

Research Report Summary

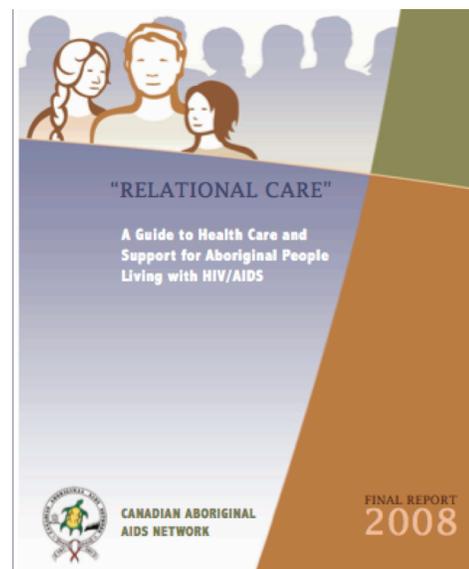
“RELATIONAL CARE”: A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS (2008)

Research Team

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Executive Summary

This study began as an investigation into the need for culturally competent care for Aboriginal People Living with HIV/AIDS (APHAs) in Canada. It resulted in an understanding of the need for what we term “relational care.” The root of relational care is connection, the link between all living things that in some Aboriginal philosophies is captured in the phrase “all my relations.” Relational care is an interactive, caring, respectful path for culturally competent services leading to the well-being of the whole person. Imagine if a Doctor or nurse took time to acknowledge that the person they are treating came across their path for a reason, some deeper purpose, such as to teach or learn from one another? As with the messenger on the preceding page, it is a tremendous responsibility and perhaps gift, to be a part of someone’s passing into the spirit world. And until they pass, being of service to assist in finding a healthier way to live also carries that same responsibility.



While most cultural concepts of care (e.g., cultural competence, cultural safety) call attention to relationships of trust, relational care embraces the entire relationship between caregiver and care recipient. Relational care encompasses the physical, social, emotional and spiritual dimensions of human connection. Healthy care relationships are critical because unhealthy relationships often result in Aboriginal people discontinuing care.

The concept of relational care is rooted in values and teachings of Inuit, Métis and First Nations cultures. These values and teachings provide pathways for our analysis of the experiences of APHAs in accessing care, treatment and support, and frame our analysis of relational care service provision. In this report we outline Seven Sacred Teachings which are found in many



First Nations to elicit care relationships that foster positive health outcomes for APHAs. We acknowledge that the Inuit and Métis also have their own belief systems which may be similar to these.

METHODOLOGY

This was a three-year qualitative research study (2005–2008) involving five target regions in Canada: Atlantic, Quebec, Ontario, Manitoba, and Saskatchewan. The study set out to meet three research objectives:

- To explore the perceptions of cultural concepts of care among APHAs and HIV/AIDS health care providers;
- To document the lived experiences of APHAs regarding culturally competent or incompetent health care; and
- To design a wise practices guide for HIV/AIDS health care providers who work with APHAs.

Data collection was conducted in two phases. Phase 1 consisted of interviews with APHAs. In Phase 2 we returned to each region where APHA participants accessed services, and conducted focus group and interview sessions with primary and community-based HIV/AIDS professionals:

- Thirty-five APHAs participated in semi-structured interviews. Within this group, 22 identified as First Nations, such as Mik'maq, Maliseet, Innu, Cree, Ojibway and Oji-Cree cultures represented. There were eight Métis participants, most of whom lived in western Canada. The remaining five persons living with HIV/AIDS (PHA) participants were Inuit, each of whom left Nunavut or Nunavik who had moved to southern urban centres, mainly in central Canada.
- Fifty-two HIV/AIDS service providers, representing 25 organizations, participated in focus groups and interviews. The service provider sample included both primary (medical) and community-based (support) health professionals who work at various types of agencies such as AIDS Service Organizations (ASOs, both mainstream and Aboriginal-specific), HIV clinics, community health centres, Native Friendship Centres, addiction treatment centres, youth agencies and HIV housing agencies.

