry about it, 15 percent said that it makes their lives worse, and 10 percent felt that they drank too much. APHAs who identified alcohol use as negatively impacting their lives said it compromised the management of their HIV/AIDS treatment and their physical, emotional, mental and/or spiritual health generally.

In contrast to APHAs, a far greater number (88%) of SPs identified alcohol use as a general problem in the lives of at least some APHA clients under their care, with 96 percent perceiving alcohol use as having a negative impact on these clients' health. Similar to APHAs, SPs viewed alcohol as problematic in their clients' HIV/AIDS treatment, and most saw alcohol use as negatively impeding their clients' decision making and thinking abilities, healthy eating, the capacity to feel good about one's self, and the ability to believe in the Creator, a higher power or inner spirit. Fifty-two percent of SPs also acknowledged that daily use of alcohol may not, in some circumstances, have a negative impact on their clients' health.

(iii) Perceptions of Alcohol Use

The survey findings showed that APHAs experience marginalization due to both their actual drinking and the perception that they had been drinking. Nearly all SPs (92%) reported they believed their APHA clients had used alcohol at some point in their care. Some SPs shared that they were confident in their ability to discern whether a client had been drinking while others could not be so sure. Those who reported confidence seemed to share an attitude about drinking being an ‘expected’ behavior. Approximately half of APHAs (52%) said they had ever been told they were drinking by a SP when they were not, and this number increased considerably among those who reported ever drinking before seeking services (63%).

APHAs and SPs were asked for reasons why APHAs might seem to have been drinking alcohol when they were not, and the majority of responses related to physical health. An APHA shared that “(if) someone is not going for dialysis and the toxins are accumulating in their body instead of the dialysis taking them out, they cannot be thinking clearly, or be groggy”. A SP added: “I would think diabetes would be a big one, and it’s so prevalent in Aboriginal communities. And other (pause) brain damage things, and when you are talking about people living with HIV too, they are at higher risk for things that affect their speech, things that affect their coordination”. The most commonly mentioned physical indicators relayed in the interviews were smell (e.g., the use of cheap cologne, ketoacidosis—fruity smelling breath that occurs when the body breaks down fat for fuel to cope with a shortage of glucose and which is common with diabetes or malnourishment, the smell of a hangover, and the smell of poor hygiene) and behavior (e.g., drowsiness and raggedness—which could be related to missing a night of sleep, side effects from a variety of medications, stroke, thyroid problems, mental illness, a historical or recent brain injury, progression of HIV or kidney failure, and diabetes).

Discrimination was also identified as a key reason APHAs were identified by SPs to have been drinking alcohol when they were not. Both APHAs and SPs relayed that overarching discrimination was experienced by APHAs based on their Aboriginal ancestry, HIV status and real or perceived use of alcohol. To illustrate, a statistical correlation was identified in the survey data between speaking an Aboriginal language and being denied services in community based and in-patient care (e.g., in a hospital). This finding encouraged our team to explore which APHAs were most vulnerable to being denied services in our interviews. Speaking an Aboriginal language as a barrier to care was not, however, uncovered in the interviews. This may be a result of our small sample size or an inadequate representation of Aboriginal people who speak an Aboriginal language. The greatest areas of concern for APHAs accessing services in their interviews were judgmental attitudes and discriminatory practices against those with a mental illness, who use solvents, are homeless, have poor hygiene, have an HIV status and use alcohol, and are transgendered. Racism was threaded throughout these identified concerns as a common site of oppression. Although poverty was seldom identified as a primary impediment to APHAs accessing services, it was a key determinant in the lives of the above identified groups.

Both SP and APHA respondents shared experiences of systemic discrimination, and specifically racism in APHAs’ receipt of care. One APHA shared:

People will deny it but there is systemic discrimination towards Aboriginal people in every com (pause) community, within their own communities and within the larger metro community as such. If you are fair skinned, your chances are a lot better. I am fair skinned and my chances are a lot better to do anything, than one of my best friends who is (pause) has the features of being First Nations and they don't (pause) it's funny because I'll get "thank-you sir" and the other will have you know, "what d'ya want?"

