

# CULTURALLY COMPETENT SERVICE PROVISION ISSUES EXPERIENCED BY ABORIGINAL PEOPLE LIVING WITH HIV/AIDS

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## ABSTRACT

Cultural identity is an important factor in how well Aboriginal people respond to HIV/AIDS prevention or, once diagnosed with HIV or AIDS, how it affects their health care. This study explores the cultural skills among service providers who see Aboriginal people living with HIV/AIDS (APHAs) and the perspectives of APHAs. The purpose is to better understand the wellness needs of APHAs and how culturally competent care affects health service access and use. Data collection included face-to-face semi-structured interviews with APHAs and focus groups/interviews with community-based and primary health professionals in five regions of Canada. Interviews and focus groups were voice-recorded, verbatim transcribed, and coded using *Atlas.ti*<sup>®</sup> software. Thirty-five APHAs and fifty-two service providers were reached. Two key themes were noticed:

1. Active addictions are a major obstacle to adherence to HIV drug regimens. Half of APHA participants said addictions are a major factor. A

similar portion noted intensified substance use was an initial coping strategy when diagnosed. A slightly smaller portion noted that addictions were dealt with soon after diagnosis in order to begin antiretroviral treatment. Service providers who inform, encourage, and support APHAs' choices are viewed as "culturally competent."

2. Addictions and HIV must be "treated together," reflecting a holistic worldview of Aboriginal people. Programs that integrate addiction treatment with HIV/AIDS and service providers who encourage and support APHA's choices are viewed as "wise practice" models by both sets of study participants offering some convergence and a set of five wise practices are identified.

Key Words: Aboriginal Peoples, HIV/AIDS, Cultural Competence, Addictions

## INTRODUCTION

Cultural issues regarding health care provision are the motivating factors behind this paper and are derived from consultations between the Canadian Aboriginal AIDS Network (CAAN) and members of the Aboriginal HIV/AIDS community. Aboriginal cultural competence for HIV/AIDS health care providers emerged as an area in need of more focused research. Support for this research topic also comes from the findings of a national study on care, treatment, and support issues for Aboriginal People Living with HIV/AIDS (APHAs) (Jackson and Reimer, 2005). One significant finding of that study is the need to more aggressively attend to issues of cultural content and process in HIV/AIDS health programming.

Aboriginal Peoples (Inuit, Métis, and First Nations) in Canada come from diverse backgrounds with unique histories, values, customs, and beliefs. Although some common elements exist — for example, connection to the land and a shared history of colonization — understanding the role of culture in addressing HIV/AIDS most effectively is increasingly important in successful interventions. It is important to emphasize that while Aboriginal cultures in Canada are diverse and distinct, previous research conducted by CAAN demonstrates the existence of barriers that are commonly experienced by HIV-positive Aboriginal persons (e.g., Jackson and Reimer, 2005). This commonality also provides an underlying rationale for exploring and examining cultural issues of care, treatment, and support.

In addition, prolonged patient-provider relationships have significant repercussions for the present study. Over the past decade, Aboriginal health

organizations, as well as practitioners and researchers working in the field of Aboriginal health in Canada, have consistently advocated for increased cultural content in health services and programming (Aboriginal Nurses Association of Canada, 1996; Browne et al., 2000; Browne and Fiske, 2001; Dokis, 2002; Gray, 1996; Hoskins, 1999; Kue Young et al., 2003; Malcolm et al., 2003; National Aboriginal Health Organization [NAHO], 2006a; Purden, 2005; Racher and Annis, 2007; Royal Commission on Aboriginal People [RCAP], 1996; Smye and Browne, 2002; Smylie, 2001; Tookenay, 1996; Warry, 2000). Unfortunately, current examples of discrimination against Aboriginal peoples and APHAs by health care providers indicate that many health professionals still do not have the cross-cultural learning that is required for culturally competent health care (CAAN, 2004; Jackson, 2003; Matiation, 1999).

Aboriginal peoples comprise an ever increasing percentage of the HIV/AIDS case load, and, as the duration of the patient-provider relationship is expected to lengthen while APHAs learn to manage their illness, it is increasingly important for health professionals to be familiar with and competent in the cultural contexts of their Aboriginal clients. HIV/AIDS is a serious health concern for all Aboriginal communities. The number of new HIV infections among Aboriginal peoples continues to grow at a time when new infections are levelling off in the non-Aboriginal population. In 2006, the proportion of positive HIV test reports attributed to Aboriginal persons was 27.3% among provinces and territories reporting ethnicity information (Public Health Agency of Canada [PHAC], 2007, p. 47).<sup>1</sup> The number of AIDS diagnoses among Aboriginal groups has increased from 1.6%, prior to 1995, to 24.4% of AIDS diagnoses in Canada in 2006 (where ethnicity is reported; PHAC, 2007). The rise in HIV rates among Aboriginal peoples is most apparent in Canada's inner cities where an increasing proportion of Aboriginal people now live. While HIV/AIDS is still not a curable disease, new knowledge and medications allow some people to better "manage" their illness. This means that the most significant issues for APHAs in care have changed from end-of-life issues to healthy-living issues, increasing the duration and changing the nature of the patient-provider relationship between APHAs and their health care professionals (Cain and Todd, 2002).