Taken as a whole, the knowledge of both APHAs and health care providers in this study represent a broad range of individual and organizational experiences in both accessing and providing care, treatment and support for HIV/AIDS. Their knowledge of Aboriginal cultural issues and health care systems in various regions across Canada provides a rich source of information toward building a meaningful and competent approach to care for Aboriginal people living with HIV/AIDS.

The APHA experience: Being Aboriginal, Being Positive

Living with HIV/AIDS is often described by APHAs as an emotionally difficult journey that begins immediately after testing positive for HIV. Many APHAs described HIV discovery as a



devastating experience and a sudden loss of hope for the future. For some APHAs, the crisis of HIV was a wake-up call to change their lifestyles. Whatever the initial reaction to discovering their positive HIV status, participants described how pathways to healing can be facilitated by health care and support that nurtures not only physical health but also emotional and mental stability — and for some, cultural and spiritual renewal.

Service providers generally recognized that APHAs express healing in more holistic terms, where physical, spiritual, emotional and mental wellness intersect. Many medical and support professionals made it clear that living with HIV/AIDS is a lifelong journey, and that many PHAs struggle to deal with a complexity of lifestyle and health issues that led to their HIV infection in the first place. While the journey itself is not Aboriginal-specific, service providers generally agreed that there are cultural components to how APHAs balance positive and negative experiences and how they respond to diagnosis, adhere to treatment, access support, overcome obstacles and learn to live with HIV/AIDS.

Relational care begins with a common understanding of past relationships between Aboriginal peoples and European colonizers. Those engaged in relational care acknowledge the historic trauma of past colonial relationships on the health of Aboriginal peoples in Canada and work with clients to minimize further harm:

- “Historic trauma” associated with centuries of colonization of Indigenous peoples of the Americas is commonly cited as a main factor in the health disparities experienced by Aboriginal peoples in Canada. Researchers commonly consider rapidly increasing rates of HIV and hepatitis C virus (HCV) infection among Aboriginal youth as a reflection of the complex effects of addiction, social dislocation, discrimination, human rights violation and poverty.
- Approximately half of the APHA participants shared their sense of disconnection from Aboriginal culture for various reasons. For some, this sense of disconnection was due to adoption or fostering by non-Aboriginal families. Several APHAs traced their disconnection to attendance at residential schools or to recent reinstatement of their First Nations status through Bill C-31. For others, traumatic experiences involving HIV stigma, homophobia, ostracism or abusive relationships have caused rifts between them and their families or home communities. Several APHAs left their home communities because of its isolation or lack of services and other opportunities. Many APHAs concluded that returning home to their communities of origin was no longer an option.

An HIV diagnosis can shatter the meaning people hold about life and their place in the world. Often APHAs described how testing positive for HIV resulted in overwhelming fear that illness would quickly lead to crippling illness and/or sudden death. For some of these individuals, coping meant withdrawing from social and family supports. Frequently, APHAs’ lives entered a period of intensified negative coping based on past street involvement and substance abuse, often reflecting high-risk behaviours that led to the diagnosis.

For most people diagnosed with HIV/AIDS, the shame and failure associated with experiences of stigma and homophobia further complicate HIV discovery. These factors also represent



recognized barriers to disclosure and to accessing treatment and support services. Service providers say that HIV stigma and racial prejudice tend to limit APHAs' access to medical and support services, both inside and outside Aboriginal communities:

- From within home communities, HIV stigma and homophobic attitudes limit access to services by APHAs who are concerned about privacy and confidentiality. From a medical services point of view, HIV stigma in Aboriginal communities discourages HIV testing and threatens to isolate APHAs from important family support networks. Service providers frequently commented on the burden being placed on APHAs' sense of Aboriginal identity due to homophobic attitudes and associated fears about HIV/AIDS. This is a serious concern for APHAs, who have been judged by and are now unwelcome in their home communities.
- From outside, attitudinal obstacles in the paths of APHAs' healing journeys include perceptions of discriminatory practices by social assistance agencies, pharmacists, clinicians and other mainstream service agencies. Racist attitudes toward Aboriginal peoples from within health care and support environments add another layer of stress to an already difficult situation. APHAs' perceptions of prejudice were often woven into and associated with stories of racism, HIV stigma and/or homophobia.
- 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. Racist attitudes were also perceived in terms of dominance of the western biomedical model of health care over alternative, complementary or traditional wellness practices.
- APHAs with overlapping identities — being Aboriginal, being HIV-positive, being gay, being an addict, being a sex worker — described pulling away from familial and medical relationships in an effort to protect against painful experiences of stigma, racism or homophobia.

