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Cultural Concepts of Care among Aboriginal People living with HIV and AIDS: A Study by the Canadian Aboriginal AIDS Network

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ABSTRACT

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 consideration of cultural context in health services and programming. The impetus for this study on Aboriginal cultural concepts of HIV and AIDS care emerged from a series of consultations between the Canadian Aboriginal AIDS Network (CAAN) and members of the Aboriginal HIV and AIDS community. Undertaken by members of CAAN with Indigenous and allied researchers, this three-year (2005–2008), qualitative study involved Aboriginal (First Nations, Inuit and Métis) people living with HIV and AIDS (APHAs) from four provinces (Quebec, Ontario, Manitoba, and Saskatchewan) and one region (Atlantic) in Canada. Individual interviews and focus groups were undertaken with 35 APHAs and 52 HIV and AIDS service providers across Canada to explore the cultural concepts of HIV and AIDS care. Analysis of the findings revealed themes related to: Canadian colonial history and historic trauma; cultural disconnection; connections to family and home communities; experiences of racism; the importance of human connectedness in HIV care; peer support as a means of belonging and HIV advocacy as meaningful work; the meaning and significance of holistic care and traditional healing. For health professionals serving Aboriginal clients living with HIV and AIDS, it is essential to acknowledge the role of historic trauma and to make an effort to learn about the social determinants of Aboriginal peoples' health. Likewise, it is critical to understand that many APHAs are stigmatized in their home communities and to acknowledge the racism that exists against Aboriginal peoples. Providers are encouraged to appreciate the need for human connectedness within HIV and AIDS care and to have regard for Indigenous and holistic approaches to wellbeing, including traditional wellness practices. Several Wise Practices are suggested to facilitate HIV and AIDS care, which consider the cultural contexts and social determinants of health affecting the lives of Aboriginal people living with HIV and AIDS.

INTRODUCTION

HIV and AIDS continue to be a serious health concern for many Aboriginal communities, with incidence and prevalence rates substantially exceeding those of non-Aboriginal Canadians and disproportionate to the representation of Aboriginal peoples in Canada (Public Health Agency of Canada (PHAC), 2010). Yet, among Aboriginal people, HIV testing, treatment, care and support remain underutilized or unavailable. Overwhelmingly, the evidence indicates that systemic barriers discourage or prevent Aboriginal people from accessing HIV services (Browne & Fiske, 2001). In fact, the Canadian Aboriginal AIDS Network (CAAN) and others have discovered that health providers often fail to create 'culturally safe' environments for Aboriginal people to access these critical resources and supports (Jackson & Reimer, 2008; Jackson, 2003). Lack of welcoming care environments as well as the absence of Aboriginal health providers often limits the degree to which Aboriginal people access HIV services, which could contribute to the HIV epidemic in this population.

A full report of the study, "Relational Care": A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS (Barlow, Loppie Reading, Akan, Jackson, MacLean, & Reimer, 2009) is available on the CAAN website (www.caan.ca/research). This paper describes and discusses findings relevant to health care professionals working with Aboriginal patients.

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LITERATURE REVIEW

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 consideration of cultural context in health services and programming (BC Aboriginal AIDS Task Force, 2002; Canadian Aboriginal AIDS Network (CAAN), 2003). Unfortunately, current examples of discrimination against Aboriginal peoples and APHAs by health care service providers indicate that many health professionals still lack the cross-cultural awareness required to provide culturally competent care (CAAN, 2003). As Aboriginal peoples comprise an ever-increasing percentage of HIV and AIDS case loads, and as the duration of the client–provider relationship is expected to lengthen while APHAs manage their illness, it is increasingly important for health professionals to be familiar with and capable of providing care that considers the cultural contexts of their Aboriginal clients.