Injecting drug use (IDU) with highly potent drugs that often lead to numerous injections in one day to maintain a high, has been a driving force

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1. In 2006, ethnicity data were available for 35.5% of AIDS cases and 29.2% of positive HIV tests. Ethnicity data is not available from Quebec and Ontario (PHAC, 2007).

in the epidemic, accounting for almost two-thirds of new HIV infections in the Aboriginal population. The Public Health Agency of Canada (PHAC) which monitors the epidemic reported:

[The] overall HIV infection rate among Aboriginal persons is about 2.8 times higher than among non-Aboriginal persons.... The proportion of new HIV infections in 2005 due to IDU among Aboriginal Canadians (53%) is much higher than among all Canadians (14%). This highlights the uniqueness of the HIV epidemic among Aboriginal persons and underscores the complexity of Canada's HIV epidemic. (PHAC, 2007, p. 56)

A related concern can be found in the rates of Hepatitis C Virus (HCV), which can also be spread through injecting drug use. A much stronger virus than HIV, there is evidence that suggests cleaning needles with bleach and water solutions may not kill HCV; hence an emphasis on discouraging or educating about the risks of sharing needles. Aboriginal Canadians are disproportionately affected by the Hepatitis C epidemic. Based on a Canadian sentinel surveillance system, it is estimated that 15% of reported acute Hepatitis C infections occur in Aboriginal people who account for about 4% of the population. When compared to the rest of the Canadian population, the incidence of acute Hepatitis C is six times as high in Aboriginal people (incidence per 100,000 of 18.9 in Aboriginal people vs. 2.8 in non-Aboriginal Canadians). Aboriginal people with acute Hepatitis C tend to be younger, female, and more likely to report drug use by injection and snorting and more risky sexual practices (Wu et al., 2007).

For both HIV and HCV, Aboriginal people are disproportionately represented. Aboriginal people are identified as a stated population in the Federal Initiative to Address HIV/AIDS in Canada, not only because of their relationship with the federal government but also because of the epidemiology. As we examine these figures and note the disproportionate rates of HIV and HCV, we need to explore how best to modify current interventions. In addition, with an estimated 3000–5000 Aboriginal people living with HIV/AIDS (APHAs), it is obvious that service providers must find culturally competent or safe ways to accommodate issues specific to the APHA population.

Finally, evidence suggests that many Aboriginal women, who make up half the HIV/AIDS cases in the Aboriginal population, are often diagnosed at AIDS stage. The Public Health Agency of Canada observes: *“Late use of antiretroviral therapy (in third trimester or intrapartum) was unequally distributed by ethnic status, occurring in 38% of Aboriginal, 27% of Black and 9%*

of *White women*" (2007, p. 53). Observations made through member agencies of the Canadian Aboriginal AIDS Network also share this perspective that many Aboriginal women report at late stages of disease progression. The inference here is that messaging, knowledge of risks, power imbalances, and perhaps negative experiences with the health care system have all combined to create a gap whereby Aboriginal women are neither offered HIV testing, nor ask for it, because they do not see risk or relevance. The question of cultural identity and what role it plays needs to be asked. Whether this is unique to Aboriginal women or there are other extenuating circumstances — such as family violence or the natural role of women being caregivers/providers placing the needs of others above their own — could also help explain why there is a clear difference between the rates among Aboriginal versus non-Aboriginal women. Likewise, there is evidence that more Aboriginal women are involved with injecting drug use than non-Aboriginal women.

The focus of this paper is to present findings that support a greater understanding of the role of culture and need for culturally competent service provision. Context is set by offering some historical influences (residential schooling) and how self-government/determination began to shape and state these needs. The current situation is then stated for the pressing health concerns of HIV/AIDS and Hepatitis C Virus (HCV); culturally competent interventions may increase success rates with respect to these epidemics. The next section combines a discussion of cultural competence and how this concept has been defined.

## CULTURAL COMPETENCE

The call for greater attention to cultural factors in care, treatment, and support for Aboriginal PHAs is reflected in the current Canadian and international literature. Cultural issues in the specific health care context of HIV/AIDS are topics of particular concern to Aboriginal Canadians (Bucharski et al., 2006; Schilder et al., 1998, 2001), particularly in relation to American Indians, Alaskan Natives, and Native Hawaiians in the United States (Aguilera and Plasencia, 2005; Foley et al., 2005; Gilley, 2006; Gilley and Cocké, 2005; Hamill and Dickey, 2005; Ka'opua and Mueller, 2004; Nebelkopf and Penagos, 2005; Speier, 2005).

The notion of cultural competence evolves as it is adapted to various health care settings and customized to meet different needs in multicultural societies in Canada, the United States, Australia, New Zealand, and

Britain. Of interest to our study is that much of the recent attention to developing effective cultural concepts of care is occurring within the context of Indigenous health and wellness.