(iv) Access to Services

Eleven percent of SPs reported having denied services to clients for perceived alcohol use and 11 percent also believed their organization had denied services for the same reason. More stark, just over one-third (36%) of APHAs reported ever being denied services because of drinking when in fact they were not and this number increases to 50 percent among those who reported ever drinking before seeking services. Actual and perceived alcohol use was identified as a significant barrier to HIV care and treatment by APHAs, and for those in need of health care this can lead to serious personal and health-related consequences, including death. Although the majority of APHA survey respondents reported positive experiences and trusting relationships with their SPs and accessing services, others however faced substantial barriers to their care and treatment based on exclusionary practices and judgmental attitudes, including being perceived to be drinking when they had not.

While many APHAs recalled positive experiences and trusting relationships with SPs in their interviews, this again was not the case for all. When asked to describe their experiences with SPs, a number of APHAs reported "feeling judged", "shuffled through really fast", "disrespected", "pushed off to the side", "invisible" and "belittled". One APHA shared, "I feel like a little kid, not understood and treated like I was a little kid that doesn't know what's good for me, you know?". One APHA shared the story of a friend who was denied services for perceived drunkenness when in fact he had not been drinking.

He got really sick and he uh, he went through the [health care facility], uh emergency, to get some care, 'cause he knew he was really, really bad off and uh, he was turned away because they thought he was totally impaired, but it was these effects that he was having from the illness, he was getting from the AIDS and they turned him away and he died.

Specific to accessing SP care while consuming alcohol, this sentiment multiplied. An APHA shared that they felt "weird...like I was naughty" when accessing services when under the influence. Fifty percent of APHAs who reported ever drinking before seeking services shared they did not seek services on at least one occasion for fear of being turned away; "go to detox or come back when you're sober". This was even more likely to occur among women who were pregnant.

DISCUSSION

(i) Perceptions of Alcohol Use

For the first time in Canada, this study has identified through a national survey the percentage of APHAs who have been denied care for drinking when in fact they had not been, as well as SP perceptions related to APHA alcohol use. The results are alarming. A damaging consequence of colonization has been stigma and discrimination toward Aboriginal persons generally, and specifically in relation to alcohol use and living with HIV and AIDS. This is well documented in the literature. For example, regardless of whether APHAs reside in an urban or rural area, discrimination and stigma have been found to significantly limit their access to services (Abonyi, 2006; DeForest, Snider, Krenz & Gill, 2005; Jackson & Reimer, 2008; Jakubec & Woloshyniuk, 2006; Meen, Thomas, et al., 2004). Stigma-related stresses and impacts for APHAs include racism, unstable housing, violence, survival sex work, co-infections, lack of social support, inadequate health care and lack of access to health care (Corneil et al., 2005; Douaihy, Stowell, Bui, Daley, & Salloum, 2005; Garmaise, 2003; Geduld & Archibald, 2005; Hwang, Henry, Raffa, & Gill, 2005; Jackson & Reimer, 2005; Mill et al., 2006; Shannon, Bright, Duddy, & Tyndall, 2005; Spittal et al., 2005; Wood et al., 2003). Areas of particular concern for women relate to experiences of sexual violence and HIV and AIDS-related stigma, discrimination and systemic violence (Hawkins, Reading & Barlow, 2009).