The call for greater attention to cultural contexts in care, treatment and support for APHAs is reflected in the current Canadian and international literature. Issues specific to the context of HIV and AIDS are of particular concern to Aboriginal people in Canada (CAAN, 2004). As well, cultural concepts of care have evolved to adapt to various health care settings and to meet different needs in multicultural societies such as the United States, Australia, New Zealand and Britain (Gray, & McPherson, 2005; Hamill & Dickey, 2005).

Conceived in the 1970s, the concept of cultural competence was originally defined as the acquisition and maintenance of a set of skills - including behaviours, attitudes and policies - for the delivery of appropriate care in a multi-cultural context (Ruben, 1976). However, health researchers and educators have become quite critical of 'content' models of competence that emphasize knowledge of cultural facts and that can inadvertently create or reinforce stereotypes. More recently, the discourse has shifted to an action-oriented model of developing a critical understanding among health care providers of their position of relative power and privilege that would better prepare them to work respectfully in diverse cultural contexts (Goode, 2004).

The concept of cultural competence has also been reformulated as a process model of lifelong learning that can be applied at individual as well as institutional or system levels of care (Purden, 2005). Purden adds that community collaboration is imperative to this process, citing for example, programs at the Churchill Health Centre (Manitoba) where "traditional practices were respected and interwoven with conventional care as a result of collaborations between local health care professionals and members of Aboriginal associations" (p. 229).

Within the bi-cultural context of Maori/non-Maori health care in New Zealand, nursing professionals and researchers have reconceptualized cultural competency within the context of cultural safety, a concept that recognizes relationships of power between the health care provider and the patient. Cultural safety also emphasizes interactions of trust in which the patient determines whether the care is "safe" (Gray & McPherson, 2005). In the Australian context, cultural safety is defined 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" (Phillips, 2005, p. 213), concluding that "a lack of culturally safe health

services place people from minorities at risk, especially Indigenous people, by dramatically reducing access to services" (Phillips, 2005, p. 214). In the Canadian context, notions of cultural safety are also applied to examine the power imbalances that characterize relationships between Aboriginal patients and their health care providers (National Aboriginal Health Organization (NAHO), 2006).

METHODOLOGY

The impetus for this study emerged from a series of consultations between CAAN and members of the Aboriginal HIV and AIDS community. In particular, the findings of CAAN's national survey-based research project on care, treatment and support issues for APHAs pointed to the need to more aggressively attend to issues of culture and process in HIV and AIDS health programming (Jackson & Reimer, 2008). That research also made it clear that while Aboriginal cultures in Canada are diverse and distinct, there exist barriers that are commonly experienced by HIV-positive Aboriginal persons. This commonality provides the underlying rationale for exploring and addressing cultural issues of care, treatment and support for APHAs.

This project was grounded in a community-based research methodology and Aboriginal ethical principles of Ownership, Control, Access and Possession (CAAN, 2003). Ethical considerations were also guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), Social Sciences and Humanities Research Council of Canada (SSHRC), 1998). This study was originally approved by the Dalhousie University Health Sciences Research Ethics Board in December 2005 and renewed in December 2006 and December 2007.

Data collection was undertaken in two phases. Phase one consisted of semi-structured interviews with 35 APHAs between January and December of 2006. Eligible participants were: Aboriginal persons (Inuit, Métis, or First Nations) living with HIV or AIDS in Canada, 18 years of age or older, who had gone to a clinic or community AIDS centre for treatment or care in the past year. APHAs were recruited by staff at local and regional AIDS Service Organizations (ASOs), local HIV clinics, and organizations identified by these sources. Some APHAs contacted the researchers directly after seeing posters displayed at these organizations. Thirty-two lived in urban centres, two lived in a reserve community, and one lived in a small town. Twenty-two identified as First Nations, with Mik'maq, Maliseet, Innu, Cree, Ojibway and Oji-Cree nations represented. There were also eight Métis and five Inuit participants.

