

Unmet needs of Indigenous peoples living with HIV

Questions

- What are the unmet needs of Indigenous peoples living with HIV?
- What interventions, strategies, and programs have been used to address these needs?

Key Take-Home Messages

- In 2016, First Nations, Métis, and Inuit peoples accounted for 4.9% of the Canadian population but represented 11.3% of all new HIV infections (1).
- When considering Indigenous health, conventional approaches to HIV and other communicable diseases are insufficient (2). Considerable disconnect exists between the priorities of the HIV care cascade and the experiences of Indigenous peoples living with HIV (3).
- The lack of coordination between mainstream HIV biomedical approaches and Indigenous worldviews appears to contribute to poor health outcomes. When applied to Indigenous people, both the HIV care cascade and HIV biomedical approaches have to be adapted to ensure they are flexible enough to incorporate the holistic Indigenous approach to well-being, which includes spiritual, emotional, and mental health as well as physical health.
- Accessing culturally safe care (3–8) free of stigma and discrimination (3, 9, 10) and self-determination over health care (8, 11) are needs specific to Indigenous peoples. Access to culturally safe care has the potential to improve both prevention and management of HIV among Indigenous peoples (3, 4, 8, 12).
- Indigenous worldviews and protocols need to be prioritized in the design, development, testing, and implementation of Indigenous health promotion interventions (13).

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• Education and training of health professionals, culturally specific programs, and increasing the Indigenous health workforce are strategies that could improve cultural competency in health care; however, rigorous evaluation of these strategies is still lacking (14).

The Issue and Why it's Important

The First Nations, Métis, and Inuit are three distinct peoples in Canada with unique histories, languages, cultural practices, and spiritual beliefs (15); their ancestors were the first inhabitants of the land that is now Canada (16). Collectively known as Indigenous peoples, over 1.67 million individuals in Canada from the 2016 census identified with one of these three groups (17).

While First Nations, Métis, and Inuit account for only 4.9% of the total population, 11.3% of all new HIV infections in 2016 in Canada were among Indigenous peoples (1). The estimated HIV prevalence rate among Indigenous peoples in 2016 was 362 per 100,000 population, which is two times higher than the rate of the general population in Canada (1). Colonialism, racism, social exclusion, and suppression of self-determination have been identified as determinants that have influenced Indigenous health (11) and led to increased vulnerability to HIV (8).

This rapid response explores the unmet needs of Indigenous peoples living with HIV, using reviews and primary studies to describe various health disparities and lived experiences. It also discusses strategies, interventions, and programs to address unmet needs.

What We Found

Unmet needs, data, and research practices

An unmet need is the "...absence of any, or of sufficient...appropriate care and services" (18). Unmet needs in health care can be measured by two approaches: clinical, which involves a clinical assessment of whether or not appropriate care was received, and subjective, which relies on an individual's personal assessment of whether or not appropriate care was received (19). In this review, we identified studies that used clinical data, subjective data, or both, in order to assess unmet needs among Indigenous peoples.

For example, the Ontario HIV Treatment Network Cohort Study (OCS) collects de-identified information on clinical, laboratory, psychosocial, and behavioural measures based on medical chart abstractions (i.e. clinical need) and conducts interviews using standardized questionnaires (i.e. subjective need) (20). In one quantitative OCS study, authors sought to identify characteristics

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associated with late diagnosis, delayed presentation, and late presentation of HIV among newly diagnosed individuals by analyzing numerical data. Using a statistical model, authors found that Indigenous people living with HIV in Ontario have higher odds of very late diagnosis (defined as a CD4 count <350 cells/µL or the presence of an AIDS-defining condition within three months of diagnosis) (21). Therefore, the authors conclude that an unmet need among Indigenous peoples is access to testing for HIV (21).

This is in contrast to qualitative research studies, which seek to build an understanding of phenomena using exploratory questions to elicit data that is comprised of words, images, or behaviours (22). For example, one study that collected "subjective" data found that stigma and discrimination caused barriers for Indigenous people in Canada living with HIV by inhibiting ease of access to services for fear of being labelled "HIV positive" (10). Open-ended interview questions and hand-drawn ecomaps (a diagram illustrating the social and personal relationships of an individual within their environment) (23) allowed researchers to gain an understanding of the experiences and needs of the participants (10).