When originally conceived in the 1980s, cultural competence was a shift away from a passive model of *sensitivity* to various client cultures, toward an action-oriented model of developing skills among health care providers that would allow them to function effectively in a cultural context other than their own (Chin, 2000; Kleinman, 1980; Kleinman and Good, 1985). Cultural *competence* is generally defined as the acquisition and maintenance of a *set of skills* – including behaviours, attitudes, and policies – for the delivery of appropriate care in a multicultural context (Gray and McPherson, 2005; Hamill and Dickey, 2005; Ka’opua and Mueller, 2004; NAHO, 2006a; Schilder et al., 1998; 2001). Campinha-Bacote (2002) provides a model that consists of the following five interdependent constructs: cultural awareness; cultural knowledge; cultural skill; cultural encounters; and cultural desire. While each of these constructs is important in its own right, it is cultural desire that provides the impetus for the journey from cultural *incompetence* by stimulating the health care providers to seek cultural encounters, to build cultural knowledge, to conduct culturally sensitive assessments and to be humble in the process of cultural awareness (Campinha-Bacote, 2002).

More recently, health researchers and educators have been critical of “content” models of competence that emphasize knowledge of cultural facts, inadvertently creating or reinforcing stereotypes, and are reformulating the notion as a “process” model of “lifelong” learning that can be applied to individual as well as institutional or system levels of care (Goode, 2004; Purden, 2005; Racher and Annis, 2007; Whaley and Davis, 2007). Margaret Purden (2005, p. 229) adds that community collaboration is imperative to this process, citing, for example, programs at the Churchill Health Centre (Manitoba) where “traditional practices are respected and interwoven with conventional care as a result of collaborations between local health care professionals and members of Aboriginal associations.”

In the bicultural context of Maori (marginal) vs. non-Maori (dominant) health care in New Zealand, nursing professionals and researchers have characterized cultural competency as cultural *safety*, a concept that recognizes the historical relationship of power between the health care provider and the patient. Cultural safety emphasizes *relationships of trust* in which

the patient determines if the care is “safe” or not (Gray and McPherson, 2005; Papps and Ramsden, 1996; Phillips, 2005; Polaschek, 1998; Ramsden, 2002; Richardson, 2004; Wepa, 2001; cf. NAHO, 2006a; 2006b). In the Australian context, Bourke et al. (2004, p. 183) define cultural safety specifically for practitioners, emphasizing “an environment which is safe for people, where there is no assault, challenge or denial of their identity, of who they are and what they need” (2004, p. 183). These authors conclude that “a lack of culturally safe health services place people from minorities at risk, especially Indigenous people, by dramatically reducing access to services.” In the Canadian context, Browne et al. (2000; 2001) apply the notion of cultural safety to analyze the “power imbalances” that characterize relationships between Aboriginal patients and their health care providers. In a study of HIV-positive Aboriginal women in Alberta, cultural safety is key to addressing “broader systemic barriers” or “lack of trust” resulting from the colonization experience, institutionalized discrimination, and child welfare involvement (Bucharski et al., 2006, pp. 732, 741).

The concept of cultural *humility* — advocated predominantly by health researchers in the United States (Juarez et al., 2006; Tervalon and Murray-García, 1998) — incorporates a lifelong commitment on the part of health professionals to *self-evaluation and self-critique* in order to redress the power imbalances in the patient-physician dynamic. The goal is to develop mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations.

Canadian researchers have referred to this self-reflective process as cultural *attunement* (Hoskins, 1999; Racher and Annis, 2007). In the context of Aboriginal health in Canada, Marie Hoskins (1999, p. 82) characterizes cultural attunement as “harmony,” “cooperation,” and “accord,” signifying “synchronicity” rather than expert positioning: “To attune oneself means *to walk beside or with an ‘other’*.” Key to the concept of cultural attunement are acts of humility: those who are part of the dominant culture have to constrain their own inclination to constantly privilege their own perspective (Hoskins, 1999, p. 79). As well, cultural attunement is characterized by reverence: a relationship in which the client is “revered” or honoured. Reverence — noted as “a highly regarded way of being in some cultures such as First Nations communities” — requires a person to think, act, and listen from the heart (Hoskins, 1999, p. 80). Racher and Annis (2007, pp. 263–265) define cultural attunement as “a way of *being*, in relation to the *other*” and

as part of a *cultural competence continuum* that includes engaging in acts of humility, self-exploration, building trust relationships, as well as “mutuality ... seeking common ground and emphasizing shared humanity” (cf. Goode, 2004). In the Aboriginal health context, these authors insist that:

Aspects of Canadian history such as Residential Schools ... must be acknowledged in order for people to be able to take responsibility for their contributions, seek to grow from them, and change oppressive tendencies. Recognizing that privilege is constantly operating to some degree and creating situations of power imbalance ... is crucial in honest communication that builds trust and respect. (Racher and Annis, 2007, p. 264)

The idea of being culturally attuned is also used by Winiarski et al. (2005) who prefer the term cultural *responsiveness* to describe health provision that “acknowledges clients’ cultural identities and takes their beliefs, norms and values into account in the interventions.” In implementing a more “practical concept” of care at an inner-city primary health clinic to integrate HIV/mental health programming serving minority populations in New York City, these authors conclude that culturally responsive health providers who are “empathic, culturally attuned, and knowledgeable in HIV care” prove effective in motivating HIV patients’ self-improvement (Winiarski et al., 2005, p. 754). Notions of cultural attunement and cultural responsiveness tend to be preferred by health researchers and educators who consider cultural competence an “unrealizable ideal” (Winiarski et al., 2005, p. 749; see also Racher and Annis, 2007, p. 267).