The literature also supports SP and APHA identified physical reasons for misperceptions by SPs. A review of the literature identified some explanations for behaviours that may inaccurately appear to be related to alcohol use by APHAs, such as confusion, drowsiness or raggedness. For example, Aboriginal people are three to five times more likely to develop diabetes in comparison to the rest of the Canadian population. Symptoms of hypoglycemia caused by diabetes include: cold, clammy or sweaty skin; pallor; difficulty concentrating; shakiness; lack of coordination; irritability; hostility; a staggering gait; fatigue; headache; blurred vision; dizziness; nausea; and fainting or unconsciousness (Canadian Diabetes Association, 2011). Diabetes is also a main cause of kidney failure, of which Aboriginal people are eight times more likely to suffer from than the rest of the Canadian population. Symptoms of kidney failure and kidney disease include fatigue and altered thinking (The Kidney Foundation of Canada, 2011). In addition, severe trauma, including brain injury, disproportionately affects Aboriginal people in Canada (Karmali et al., 2005). Symptoms of brain injury include memory loss, impaired reasoning, one-track thinking, speech impairment, difficulty organizing thoughts into meaningful speech, difficulty cultivating and maintaining relationships and a loss of subtle social skills (Brain Injury Association of Canada, 2011).

(ii) Role of alcohol in becoming positive

Our research is also the first known study in Canada to document through a national survey the role of alcohol in sero-conversion of Aboriginal persons. The fact that nearly half of APHAs in our study reported this is supported by the research on drinking generally. The literature reports that alcohol consumption is broadly associated with risky behaviours, including sexual risk taking and IDU, as likewise identified in our study (Cook and Clark 2005; Kalichman, Simbayi, Kaufman, Cain, & Jooste, 2007). The literature shares that people who drink alcohol engage in

more unprotected sex, multiple partnering and commercial sex than non-drinkers (Kalichman Simbayi, Kaufman, Cain, & Jooste, 2007; Zablotska et al. 2006). Some evidence has also been established between alcohol consumption and an elevated risk for injection related HIV (National Institute on Alcohol Abuse and Alcoholism, 2002; Thompson, Bonar, Greville, Bessarab, Gilles, D'Antoine, & Maycock, 2009; Fritz, 2011).

(iii) Alcohol Use

Our study also relayed an imbalance between concern expressed by SPs in comparison to APHAs regarding the impact of alcohol consumption on APHAs' health. The majority of APHAs did not see it as a potential problem whereas SPs did. On the surface this makes logical sense; if alcohol was recognized as a contributing factor to contracting HIV then one's relationship with it may change upon this realization. This finding is a contribution to the literature as there is a dearth of research on the use of alcohol by APHAs and its impact.

Both SPs and APHAs agreed, however, that alcohol misuse can negatively influence all areas of APHAs' health, including physical, emotional, mental and spiritual as well as a HIV/AIDS treatment regime. According to the World Health Organization, alcohol use is the world's third largest risk factor for disease and disability (World Health Organization, 2011). Alcohol consumption is attributed in the HIV/AIDS literature to depression (Cain, Jackson, Prentice, Mill, Collins, & Barlow, 2011; Cain & Todd, 2008; Jackson et al., 2005), non-adherence to ART (Shield, Shuper, Gmel & Rehm, 2013), increased toxicities due to alcohol interactions with ART and immunosuppressant effects which may influence the course of HIV illness (Petry, 1999) and potentially HIV-1 replication (Zha, Chen, Zhuo, Nishitani, Zack & Liu, 2004; Dole et al., 2004; Mtwisha, Seabe, Wood, & Bekker, 2006; Perretti-Watel, Spire, Riandey, & Obadia, 2004), increased rates of hospitalization (Palepu, Horton, Tibbetts, Meli, & Samet, 2004; Palepu, Horton, Tibbetts, & Samett, 2005; Palepu et al., 2005), and progression of HIV (National Institute on Alcohol Abuse and Alcoholism, 2002). Both SPs and APHAs also agreed that alcohol use may serve a positive function in some situations. Researchers, for example, have linked alcohol use specifically with managing coping (Chander, Himelboch, & Moore, 2006; Mill, Kennan, & Lambert, 2004; Chander, Himelboch, & Moore, 2006).