Phase two of the study was undertaken between October 2006 and May 2007 and consisted of 11 focus groups and eight interviews with primary (medical) and community-based (support) HIV and AIDS professionals. Eligible service providers were: employed by an HIV and AIDS health care facility or AIDS Service Organization (ASO), 18 years of age or older, and had provided services to Aboriginal persons living with HIV and AIDS within the past year. Service providers were recruited by letters of invitation sent to ASOs, HIV clinics and other related organizations that were accessed by APHAs in the study sample. Local and regional ASOs also provided contact information for health professionals known to provide care, treatment and/or support to

APHAs in their areas. Participants were given the option to participate in a focus group with other service providers in their region, or to participate in a one-on-one interview.

Fifty-two HIV and AIDS service providers, representing 25 organizations, participated in focus groups and interviews. The agencies included: AIDS Service Organizations (both mainstream and Aboriginal-specific), HIV clinics, community health centres, Native Friendship Centres, addiction treatment centres, youth agencies and HIV housing agencies. Service providers included five medical doctors, 11 HIV nurse-practitioners, 11 social-support-outreach workers, two addiction program Managers, seven ASO Executive Directors, eight ASO staff-board members, five HIV Educator-Consultants, and three Aboriginal wellness program Coordinators.

The majority of interviews and focus groups were facilitated by the project coordinator, with the remaining sessions co-facilitated with research team members in their respective study regions, and one facilitated solely by a co-principal investigator. Each interview and focus group session was audio-taped and transcribed, cleaned of all identifying information, and coded using ATLAS.ti®, a qualitative data management software program. Data analysis began with open and directed coding, from which emergent themes were identified, categorized and conceptualized. Several research team discussions (which included APHAs) on the integrity and interpretation of themes were facilitated through teleconferences and face-to-face meetings. These meetings allowed research team members to discuss and refine coding definitions, present diverse perspectives about interpretations of the data, reach consensus on emerging themes, and prioritize analysis on themes deemed most relevant to Aboriginal HIV and AIDS care.

FINDINGS

The findings reveal several key cultural concepts of care for Aboriginal people living with HIV and AIDS including knowledge, understanding, and consideration of: Aboriginal history and historic trauma; family and home community dynamics; racism; the need for human connection and meaningful work; holistic care; and traditional wellness practices.

Aboriginal History, Historic Trauma, and Cultural Disconnection

Learning about Aboriginal history and colonial relations in Canada, without losing sight of individual differences between APHAs, was identified as a critical feature of appropriate HIV and AIDS care. Several APHAs and service providers linked APHAs' struggle for identity with Canada's colonial history and unequal Aboriginal–European relations. Generationally transmitted stress and grief is often the result of repeated relocation from traditional lands and long-term assimilation policies, including the forced removal of children to residential schools. The last residential schools closed in the 1990s — and while not all survivors experienced abuse, many did and others witnessed it vicariously. The 'collective trauma' of these experiences sometimes manifests as social and health problems (Gray & McPherson, 2005). Several APHAs traced a cultural disconnection, such as the inability to speak their Aboriginal language, to their own or their parents' attendance at residential schools. More than half of the APHA participants shared a measure of disconnection from their Indigenous culture. Some were unaware of their

Aboriginal roots until their First Nations status was reinstated through Bill C-31*. Others were fostered or adopted into non-Aboriginal homes, while still others have simply drifted from their cultural roots.

Besides having Aboriginal friends, I don't really follow the sweats or the Native medicine or anything like that. I'm more just, I'm more conventional. And everybody actually, there's a lot of people saying, "Well, because you're adopted into a white family — that's why you do that." I guess, maybe, that does have a role in it. The Aboriginal way — not to sound racist or anything — but I'm just not interested.

First Nations PHA adopted by non-Aboriginal family

Inasmuch as some APHAs might struggle with identity, HIV caregivers must have a greater understanding of how coping with 'cultural trauma', particularly through addictions, plays a role in some APHAs' journey. Support workers noted that APHAs who are seeking cultural reconnection, or those already connected to their culture, appreciated service providers who are familiar with Aboriginal resources in the local area.