The cultural concepts of care discussed above are directed at health care service providers and institutions operated within a mainstream or dominant cultural system. The common demand is for health education and service models to attend to cultural factors of care that may improve health outcomes for members of minority groups, including Aboriginal people living with HIV/AIDS. On rare occasion, anthropologists and Indigenous researchers turn their gaze to the dynamic role played by the minority community on that cultural competence continuum. In the United States, for example, Brian Gilley and John Hawk Co-Cké (2005) coin the term cultural *investment* to describe the sense of ownership a Two-Spirit individual feels in the success and continuation of a particular social group or community. Regional support groups for Gay American Indians (GAI) provide opportunities for cultural investment in social practices that most of the men feel are not available to them due to homophobia within their tribal and

ceremonial communities. These opportunities also address issues around Native male HIV infection by encouraging cultural investment in Native social practices versus the sometimes bar-based culture of the gay community (Gilley and Co-Cké, 2005, pp. 294–295). The concept of cultural investment focuses on the *Aboriginal self*, situating HIV positive individuals in the learning and self-reflection processes required by specific traditional cultural and healing practices. Gilley (2006) also advocates for cultural *integration*, a concept that focuses on the role of the *Aboriginal community*. Instead of simply “translating” HIV/AIDS programming into Native culture, HIV prevention strategies must be decolonized and integrated by Native peoples into their own disease theories and contemporary culture (Gilley, 2006, p. 561).

## STUDY DESIGN AND RESEARCH METHODOLOGY

A CAAN Study titled “Canadian Aboriginal Cultural Competence for HIV/AIDS Health Care Providers,” herein called CAAN’s Cultural Competence study is the basis for this article. The design and methodology are outlined here.

### COMMUNITY-BASED RESEARCH (CBR)

This research study is grounded in a community-based methodology in keeping with the Aboriginal ownership, control, access, and possession (OCAP) model. The OCAP principle is “self-determination applied to research,” as follows:

- An Aboriginal community or group *owns* the information collectively;
- Aboriginal groups or individuals *control* the research process from conception, to analysis, to dissemination;
- Information and data about Aboriginal people are *accessible* to Aboriginal people;
- Aboriginal groups or individuals have the right to *possess* the data (CAAN, 2003).

At the national level, CAAN represents the community of Aboriginal people living with HIV/AIDS in Canada. The community-based approach is manifested in the research team: four of the five investigators are either employed by CAAN, or are representatives of organizations that are full members of CAAN. The principal investigators and the research team have been engaged at every stage of this research process. Regular electronic and face-to-face meetings ensured continuous interaction and collaborative decision-

making. This process created opportunities to learn from each other, refine research questions, discuss and agree upon culturally sensitive methodological approaches, and address ethical considerations on an ongoing basis.

The CAAN Research Advisory Committee — which includes individual members (APHAs) of the CAAN Network, but functions at arms' length from the research team — represents the grass-roots of the Canadian Aboriginal HIV/AIDS community. The Research Advisory Committee plays a significant role in promoting accountability by continually assessing the research study as a reflection of real community needs. At the end of each stage of data collection, "member checks" have been conducted to allow feedback and questions from CAAN members on preliminary findings. In February 2007 and September 2007, public presentations were given at CAAN conferences allowing individual and organizational members of the CAAN Network to comment on the content and direction of the cultural competence study. For the most part, preliminary interpretations were confirmed by the membership, and useful contributions were made with respect to study protocols.

## A QUALITATIVE APPROACH

The research strategy was devised and refined by members of the research team who represent different aspects of work in the Aboriginal HIV/AIDS field. The research team determined that a qualitative approach was best suited to the objective of understanding the social and cultural context of health care provision. Qualitative methods (semi-structured interviews and focus groups) allowed for interpersonal interaction and provided an avenue from which to gain information on attitudes, beliefs, and levels of satisfaction, all of which are crucial to improving the provision of health care services for APHAs. This approach resulted in detailed descriptions of how APHAs experience their health care world from a social and cultural perspective, and elicited the meanings APHAs assign to events and practices associated with their care, treatment, and support. Similarly, this open-ended qualitative approach allowed for questions to service providers (SPs) in direct response to what APHAs told us, and invited discussion about issues not raised by the APHA participants but of particular concern from a provision perspective.

## RECRUITMENT

Community involvement was key to recruitment of APHA participants. Local and regional AIDS Service Organizations (ASOs) and local HIV clinics in each of the five target regions were invited to assist in recruiting Aboriginal PHAs

for Phase I of the study. Aboriginal ASOs were particularly instrumental in identifying potential recruitment agencies and in several cases organized recruitment in their region. Ten organizations agreed to place posters advertising the study in waiting rooms, examination rooms, and other meeting areas. Each poster had tear-off sheets that could be freely taken by APHAs interested in participating in an interview. Approximately ten participants contacted the project coordinator directly by calling the project "hot-line" (confidential toll-free number listed on each tear-off sheet). As well, staffs at ASOs and clinics were instructed to make appointments on behalf of APHAs if requested by them. In four of the five study sites, ASO and/or clinic staff organized the interview schedule and provided a quiet and private space for the interviews to be conducted. These staff members were essential in brokering the trust relationship between APHAs and the interview facilitator.