These two studies demonstrate that research utilizing quantitative or qualitative data can be useful in identifying health disparities, the underlying mechanisms, and the nature of the unmet need. In the OCS study, authors suggested that late HIV diagnosis was the result of suboptimal HIV test uptake (21); the qualitative study (unrelated to the OCS study) offers a greater understanding of phenomena like this, noting that stigma and discrimination act as barriers to HIV services (10). Indeed, stigma has been identified as a social determinant that causes health inequalities across populations (24).

The following section describes results from reviews and primary studies that explore unmet needs among Indigenous peoples living with HIV: quantitative studies use numerical data to identify disparities or poor health outcomes (e.g. late HIV diagnosis) while qualitative studies explore the context surrounding an unmet need (e.g. stigma and discrimination) (22).

A note on research practices and data collection

While Indigenous knowledge has always been informed by research (i.e. the collection of information and distillation of meaning), one 2004 study notes that, in general, research by academics and government has developed a poor reputation among Indigenous peoples, as it often could be "misguided and harmful" (25). For example, Indigenous population statistics, as used in quantitative research, can reflect particular assumptions about Indigenous identity, way of life, and well-being by deciding what should be counted and how (26). This is underscored by the fact that that there are large gaps in Indigenous health data in Canada (11, 27, 28) and in other Indigenous communities abroad (29). A 2016 publication in *The Lancet* recommends that Indigenous data systems be

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developed in close collaboration with Indigenous peoples to ensure that Indigenous values, health concepts, and priorities are reflected (30).

While some studies presented in the following section considered Indigenous ethics and research standards, not all took into consideration Indigenous research protocols or conducted studies "in a good way", an expression used by many Indigenous peoples to indicate participation that honors tradition and spirit (31). For example, research done "in a good way" might include culturally appropriate Elder involvement (3), an essential part of Indigenous community-based HIV research (31). Elders are recognized as culturally safe supports who promote positive relationships respecting ceremony and Indigenous ways of knowing (31).

Unmet needs among Indigenous peoples living with HIV

Reviews identifying unmet needs

A 2019 systematic review by Jongbloed *et al.* assessed the evidence surrounding experiences of the HIV care cascade among Indigenous peoples in Canada, Australia, New Zealand, and the U.S., and sought to understand whether the HIV care cascade framework meets the needs of these peoples (3). Qualitative (n=14), quantitative (n=72), and mixed method studies (n=7) were used in the analysis. Of the 21 studies that contained qualitative data, authors identified six overarching and interconnected factors that promoted or hindered involvement in the HIV care cascade (3):

• Promote	⊕ Hinder
Indigenous culture, identity, and ceremony	Historical, intergenerational, and lifetime trauma
Strength, resilience, and determination	Stigma and discrimination
Social support systems	Intersecting health concerns

Among all included studies, authors found considerable disconnect between the priorities of the HIV care cascade and the journeys of Indigenous peoples living with HIV (3). Indeed, the cascade is a clinically-focused, biomedical model quantifying the stages of engagement in care for populations living with HIV (32, 33), and its focus is achieving therapeutic outcomes (3). Findings from this model are used to identify gaps in current care, evaluate care improvements, and improve services (34). This is in contrast

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to Indigenous views, where health is a holistic concept: physical, spiritual, emotional, and mental dimensions are interrelated (11). Authors concluded that more work is required to reflect the perspectives of Indigenous peoples living with HIV in the HIV care cascade. For example, a framework that includes social, spiritual, emotional, cognitive, and daily life outcomes would be more culturally inclusive, and could better support Indigenous peoples in HIV care (3).

It is also worthwhile to note that this particular systematic review assessed the quality of each included study through Indigenous and mainstream lenses (3). Authors were not able to identify a tool used to evaluate the quality of evidence from an Indigenous perspective; therefore, one was created. The team of Indigenous and non-Indigenous scholars developed a checklist to assess if included studies were conducted "in a good way". Authors considered involvement of Indigenous scholars and Elders, engagement with a community advisory board, inclusion of ceremony, and contextualization of both health and risk in terms of determinants of Indigenous health (3). Based on this checklist, it was determined that 51.6% (n=48) of studies were conducted "in a good way".