There was overwhelming agreement among service provider participants that building rapport with Aboriginal clients takes longer than with non-Aboriginal clients, perhaps because many have come from a place of trauma and need time to "open that door" and develop a trusting relationship. For virtually all of the APHAs we spoke with, being able to trust a service provider was the critical feature of high-quality care. Taking steps to minimize inherent power relationships was reported as one of the most effective ways to develop trust.

Family and Home Communities

Service providers observed that Aboriginal clients tend to possess a strong sense of family but that perceptions of family were either very positive or very negative. In this regard, family could represent a source of strength, painful memories of abuse or become linked with sorrow related to multiple deaths within an extended family and the anticipation of loss linked to being HIV-positive. A service providers spoke about Aboriginal values that emphasize staying close to family and may mean an APHA would not move away from home to access better services. This same value makes it all the more difficult when prejudicial attitudes exist within families.

Within home communities, HIV stigma and homophobic attitudes can discourage HIV testing, limit access to services and medical care by APHAs, and threaten to isolate APHAs from important family support networks. One service provider claimed that several clients "would fear for their life" if their HIV status was disclosed. According to another service provider:

"Sadly, some of them die alone . . . some of the people who have HIV, they just want to come home to their home communities, to die with dignity. And they can't do that."

HIV or AIDS-phobia was also linked to long waits in emergency rooms, fear or outright refusal to provide care by medical professionals and concerns from Elders about participation in

^{*} Bill C-31 of the Indian Act provided an opportunity for First Nations women (and their children) to regain the 'Indian' status they had lost as a result of gender discrimination in the original Act (Communications Branch. Department of Indian Affairs and Northern Development, 1985).

ceremonies. Fear of disclosure can also lead to difficulties adhering to treatment regimens, as medication cannot be obtained or taken openly. Not surprisingly, trust in the level of confidentiality and quality of care within a service environment was described as imperative.

Racism

Many of the APHAs related experiences of racism within primary medical services. In particular, there was a perception that health care professionals associated Aboriginal identity with addictive behaviour. As well, one APHA participant reported that she is often presumed to be on disability or social assistance and is seldom asked if she has a job or career. A service provider further suggested that many doctors are invasive in their approach with Aboriginal women. There is a perception that doctors ask many more personal questions about Aboriginal women's sexual activity, number of children, or state of housing, than they would of non-Aboriginal women. Systemic racism was also perceived in terms of the dominance of the western biomedical model of health care over alternative, complementary or traditional wellness practices.

If you're identified as First Nation, or Inuit, and you are drunk on the street, you get the comments that bring shame. It's not just your individual shame. You are held accountable as this emblem of your whole race...in a way that a white guy on the corner panhandling doesn't have to deal with. He's an obnoxious panhandler, or an aggressive panhandler. But I think that the more you have the strength of pride of who you are — and pride in your history, and pride in the survival of your people — the more painful it is if you feel you're not doing your part, if you're bringing shame on your people. So I think people have extra burdens when they're a member of an identifiable group in a racist society.

Service Provider: HIV nurse, ON

Sadly, in this study, subtle forms of racism were revealed by non-Aboriginal health care professionals, who claimed that Aboriginal clients "pulled the race card" when situations were not in their favour. Although health practitioners may not be aware of their own biases, many Aboriginal participants reported experiencing racialized assumptions, stereotyping and/or disrespectful statements within health care environments. Apprehensions about racism and a lack of cultural safety were often the reasons APHAs gave for preferring an Aboriginal health care provider.

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 in and took a glance and [said], "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."

Oliver, First Nations PHA

Human Connectedness, a Sense of Belonging and Meaningful Work

Following an HIV-positive or AIDS diagnosis, human connectedness and a sense of belonging have proven to be crucial elements in learning to cope and live with HIV and AIDS (CAAN,

2004), especially for APHAs who live away from their home communities. Connection strategies used by APHAs in this study include: volunteering at HIV drop-ins and Native Friendship Centres, joining support groups such as talking circles, becoming active members of Aboriginal AIDS organizations, and speaking to Aboriginal students about the risks of HIV and AIDS. For many APHAs, becoming meaningfully involved allowed them to not only connect with others but to remain productive and creative.