Recruitment of service providers for focus groups and interviews was conducted mainly by direct telephone contact between the project coordinator and personnel at ASOs, HIV clinics, and other related organizations, known to be accessed by APHAs in the study sample. Local and regional Aboriginal ASOs also provided contact information for service providers known to provide care, treatment, and support to APHAs in their areas. Primary (medical) and community-based (support) HIV/AIDS professionals were given the option to participate in a focus group with other service providers in their city or region, or to participate in a one-on-one interview if the focus group schedule was not suitable.

The eligibility criteria for participation by APHAs in this study were: participants must be an Aboriginal (Inuit, Métis, Innu, First Nations) person living with HIV or AIDS in Canada; participants must be 18 years of age or older; and participants must have gone to a clinic or community AIDS centre for treatment or care in the past year. Eligibility criteria for participation by service providers in this study included: participants must be currently employed at an HIV/AIDS health care related facility or AIDS service organization; participants must be 18 years of age or older; and participants must have provided services to Aboriginal persons living with HIV/AIDS within the past year.

## DATA COLLECTION METHODS

Two main methods of data collection were used in this study: in-depth, semi-structured interviews and focus groups. Both of these methods encouraged open and unsolicited responses and explanations beyond mere

descriptions, and invited respondents to raise questions of their own. Semi-structured guides (lists of main topics for discussion) were used by the facilitator to steer responses toward relevant study objectives and research questions. This resulted in comparable findings across interview and focus group sessions. During interview and focus group sessions, each participant was also asked to complete a background survey form eliciting demographic, cultural, health status, and occupational information.

Phase 1 of the study consisted of interviews with 35 APHAs from 5 regions of Canada. In Phase 2 of the study we returned to each region where APHA participants accessed services, and conducted 11 focus group sessions and 8 interview sessions with primary and community-based HIV/AIDS professionals in those locations. In total, 52 service providers participated in the study, representing 25 organizations. The majority of interviews and focus groups were facilitated by the project coordinator. Several sessions were co-facilitated with research team members in their respective study regions, and one focus group was facilitated solely by a research team member.

## DATA ANALYSIS

Each interview and focus group session was transcribed, cleaned of all identifying information, and then coded using *ATLAS.ti*<sup>®</sup> a qualitative analysis program. Data analysis began with “open coding” in which phenomena found in the text of interview and focus group transcripts were identified, categorized, and described. The project coordinator then generated output of all coded responses for review by the research team members. Several discussions on the integrity and interpretation of code output were facilitated through teleconferences and face-to-face meetings held between April and November 2007. These discussions allowed the research team members to agree on coding definitions, to present their various perspectives and ideas about interpretations of the data, to reach consensus on emerging themes, and to prioritize analysis on those themes deemed most relevant to Aboriginal cultural competence as stated in the original research questions. Information from the background surveys was entered into *SPSS*<sup>®</sup> and frequency tables were generated to accurately assess the most salient characteristics of the APHA sample and the service provider sample.

## ETHICS PROTOCOL

Ethical considerations were guided by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al., 1998). Participation in

this study was voluntary and informed. Each participant kept a copy of the information sheet which provided a general outline of the nature and purpose of the study, and specified the measures taken to protect participant confidentiality and anonymity. Two copies of the consent form required the participant's signature, one to be kept by the participant and the other to be given to the researcher. The researchers' copies of all consent forms were secured in a locked safe in the project coordinator's office. Only the project coordinator had access to the master code-lists that matched true names to pseudonyms and codes.

Participants were given assurances that they could withdraw from the study at any point and, should they opt to do so, this would not affect APHAs' continued access to services or service providers' employment, nor would it affect the offer of an honorarium. All volunteers chose to complete the interview or focus group (i.e., no withdrawals), although in the case of several service providers, abbreviated question guides were used to accommodate time constraints.

Each participant was compensated with an honorarium for their involvement in the study. Many service providers initially refused the honoraria stating that the interview or focus group was held during work hours. In such cases, the facilitator suggested that the honoraria be donated to a "PHA fund" or similar fund managed by the institutions where service providers were employed. Generally, service provider participants were very agreeable to this alternative and accepted the honoraria on behalf of such a fund.

Interview and focus group sessions were recorded (digital and cassette-tape) only after consent was given by each participant. Only one participant declined to have the session recorded and in this instance, the facilitator took detailed hand-written notes and later transcribed responses into an electronic word-processing file. All recordings were transcribed by a CAAN research assistant or by a professional transcription service (Verbatim Ottawa Services). Transcribers were required to sign a confidentiality agreement. The project coordinator reviewed all verbatim transcripts and removed ("cleaned") all identifying information. Each participant was assigned a code number and/or pseudonym, and each location and person named during the session was also assigned a place and name code.