A second systematic review, authored by Negin *et al.* (2015), examined the literature on the determinants of HIV-related behaviour among Indigenous peoples (9). Similar to the study above, the countries of focus were Canada, Australia, New Zealand, and the U.S. More than 72% of the included studies were quantitative (n=77); 25% used qualitative methods (n=27), and 4% (n=4) used mixed methods. Authors concluded that broader determinants of risk among Indigenous peoples – such as social disadvantage, high rates of injection drug use, poor access to health services, and exposure to stigma and discrimination – need to be addressed. In addition, approaches that focus on empowering and including Indigenous peoples, complemented by leadership that supports and acknowledges HIV and its impact on the community as a whole, are required (9).

The following section discusses a selection of primary studies (not captured in the above reviews) that address unmet needs among Indigenous peoples.

Primary studies identifying unmet needs

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) analyzed the stages of the care cascade among women living with HIV in Canada (n=1,424; 22% Indigenous women) and used a baseline quantitative survey to determine the prevalence and correlates of attrition at each stage (5). The CHIWOS study used a modified version of the care cascade and included the following stages: 1) diagnosed, 2) linked to care, 3) retained in care, 4a) initiated ART, 4b) currently on ART, 5) adherent to ART, and 6) viral suppression (5). The greatest attrition occurred between current

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use of antiretroviral therapy and adherence; one subpopulation with significant loss at this stage was Indigenous women. Authors note that this finding does not necessarily translate to Indigenous women being "at risk" of attrition; rather, women's health-seeking experiences (such as institutional racism) have affected their interaction with the cascade (5). Indeed, evidence from qualitative studies among female Indigenous peoples indicate the need for HIV care that is culturally safe (6, 7).

One author identified the need for literature on sexual health within Inuit communities, and designed a qualitative study to inform prevention programming (35). The study was informed by two worldviews: Inuit Qaujimajatuqangit (i.e. Inuit ways of knowing) and postcolonial research theory (i.e. academic ways of knowing). Two-Eyed Seeing (Etuaptmumk in Mi'kmaw), a concept developed by Mi'kmaw Elder Albert Marshall (36), brought these two worldviews together, drawing on the strengths of each. From nine storytelling sessions among 21 Inuit women, five themes emerged: the way it used to be, change, family, intimate relationships, and holistic strategies (35). Participants emphasized the need for sexual health programming that was holistic, community-wide, and family-focused. The author notes that this qualitative data complements epidemiologic data from Canada which illustrates the need for prevention programming among Indigenous peoples (35).

Another study identified a need for research with Indigenous peoples in a specific region of Canada (37). Winnipeg, Manitoba has the largest Indigenous population of all major Canadian cities, with 46% of the Indigenous population aged 24 or younger (38). Despite this, the majority of literature on young Indigenous people has primarily focused on British Columbia and Québec (37). A qualitative study conducted in Winnipeg among 21 Indigenous people who contracted HIV as youth sought to fill this gap (37). Open-ended questions during interviews allowed researchers to gather indepth and detailed accounts of lived experience. From the results, authors illustrated how multiple, intersecting social determinants (e.g. trans-generational trauma, the child welfare system) shaped participants' experiences prior to infection and in later years. Thus, various social determinants were present and interconnected at different life stages. Findings demonstrated the need for policies and programs to address multiple social determinants together (37).

A 2018 study using Australian surveillance data from 1996–2015 found that Indigenous peoples had poor HIV-related outcomes compared to the general population; one strategy proposed by the authors was that Indigenous peoples be included in new biomedical prevention strategies, such as pre-exposure prophylaxis (PrEP) (39). However, a commentary made by representatives from the First Nations Health Authority in British Columbia notes that the potential of these strategies to address HIV will be suboptimal unless Indigenous peoples are given self-determination over their health care and interventions are delivered in culturally safe settings (8).