According to the APHAs, peer-support models are considered most desired as Aboriginal HIV-positive peers can provide comfort and cohesion, a shared sense of humour, and opportunities to assist in each other's health work. APHAs often reported a strong emotional connection with this "family" of peers. Moreover, they repeatedly asserted the value of peer support and drop-in type services in avoiding high-risk behaviours. Service providers also recognized the value of a drop-in environment in which providers are openly available and APHAs do not have to commit to appointments. APHAs value the comfort and security of HIV clinics that are housed within drop-in type centres, where they can congregate for social reasons or access services such as food banks.

I find one thing that is unique about APHAs that we see in the [drop-in] is a strong need and desire for the peer—support model. And I find we're lucky to have a space where we can provide that. And because of the space we do have, we can really see those interactions going on — the sharing of stories or experiences ... I find that APHAs really seek out that peer support. I think some of that stems from the fact that because we are located in a city, that some of the APHAs probably feel very isolated . . . So I think that really gives a sense of home, and somewhere where they can relate. And relatively speaking from my experience, most people find it a safe space.

Service Provider: HIV drop-in support worker, ON

For APHAs accessing services, a familiar face, a shared experience, a friend who is not an authority figure, and the knowledge that they are not alone is critically important. In some cases, an Aboriginal presence (e.g., staff) was seen as more welcoming, which served to enhance the responsiveness of clients to the environment, and could foster an "instant connection". A number of APHAs preferred Aboriginal caregivers for emotional, spiritual and psychological support, because they felt more trusting, accepting and respectful. However, physical care by an expert in the <u>treatment</u> for HIV and AIDS was reported to be more important than the cultural identity of the practitioner.

Holistic Care

Service providers generally recognized that APHAs express perceptions of healing in more holistic terms, where physical, spiritual, emotional and mental wellness intersect. APHAs often sought holistic healing and were, in fact, sceptical of care providers who opposed approaches beyond physical or medical care.

There's so many little things a person can do to help the immune system. They can do nothing to the disease, but they can help themselves with their immune system. That's how I look at it. Which is totally opposite of any medical profession. Which is why I'm [in touch] with the Aboriginal community and HIV and AIDS, because they are taking the

approach as a holistic healing, you see? And there is not any other community looking at it that way, that I know. First Nations PHA

When asked about the physical space in which they receive care and support, APHAs responded that the ideal space was one in which they felt welcomed, respected, relaxed and safe. A space that felt "like home"; that acknowledged the local Aboriginal culture in its art and design. On a grander scale, a few APHAs imagined their "ideal care" facility as one based on traditional Indigenous architectural designs such as the tee pee, wigwam or medicine wheel, which incorporates the natural features of Mother Earth, has circular spaces for traditional ceremonies, and where multiple services would be provided within a single holistic environment.

Our HIV drop-in tries to provide an environment of comfort where people can be casual, a space arranged like a living room and not a counselor's office, so that people are meeting on a peer level. For me that's very effective in the Aboriginal community because here they don't feel that power imbalance.

Service Provider: HIV drop-in support worker, ON

APHAs as well as service providers talked about the importance of outreach care, including home visits by HIV physicians or nurses, or HIV clinics in familiar environments such as Native Friendship Centres. Outreach health care is necessary for those individuals - homeless or too ill to leave home - who experience substantial difficulty adjusting to the health care system or who the health system seems unable or unwilling to accommodate.

APHAs revealed that, for them, holistic care embraces a spiritual connection as well as features of compassion and acceptance. It celebrates diversity with respect to race, gender, sexuality and HIV status, including the diversity of the APHA population. Along with creating a spiritual connection, one service provider asserted that the Aboriginal community is more likely to consider spiritual pathways as "opportunities for healing".