The majority of participants (APHAs,  $n=34$ ; SPs,  $n=48$ ; 94% overall) agreed to be contacted again during the course of the study, should follow-up questions or clarification be necessary. Although half ( $n=17$ ) of the

APHA participants asked to review the transcript of their recorded interview session, only three participants returned the transcripts with minor requests for revision or to indicate their approval of the transcript. The study was originally approved by the Dalhousie University Health Sciences Research Ethics Board in December 2005 and renewed in December 2006 and December 2007.

## FINDINGS

### PARTICIPANT CHARACTERISTICS

This qualitative study, conducted over a three-year period, reached a total of thirty-five Aboriginal people living with HIV/AIDS and fifty-two primary and community-based service providers. The APHA study population included twenty-two people who were First Nation; eight who were Métis and five who identified as Inuit. Ages ranged from four people in the 15–29 group, nine in the 30–39 group, fifteen between 40–49 years of age, and another five who were 50 years or older. Two did not provide ages. Thirty-two lived in an urban area; only two lived on-reserve, and one person lived in a rural/isolated area. Fifteen were female, nineteen male, and one was transgender. Sexual orientation showed twenty identified as heterosexual; eight as being homosexual; seven were bisexual. In addition, eight also identified as being two-spirited. In terms of how long individuals had been living with HIV or AIDS: eleven were in the 1–6 year range and nine in the 7–10 year range. Fifteen people had been living ten years or more with HIV or AIDS. Transmission categories showed that twenty-one people became infected through sexual contact, eight through injecting drug use (IDU), four had multiple risk factors, and one through blood products. One-quarter, or nine, had attended a residential school which suggests a direct link between the legacy of physical and sexual abuse in residential schools to HIV/AIDS.

The previous figure raises an important factor, suggesting a direct link between the legacy of physical and sexual abuse in residential schools to HIV/AIDS. Historical influences such as Indian Agents, residential schools, and assimilation policies seemingly were in conflict with whether mainstream society welcomed Aboriginal people. That the direct and intergenerational impact of the residential school legacy is a factor in the high rate of HIV/AIDS within the Canadian Aboriginal population is suggested in CAAN's *Care, Treatment and Support* study: *almost half of the study group were sur-*

*vivors themselves and/or their parent(s) were survivors* (Jackson and Reimer, 2008 [2005]) Taken together, historical, political, and cultural factors have all contributed to the current set of conditions for Aboriginal people that most believe are below Canadian standards.

Over time, and largely after the last residential school closed in the late 1960s, Aboriginal people mobilized. Through the formation of groups like the National Indian Brotherhood (now called Assembly of First Nations) greater community control by Aboriginal people began to occur. It became evident that not enough Aboriginal people were trained in many of the disciplines needed to address health care and other aspects related to self-government/determination.

As this need became evident, training strategies were developed. To accommodate immediate and short-term needs, non-Aboriginal service providers were encouraged to be culturally sensitive. This strategy largely failed, because it is extremely difficult to be knowledgeable of and sensitive to such diverse cultures.

Access to a healthcare facility or health professionals by an Aboriginal person who may feel marginalized, can contribute to why this same person may not go back for test results or for subsequent visits for other health complaints. While many Aboriginal people cannot explicitly name discrimination, many do report a negative experience in the health care system. By virtue of their illness, APHAs find themselves engaged in a lot of *health work* involving numerous, repeated visits to clinics and other medical or support facilities. Health care providers who participated in CAAN's *Cultural Competence* study reported that gaining the trust and building rapport with Aboriginal patients is a *slower process* and greater challenge than with other clients. However, improved health outcomes are apparent when relationships of trust and openness with service providers ensure that Aboriginal PHAs can make informed decisions about a range of choices and strategies for living with HIV.

To better understand the limitations of cultural sensitivity, consider this example:

An elderly First Nations man was experiencing a hospital stay. A nurse wanting to make him feel more comfortable bought in a dream catcher and hung it in his window. He said nothing to the nurse. When his family visited, one person asked what the object was in the window. The elderly man replied by saying he didn't know and that the nurse hung it up. (Personal communication, health care provider, 1996)

Despite dream catchers being sold everywhere, and many First Nations claiming some cultural linkage, dream catchers are not traditionally part of every First Nations group. The nurse, with the best of intentions, did not effectively respond to the cultural comfort of this patient. Hence a move toward cultural competency: the acquisition and maintenance of a set of skills – including behaviours, attitudes, and policies – for the delivery of appropriate care in a multicultural context (Campinha-Bacote, 2002). This shift involves more practical measures to accommodate diverse cultural issues. Some examples are:

- Playing Traditional music when an Aboriginal woman is giving birth or permitting sacred objects, such as an Eagle feather to be present;
- Building Sweat Lodges and having Elders conduct sweat lodge ceremonies on prison grounds;
- Turning off sprinkler systems or designating a room where smudging can occur in a public facility despite “no smoking” regulations;
- Creating physical spaces, such as a round room that resembles a Sweat Lodge (Nine Circles Community Health Center, Winnipeg MB) where Aboriginal clients can obtain traditional support after a diagnosis.