For some APHAs, testing positive was a turning point in their lives, leading to a “good journey” or “better path.” More than one-third of the APHAs interviewed talked about reconnecting with their Aboriginal heritage since testing as HIV-positive. Culture was seen as a path toward new meaning in life, learning to take pride in being Aboriginal and generally improving self-esteem. Other APHAs did not seek cultural or traditional avenues but nevertheless viewed HIV as an opportunity to grow. In this sense, HIV was seen as a “gift” that triggered reflection, introspection and re-evaluation of life and health priorities.

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/AIDS. APHAs often described this human connectedness as “second family.” Strategies included volunteering at HIV drop-ins and Native Friendship Centres; joining support groups such as talking circles; becoming active members of local, regional, and national Aboriginal AIDS organizations; learning speaking skills in order to inform Aboriginal students about the risks of HIV/AIDS; and accepting help from others, especially family and friends.



Among those APHAs who were seeking to reconnect with their cultural heritage, exploring traditional Aboriginal approaches to wellness was an important pathway. Health care and support professionals generally agreed that traditional wellness approaches promoted positive health outcomes. Relational care in this instance required that the health care provider be willing to have a conversation with their Aboriginal patient about how to integrate western medical treatments and traditional wellness practices.

Relational Care: Promoting Healing

APHAs described relational care as involving two main themes — connecting and relationships:

- Connecting refers to APHAs' perception that a safe environment is one in which they felt comfortable, important and cared for as a person, not a disease.
- Relationships were conceptualized as the ways in which service providers interacted with APHAs, and how they negotiated the care, treatment and support appropriate to each situation. Good care relationships reflected the Seven Sacred Teachings: love, respect, courage, honesty, wisdom, humility and truth.

Service providers emphasized that competency had many more components than just provision of culturally relevant skills and knowledge. Core elements of relational care include trust; rapport; respect for individuality; regard for Aboriginal and holistic approaches to wellbeing; flexibility and openness toward alternative, complementary and integrated care strategies; and willingness to relinquish expert status and learn about how better to meet the needs of Aboriginal PHAs.

In connecting with health care and support, APHAs revealed ways in which they could relate to physical, social, emotional and spiritual environments. Similarly, service providers shared their observations and experiences about how, when and why they were able to connect with their Aboriginal clients:

- Physical connection was described as a sense of space and place where APHAs felt welcomed, comfortable, relaxed and safe. In their descriptions of “ideal care,” many APHAs described physical spaces that felt “like home” and that acknowledged the local Aboriginal culture in its art or architecture. Trust in the level of confidentiality within this environment was imperative.
- Social connection was recognized as a familiar face, a shared experience, a friend who was not an authority, and knowledge that an APHA is not alone. An Aboriginal presence (e.g., staff) was seen as more welcoming and had the potential to enhance the responsiveness of some clients to the environment, resulting in improved access to care. In other cases, service providers who were themselves HIV-positive were viewed as the foundation upon which some APHAs felt they could best relate.
- Listening, sharing and sense of family were described as ingredients of emotional connection. Inasmuch as an Aboriginal presence within care environments was viewed as



- favourable by almost all APHA participants, creating and providing a safe emotional space was equally important. A common theme in APHAs' stories about the drop-ins, community health centres, or Native Friendship Centres they frequented was the strong emotional connection they had with HIV-positive peers who were like "family."
- Spiritual connection embraced notions of acceptance, open-mindedness and human competence. It celebrated diversity of race, gender, sexuality and HIV status. This meant acknowledging the diversity of the APHA population in terms of cultural background, personal experience and sexual orientation. APHAs objected to being stereotyped, and advocated equal treatment for all, regardless of culture. Fundamental to making a spiritual connection were service providers characterized as understanding, open-minded and dynamic.