I listen differently when I have Aboriginal PHAs because there's a whole sort of cultural background that is attached to being Aboriginal. Sometimes it's about being adopted, being fostered, growing up on a reserve, having either been in a residential school or parents who have been in a residential school ... So I sort of listen for clues that might help me understand where the person's coming from, what the person's connections are, what their experiences might be. Which makes me ask related questions ... If the person is a non-Aboriginal PHA, all of that stuff is not relevant.

Service Provider: Métis HIV support worker, MB

Traditional Healing

More than one-third of the APHAs talked about reconnecting with their Aboriginal heritage since testing HIV-positive. Exposure to Aboriginal wellness practices and cultural events can elicit a sense of "coming home", new meaning in life, pride in being Aboriginal, and improved self-esteem. Generally, service providers also observed that APHAs who explore and engage in traditional practices "seem to cope better with HIV/AIDS and with everyday life in general". To foster this, several mainstream service providers have created space for Aboriginal traditional ceremonies and/or a room for Elders to provide private counsel and support to APHAs.

Bringing medical and Indigenous practices together also seems to help APHAs cope with adherence to HIV medications as well as facilitating an atmosphere of peace. According to one service provider:

We had a client living with both a mental illness . . . and also HIV. So the work with the Elder, in this case, helped the client put the visions and dreams and hallucinations, many of them, in a spiritual context of meaning ... of what those meant. So they became less distressing for the client and therefore the client was able to consider taking on this additional bit of stress, of the HIV medications.

Elder counselling was identified as beneficial in terms of providing cultural and spiritual support to accept living with HIV, connecting with ceremony that "has history" and helped to stabilize people's lives ultimately supporting a "healing journey" for APHAs who chose traditional approaches.

Most primary service providers reported that they valued the integration of mainstream medical and Indigenous approaches. Yet, in practice, they were more likely to 'tolerate' complementary therapies as long as they do not conflict with HIV drug regimens. Indigenous healing practices are sometimes perceived as challenging for service providers because fasting, drinking herbal teas, or participating in ceremonial activities might interfere with medications. Several physicians pointed out that there is insufficient information about how traditional medicines can be combined with HIV drug regimens.

DISCUSSION

When considering the health care experiences of Aboriginal people living with HIV and AIDS, we are reminded that, although there are unique care, treatment and support issues related to HIV and AIDS, there are also challenges and barriers specifically related to being Aboriginal (Adelson, 2005). Some of these barriers may be linguistic, others may be gender-based and some may be related to substance abuse or mental health issues. Stigma and discrimination certainly sets HIV and AIDS apart from other health issues, yet even before an Aboriginal person tests HIV-positive, they have likely experienced negative experiences in the health care system (Vance & Denham, 2008). It is often a culmination of both tacit and explicit prejudicial treatment over a lifetime that taints their view of health care provision. These experiences contribute to many APHA's choice not to engage in, or to disengage from, the health care system. Three nurses from different sites participating in this study identified "using your privilege to learn" about general issues of Aboriginal history and relations in Canada, without losing sight of individual's experiences.

Although Aboriginal people may not specifically name racism, many leave health care environments feeling that they were not treated respectfully or equitably (Matiation, 1999). This study clearly demonstrates that service providers are susceptible to stereotypes and biases about Aboriginal peoples. Although statistics confirm that almost two-thirds of new HIV infections among Aboriginal people are due to injecting drugs (PHAC, 2010), many Aboriginal people who may or may not be using substances sense they are immediately perceived as "junkies" and those

who are struggling with addictions often feel dehumanized within care environments.

APHAs who participated in this study described two main themes for relational care: connecting and relationships. As fewer health professionals are available to serve growing numbers of HIV-positive Aboriginal clients, there will be a greater challenge to nurture humane therapeutic relationships. As HIV is seen as an episodic illness in which APHAs shift from periods of physical strength to those of significant downturns in their health, support networks need to be well-rounded and provide connections on physical, social, emotional and spiritual levels.