Understanding culture is critical not only in preventing new infections but also in how care, treatment, and support can be offered to Aboriginal people living with HIV/AIDS (APHAs). As previously stated, there is wide diversity among the three Aboriginal groups and even within one Aboriginal group there are multiple layers to consider. Understanding subcultures, such as a “street” culture or “gay” culture, also becomes part of the formula.

Language, customs, values, and beliefs all contribute to a different worldview. Many Aboriginal cultures can be classified as family-based cultures operating within an extended family system. That damage to this system has serious effects is demonstrated in *Canadian Aboriginal AIDS Network's (CAAN) Cultural Competence* study, in which almost half of the APHA participants spoke about being disconnected from their families, communities, and culture base for various reasons. For some, this is because they were removed from their Aboriginal parents' care and fostered or adopted into non-Aboriginal families. Several APHAs trace their “disconnectedness” to attendance at a residential school, or the recent rediscovery or regained status through Bill C-31. For others, traumatic experiences including ostracism, stigma (e.g., homophobia), and abusive relationships have caused rifts between APHAs and their families or home communities.

There may be different reasons why a service provider may not know the culture of a person to whom they are providing services. There are also various reasons related to residential schooling, foster care, etc. which contribute to a disconnection that some Aboriginal people feel. Physical appearance is also a factor; some Aboriginal people could be mistaken for being Asian or could be blond, blue-eyed, and light-skinned.

Likewise, some Aboriginal people may not follow traditional ways or be knowledgeable of certain traditional ceremonies. Several APHAs in CAAN's *Cultural Competence* study emphasized they did not want to be stereotyped just because they were Aboriginal. Health care and support service providers must be cognizant that participation in sweet grass smudges, sweat lodges, fasting, and other traditional ceremonies and practices is a very personal decision, varying according to family, religious, and cultural backgrounds, as well as individual experiences and beliefs. However, HIV/AIDS health professionals who care for Aboriginal PHAs also indicated that those who participate in traditional practices seem better able to *come to terms with HIV or deal with addictions and to adhere to treatment regimes*.

There also is an issue whereby some Aboriginal people are wrongly seen to be drug addicts or sex trade workers by a service provider. This labeling compounds negative experiences by Aboriginal people and deters them from coming back. Prejudicial and discriminatory attitudes associated with racism, HIV stigma, and homophobia continue to pose obstacles in the healing journeys of Aboriginal PHAs. In CAAN's *Cultural Competence* study, APHAs who related experiences of perceived racism did so almost exclusively within the context of primary medical services. In particular, there was a perception that health care professionals associated Aboriginal identity with addictive behaviour, as expressed by one APHA:

I've been to clinics when I've had an injury, whether it was due to drinking or not even drinking, that I think I felt a prejudice where they just kind of came and in and took a glance, and "Oh, yeah, you did something stupid when you were drunk. And it doesn't really matter because you're just an Indian, and you're probably going to just go get drunk and do it again. (CAAN *Cultural Competence* study participant, 2006)

Other APHAs perceived racism in situations where Aboriginal patients were refused pain medication because the doctor "*did not want to contribute to addictions,*" where Aboriginal women were assumed to be "*hookers,*" or where they waited for hours in an emergency ward while "*they take*

*white people right away*" (CAAN *Cultural Competence* study participants, 2006).

As cultural issues remained unaddressed, another shift occurred toward what is now being called cultural safety. Cultural safety emphasizes relationships of trust in which the patient determines if the care is safe or not. For health practitioners, this means creating "an environment which is safe for people, where there is no assault, challenge or denial of their identity, of who they are and what they need" (Bourke et al., 2004, p. 181). A lack of culturally safe health services place people from minorities at risk, especially Indigenous people, by dramatically reducing access to services.

Given that many APHAs now live in urban areas and are disconnected from their homes and families due to the historical and social factors mentioned previously, it is significant that they commonly refer to culturally safe care and support services in terms of "*second family*" or "*like home*" (CAAN *Cultural Competence* study participants, 2006). Notions of family include an emphasis on HIV-positive peer support, although the importance of whether peers are Aboriginal or not varies among participants. Many are *reconnecting* with their Aboriginal heritage since testing HIV-positive, including traditional healing practices and events provided through community-based centres.

A group called Creative Exchange (HealthLink, 2007) states that current structures often focus on the message being delivered to a given cultural group. They go on to say that a culturally safe framework relies on building dialogue, facilitating participation, and creating empowerment. Recognition of different worldviews and historical issues would also be part of this framework.

CAAN's *Cultural Competence* study builds on this. It reveals that half of Aboriginal people living with HIV/AIDS who participated in this study said that addictions are a major factor in living with HIV/AIDS. Some, as an initial means of coping with their diagnosis, intensified their use of drugs and alcohol. Many identified that dealing with their addiction soon after diagnosis was needed in order to begin antiretroviral treatment. For these people, getting "*cleaned up*" became more important than dealing with their HIV diagnosis (CAAN *Cultural Competence* study participants, 2006).

This study found that service providers were considered to be culturally competent when they informed, encouraged, and supported APHAs' choices. They felt that future programs should integrate addiction treatment with HIV/AIDS care. Such programs were also viewed by study participants

as being a “wise practice.”<sup>2</sup> Another key finding of this research revealed that, for many APHAs, adherence to HIV/AIDS drug regimens was seen as a journey presenting choices regarding health priorities.