Personable relationships were critical to APHA participants' perceptions of culturally competent and safe care. In particular, having a one-on-one and dependable relationship with service providers, whether they were Aboriginal or non-Aboriginal, was often reported as the most important component of care. APHAs talked about how meaningful interactions and affirmative social encounters shaped their experience with health care facilities and service organizations.

For virtually all of the APHAs we spoke with, being able to trust a service provider was the dividing line between good and bad care. There was overwhelming agreement among service provider participants that building rapport with Aboriginal clients takes longer than with non-Aboriginal clients. There was an initial mistrust by APHAs of health and social service organizations, and apprehension about being judged by those in authority. Trust was defined by both APHAs and service providers to include non-judgmental attitudes and behaviours; knowledge and capacity to understand issues around HIV/AIDS; sexual orientation, or addictions; and comprehension of confidentiality and anonymity concerns.

A number of APHAs were explicit about the importance of a holistic approach. They sought it out and were critical of care providers who were closed to approaches that go beyond physical or medical care. Service providers who acknowledge and help APHAs address emotional, mental, social and physical needs, and engage in relational care by encouraging APHAs to access a range of care and support for their whole well-being.

Relational care reflects a willingness on the part of service providers to regard individual differences by offering care options to APHAs, and the courage to respect APHAs priorities and support their decisions. At the same time, relational care providers seek to balance sometimes contradictory needs, and to administer wisdom in helping APHAs to integrate types of care, such as Aboriginal traditional with western medical practices, or HIV and addiction treatments.

Relational care suggests that service providers are not always the experts. It demands a willingness and desire to learn about the contexts within which APHAs seek support or care. Relational care providers make it their business to understand Aboriginal clients' histories of trauma, social, economic and logistical matters that affect how and where appropriate care can be found, as well as resources to fulfil information and referral service requests:



Service providers recommended both immediate and long-term cultural resources. Immediate resources include information and clarification about access to services by off/on-reserve and Status/Non-Status Aboriginal clients; centralized access to Aboriginal resources; and HIV/AIDS resources that are culturally appropriate at a local/regional level. Long-term recommendations include community partnerships with Aboriginal organizations such as Aboriginal ASOs and Native Friendship Centres, outreach and mobilized services, and integrated addiction and infectious disease services.

Wise Practices for Providing Relational Care

A legacy — Acknowledge that many Aboriginal people wear the legacy of colonialism, including historical trauma impacts to varying degrees. Observe those who may more noticeably experience multiple challenges as a result of this legacy.

Cultural connection and disconnection — Approach Aboriginal families as a unit. Increasingly, several generations within a single extended family are infected with HIV. In Aboriginal communities — urban or rural — it is not enough to provide education and information at an individual level; make the information available to everyone.

Living with HIV/AIDS in Aboriginal communities — 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/AIDS to Aboriginal families and communities. Don't wait for HIV to infect a community, or ostracize someone with HIV or AIDS to solve the problem.

Racism and perceived racism — 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. Make every effort to reduce the perception that because they are Aboriginal, substance abuse or social assistance is presumed to be part of their life. 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 choices.

Overcoming barriers — 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). Encourage patients' participation in decision-making and honour APHAs' health choices.

The catalyst and culture — 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 interaction and protect confidentiality.

Second family — Create a safe space for APHAs to connect and support one another, one where they are assured of confidentiality and a non-judgmental 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.



Making care connections — Take practical steps in care provision (e.g., allow a space within a facility where traditional Aboriginal wellness practices and ceremonies can take place). Work with Aboriginal agencies that have Elder services so that support can be obtained when needed. Acknowledge that many Aboriginal facilities are situated in poorer neighbourhoods yet fill an important role in the social fabric of the community.

Negotiating care relationship — 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 the foundation of relational care.

Cultural resources — Aboriginal ASOs require long-term funding to provide mainstream service agencies and HIV clinics with cultural resources appropriate to their regions. Organizations should fund and accommodate access to Aboriginal, HIV/AIDS and educational resources. Staff should be flexible, develop new programs, and get to know their clients, communities, Aboriginal referral contacts and partners.

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