(iv) Access to Services

Our study also corroborates with the literature that documents the excellent care and supports APHAs receive in Canada from their service providers and an ability to readily access it (CATIE, 2014). At the same time, it confirmed what the study set out to examine; some APHAs face substantial barriers and damaging consequences to their health based on exclusionary practices and judgmental attitudes, including being perceived to be drinking when they had not been. Interestingly, it also challenged our team to broaden our focus to both the barriers and facilitators for care, treatment and support for APHAs based upon the range of responses we received.

The majority of strategies that have been shown to improve access to health care services for people living with HIV/AIDS are harm- or risk-reduction based (Callahan, Flynn, Kuenneth, & Enders, 2007; Canadian Aboriginal AIDS Network, 1998; Dell & Lyons, 2007). For example,

considerable research has shown that such community controlled strategies for alcohol and drug use enhance service access, and specifically antiretroviral therapy (ART) adherence (Greet & Connor, 2006; Marsh et al., 2006; Palepu et al., 2004; Palepu et al., 2005; Tyndall et al., 2006; Wood, Montaner, Bangsberg, Tyndall, Strathdee, O'Shaughnessy, & Hogg, 2003). For example, improving treatment access by dispensing care at user-friendly sites has been found to improve ART adherence (Shannon, Bright, Duddy, Seradis, Ishida, & Tyndall, 2004) and lead to fewer hospitalizations (Fielden et al., 2006). There is also some evidence that APHAs using the Vancouver supervised injection facility and a supervised ART program have higher rates of ART adherence and access to additional health care and support programs (Tyndall, et al., 2006). Aboriginal women have also been found to be more likely to access ART through community-based interventions and women-specific services (Shannon, Duddy, & Tyndall, 2005). This is a particular concern for pregnant APHAs.

IMPLICATIONS

The findings from this project need to be carefully considered for their policy and practice implications across the country, focusing on APHAs' access to and SPs' delivery of care and treatment. Without improvements, APHAs who use or are perceived to be using alcohol may not receive adequate treatment, may suffer more from HIV illness or other health-related complications, and may even die younger. Best practices in the field need to be shared and expanded upon and their relation explored with the empirical literature, including this study, heterogeneous lived experience (e.g., gender, age) and Indigenous and Western ways of knowing. Health is a basic human right of every person in Canada.

On many levels, however, Aboriginal people in Canada do not enjoy the same level of health as non-Aboriginal people. The findings of this study need to be placed within this context. The social determinants of health are known factors that contribute to or influence health. Aboriginal people and communities who experience inequities in the social determinants of health face numerous health disparities, and are often denied access to resources that might mitigate those circumstances. To illustrate, poverty is a key determinant of HIV infection (Fenton, 2004; Shelton, Cassell, & Adentunji, 2005). In fact, poverty increases biological susceptibility to HIV infection through elevated rates of malnutrition and sexually transmitted infections (Stillwaggon, 2002), and is linked to a lack of access to health care, lower education and illiteracy (i.e., for risk and prevention messaging), inability to afford condoms and perceptions of risk overshadowed by immediate survival needs (Larkin, 2000). The insightful reflection offered from the APHA interview respondent at the start of this paper should be heeded – context must be considered in any and all responses for progress to happen. An analysis of the contextual roots of the findings of this study would be welcomed.

CONCLUSION

The lack of documented literature was the impetus for this study's investigation into the role of alcohol in the transmission of HIV and access to health services for persons infected with HIV and AIDS. The study confirmed what many APHAs and SPs experience on a regular basis in Canada's health care system; the care is excellent. This study also uncovered a concern that had not been documented empirically until now; APHAs are being denied services for drinking by

SPs, whether it is perceived or real. There is an ongoing concern reflected in the disparity between APHAs and SPs about the potentially problematic role of alcohol in APHAs' lives. Agreed upon, however, are the holistic health impacts when it is a concern. The role of discrimination in the care APHAs receive from SPs continues to persist in deeply complex and rooted ways within Canada's colonial history. The findings point to the need for a nuanced strategy to solidify the strengths and address the shortcomings in APHA's service provision.

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