APHAs in this study clearly described what "ideal care" means to them: connection with care givers and respectful interactions to negotiate care, treatment and support. In terms of features that would make their visit to a clinic more comfortable: Aboriginal staff, art or design; cultural opportunities in the form of traditional wellness practices; relinquishing expert status and learning together to meet APHAs' needs and emotional supports in which service providers and/or Elders take the time to really listen.

When serving Aboriginal clients, it is important to truly understand and acknowledge historic trauma and to make an effort to learn about the diversity of Aboriginal cultures. Providers must also consider that many APHAs are stigmatized in their home communities and acknowledge the racism that continues to exist against Aboriginal peoples. Likewise, high-quality care is based on an appreciation for human connectedness, development and maintenance of equitable provider/client relationships as well as regard for holistic approaches to wellbeing, and traditional Indigenous wellness practices. Flexible care – exploring the timing of clinics, the full range of medical options, the APHA's readiness to commit to treatment and taking into consideration the social concerns a person is managing – can lead to an environment that supports a reciprocal process where APHAs and primary care/service providers share responsibility for well-being.

The following *Wise Practices* offer guidelines to help discover and nurture a shared vision of relational care between providers and clients:

- Acknowledge that many Aboriginal People wear the legacy of colonialism to varying
 degrees. Observe those who may more noticeably experience multiple challenges as a
 result of this legacy. Despite the challenges, many Aboriginal People take pride in their
 identity and demonstrate their values of survival and resilience in the face of challenges
 to their culture and health.
- Approach Aboriginal families as a unit. In Aboriginal communities urban or rural it is not enough to provide education and information at an individual level. Ask direct questions, for instance, about who shares needles. Offer to do home visits to share information, perhaps to show how to avoid risks of transmission or manage treatment and make the information available to others in the household.
- Health practitioners, chiefs, mayors, council members, elected and non-elected leaders, Elders and community members who want to create a safe environment and provide relational care should deliver a deliberate and sustained message normalizing HIV and AIDS to Aboriginal families and communities.

- Be acutely aware that many Aboriginal people have experienced racism and discrimination and do not presume that substance abuse is a factor in their lives.
 Recognize that each Aboriginal client comes from a unique background, and treat each client as an individual who has the capacity and right to make their own informed health decisions.
- Treat the person and not the disease. Be willing to find ways to help APHAs overcome lifestyle and health barriers (e.g., integrate addiction treatment and HIV care if relevant). Encourage patients' participation in decision-making and honour APHAs' choices. Show compassion for the whole person by allowing APHAs to reveal what they feel safe to reveal.
- Maintain a close working knowledge of Aboriginal-specific services in order to help APHAs who consider their HIV-positive diagnosis as a catalyst toward seeking a better path in life and health, particularly through reconnecting with their Aboriginal identity and culture. For referrals, contact knowledgeable Elders and Aboriginal organizations that provide discreet and confidential services.
- Create a safe space for APHAs to connect and support one and other, one where they are assured of confidentiality and a non-judgemental atmosphere. Show understanding, and help APHAs who cannot be with their families of origin to find a "second family" that they can belong to who will walk with them on their healing journey.
- Take practical steps in care provision (e.g., allow a space within a facility where traditional Aboriginal wellness practices and ceremonies, such as smudging or Inuit qulliq, can take place). Work with Aboriginal agencies that have Elder services so that support can be obtained when needed. Include murals and other imagery to enhance the space and create positive images where Aboriginal clients feel good about entering and staying awhile.
- Express a genuine respect and trust for Aboriginal clients in providing care. Respect for the resilient nature of individuals, even when it's not obvious, is vital and a foundation of relational care.
- Be flexible, develop new programs, and get to know clients, communities, Aboriginal referral contacts and partners.