Five wise practices were identified in the CAAN *Cultural Competence* study, and as stated, there is some convergence between the lived experiences of APHAs and the service providers who see them.

1. Stronger community partnerships with Aboriginal organizations, such as mainstream AIDS Service organizations networking with Aboriginal groups to ensure traditional services are available to Aboriginal people who request them.
2. Information about basic Aboriginal-specific health issues for service providers, in particular about understanding constraints around such programs as noninsured health benefits which Métis people are not eligible for.
3. Centralized access to Aboriginal resources presents advantages, such as an internet-based portal, listserv, etc. where those seeking Aboriginal services may refer to.
4. Use and importance of a holistic approach. Both APHAs and service providers spoke to the value and benefits of treating people as “a person” or “with a name” instead of feeling like a number. Addressing emotional, mental, social, physical, and spiritual needs offers more choices and encouragement to manage health needs.
5. The importance of respecting and providing treatment choices to people at all places in their journey. Both APHAs and service providers saw the journey as a process of coming to terms with diagnosis, medication side effects, other issues such as substance use or homelessness, and both sides felt that culturally competent care informs people and supports them in a range of choices as they come to terms with what is right for them.

## CONCLUSIONS

As the HIV and HCV epidemics continue to rise in Canada among Aboriginal people, increased emphasis on understanding the role of culture in design-

2. CAAN has adopted the term “wise” over best, good, or promising practices, as it is felt to be more culturally attuned. The premise is that wisdom is knowledge put to use, which is the essence behind the best practice framework.

ing HIV/AIDS interventions must be examined. It needs to be understood that Aboriginal people have negative histories not only with other health issues that took many lives, such as tuberculosis, which may still be remembered. Aboriginal people also have negative experiences of being discriminated against. Whether real or perceived in today's context, this element continues to be a key factor in why Aboriginal people may not engage the health care system in an ongoing way.

Education levels and cultural norms such as not asking questions or making eye contact may also affect whether the information provided by a health professional is understood. Shorter visitation periods, lack of family doctors, while affecting all Canadians, certainly do not maximize successful interventions if the health professional is not able to establish a rapport with the consumer or does not understand certain cultural norms.

A lack of understanding and respect by some likely resulted in a lack of value around the role of culture that perhaps contributes to what can be called cultural depression. Looking back over past and current efforts, an opportunity exists to utilize lessons learned from these experiences, countering the residue found with cultural depression — a malaise that may exist in certain communities that have experienced multiple losses and a lack of time and support to properly grieve the loss before the next one occurs

Despite generations of assimilation and other failed government policies, Aboriginal people continue to exist with their languages (although threatened) and with many of their customs, values, beliefs, and traditions. While some suggest that Aboriginal people are surviving, there is increased need to present resiliency as a cornerstone to how Aboriginal people respond to these new opportunities.

In response to and within the context that Aboriginal culture was not always understood, nor, perhaps, respected by non-Aboriginal service providers, efforts to educate Aboriginal people around health issues often focused on what is termed a "deficit" model, essentially telling the community or individual what was wrong in the community. The possible impact of being told over and over that you are at risk for this or that disease can be that people tune it out or give up.

A joint collaboration between New Zealand, Australia, and Canada has taken a different approach, exploring the role of resiliency among the Indigenous populations in the three countries, as it relates to HIV, Blood-borne Viruses (e.g., Hepatitis C), and Sexually Transmitted Infections (STIs). While this collaboration is still in the data collection phase, the research

reinforces the notion that cultural traits may be used to reinforce an “asset” model, meaning that cultural strengths are framed to design more effective interventions to combat the risks associated with various health concerns.

It is hoped that, as the study proceeds and issues are compared within the three countries, cultural resources such as Elders, ceremony, connection to family and community may be better understood and positioned to reinforce positive messaging about these cultural strengths. This may support changes in the way these health concerns are manifesting themselves within each country, albeit at different rates. High levels of diabetes, HIV, asthma, and many other health issues do exist, yet it is the spirit and will of the people, and reinforced pride in their cultural identity which may be the answer to reversing the negative health trends being seen. Within this context of culture, is the issue of resiliency. Due to changing economies, loss of access or use of traditional lands, one of the outcomes seen in most Aboriginal communities, has been a wide disparity in health, when compared to non-Aboriginal people in Canada. This type of disparity is also seen in other developed countries where colonization has occurred.

The CAAN *Cultural Competence* study reinforces the need to meaningfully address cultural needs. While most Aboriginal people living with HIV/AIDS could not necessarily name discrimination or stigma as a cause, many felt there was a different type of treatment they had received compared to mainstream individuals. When asked, it was clear that having a qualified health professional who knew about HIV/AIDS was paramount. However when prompted, a majority went on to describe the added value of having Aboriginal service providers. The term “second family” was often used. As one study participant put it:

The Native people I hang around with here who are HIV positive I can understand. I can relate where they're coming from because they grew up almost the same way as I was raised up. So how we joke around, we can laugh at the same thing, we joke around and you're building a new family. And I don't like feeling being isolated.... (CAAN *Cultural Competence* study participant, 2006)

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