REFERENCES

- Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. Canadian Journal of Public Health, 96(S2), S45-S61.
- Barlow, K., Loppie Reading, C., Akan, M., Jackson, R., MacLean, L., & Reimer, G. (2009). Relational Care: A guide to health care and support for Aboriginal people living with HIV/AIDS. Ottawa, ON: Canadian Aboriginal AIDS Network. Retrieved from http://www.caan.ca/wp-content/uploads/2012/05/Relational-Care-20082.pdf
- BC Aboriginal AIDS Task Force. (2002). The Red Road: Pathways to wholeness: An Aboriginal strategy for HIV/AIDS in BC. Retrieved from www.health.gov.bc.ca/library/publications/year/1999/red-road.pdf
- Browne, A. J., & Fiske, J. (2001). First Nations women's encounters with mainstream health services. Western Journal of Nursing Research, 23(2), 126-147.
- Canadian Aboriginal AIDS Network (CAAN). (2003). Strengthening ties Strengthening Communities: An Aboriginal strategy on HIV/AIDS in Canada for First Nations, Inuit and Métis people. Ottawa, ON: Author.
- Canadian Aboriginal AIDS Network (CAAN). (2004). Aboriginal HIV/AIDS anti-discrimination policy framework. Unpublished draft report. Ottawa, ON: Author.
- Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), Social Sciences and Humanities Research Council of Canada (SSHRC). (1998). Tri-council policy statement: Ethical conduct for research involving humans (with 2000, 2002 and 2005 amendments). Ottawa, ON: Authors.
- Communications Branch. Department of Indian Affairs and Northern Development. (1985). First Nations, Bill C-31, Indian Act. Retrieved from http://www.johnco.com/nativel/bill c31.html
- Goode, T. D. (2004). Cultural competence continuum. National Centre for Cultural Competence. Georgetown University Center for Child and Human Development.
- Gray, M., & McPherson, K. (2005). Cultural safety and professional practice in occupational therapy: A New Zealand experience. Australian Occupational Therapy Journal, 52, 34– 42.
- Hamill, S., & Dickey, M. (2005). Cultural Competence: What is needed in working with Native Americans with HIV/AIDS? Journal of the Association of Nurses in AIDS Care 16(4), 64–69.
- Jackson, R. (2003). Experience and HIV-related stigma (One Aboriginal person's perspective):

- Implications for nursing practice. Ottawa, ON: Canadian Aboriginal AIDS Network. Jackson, R., & Reimer, G. (2008). Canadian Aboriginal people living with HIV/AIDS: Care, treatment and support issues. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Matiation, S. (1999). *Discrimination, HIV/AIDS and Aboriginal people: A discussion paper*. Montreal, QC: Canadian HIV/AIDS Legal Network.
- National Aboriginal Health Organization (NAHO). (2006). *Environmental scan of cultural competency/safety in health curricula*. Ottawa, ON: Author.
- Public Health Agency of Canada (PHAC). (2010). *HIV/AIDS Epi-updates: HIV/AIDS among Aboriginal people in Canada*. Ottawa, ON: Public Health Agency of Canada.
- Purden, M. (2005). Cultural considerations in inter-professional education and practice. *Journal of Interprofessional Care*, 19(Supp.1), 224–234.
- Ruben, B. D. (1976). Assessing communication competency for intercultural adaptation. *Group and Organization Studies*, 1, 334-354.
- Vance, R., & Denham, S. (2008). HIV/AIDS related stigma: Delivering appropriate nursing care. *Teaching and Learning in Nursing*, *3*, 59–66.
- Warry, W. (2000). Unfinished *dreams: Community healing and the reality of Aboriginal self-government*. Toronto, ON: University of Toronto Press.
- Wesley-Esquimaux, C., & Smolewski, M. (2004). *Historic trauma and Aboriginal healing*. Ottawa, ON: Aboriginal Healing Foundation.
- Williams, R. (2008). Cultural safety: What does it mean for our work practice? *Australian and New Zealand Journal of Public Health*, 23(2), 213-214.

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