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A 2019 qualitative study evaluated the presence of PrEP health promotion and perceived barriers to HIV prevention for Australia's Aboriginal and Torres Straight Islander gay and bisexual men (40). The study focused on the structure of health care promotion, and recruited providers, researchers, and AIDS Council employees for interviews; of the 18 participants, five were Aboriginal. Barriers included the underrepresentation of Aboriginal peoples in PrEP trials in Australia (40); this is supported by the fact that the Expanded PrEP Implementation in Communities in New South Wales (EPIC-NSW) trial reported a 2.1% proportion of Indigenous-identified participants (41), though these peoples represent 3.4% of the NSW population. Respondents also identified an unwillingness or inability on the part of Aboriginal men to identify with mainstream gay communities, which in turn prevented men from accessing gay-focused health promotion and services that are generally disseminated through gay communities. Participants described the shortage of PrEP-related health promotion specific to Indigenous communities, reasoning that culturally appropriate, targeted health promotion developed with Indigenous peoples was required. Of note, authors were unable to identify any research examining the attitudes of Aboriginal gay and bisexual men towards PrEP (40).

Summary of findings

From the included reviews and primary studies, it appears that mainstream approaches to HIV prevention and care lack compatibility with Indigenous worldviews, a concept supported in other literature (4, 11). Indigenous peoples define wellbeing as more than just the absence of disease (42); a holistic concept, health is reflected in physical, spiritual, emotional, and mental dimensions that are interrelated (11). Furthermore, Indigenous peoples recognize an inclusive aspect of wellbeing that extends to connections, relations, and family; healing requires an individual to live in harmony with their community and the spirit worlds (42). Thus, it is important to recognize that conventional approaches to HIV and other communicable diseases are insufficient when considering Indigenous health (2).

While the HIV care cascade is a critical metric for assessing treatment coverage and viral suppression across populations (33), it is not a culturally inclusive model for Indigenous peoples as it fails to reflect their perspectives (3). The need for tailored health promotion and prevention programming is discussed in studies among Inuit women (35) and PrEP providers in Australia (40), and has been identified as a need by Indigenous communities at large (29). Furthermore, researchers suggest that policies and programs need to be wider in scope, as social determinants such as abuse, housing, and food security are interconnected at various life stages, resulting in multiple influences on health trajectories (37).

The need for culturally safe HIV care is also widely discussed in the literature (3–5, 8). Culturally safe care is an approach that considers

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how one's own beliefs, practices, and histories shape the health care experiences of another; it calls on practitioners to be self-reflective of their position of power and how this can impact patients (43). It is concerned with relationship and respect, and results in trust (44). Of note, the systematic review authored by Negin *et al.* found that determinants associated with HIV risk (e.g. domestic violence, injecting drug use) contributed to Indigenous peoples' mistrust in health services, which in turn contributed to suboptimal health outcomes (9).

The next section discusses a selection of studies that either developed interventions or tailored pre-existing programs to needs of Indigenous peoples.

Addressing unmet needs

Cultural competency is an approach that "...focuses on practitioners' attaining skills, knowledge, and attitudes to work in more effective and respectful ways with Indigenous patients and people of different cultures" (43). Cultural competency was developed in response to cultural and linguistic barriers between patients and providers, which in turn impacted the quality of health care delivery (45). One systematic review published in 2015 describes the characteristics of interventions designed to improve cultural competency in health care for Indigenous peoples in Australia, New Zealand, Canada, and the U.S. (14). Sixteen published evaluations were included: 11 from the U.S. and five from Australia. A main finding of this review was lack of rigorous evaluation of the effectiveness of interventions for improving cultural competency in health care for Indigenous peoples (14).

This review identified three main types of intervention strategies that addressed cultural competency (14):

- Education and/or training of health professionals
 which include video, study materials, group work, and
 placements; measured outcomes are based on knowledge
 and confidence related to cultural competency;
- Culturally specific programs or resources (e.g. interventions or campaigns) designed for Indigenous peoples (i.e. culturally sensitive) or those that have been developed for the general population and then modified to improve acceptability (i.e. culturally tailored). Outcomes measured are health-care delivery, patient satisfaction, and health outcomes;
- Indigenous health workforce increases Indigenous involvement in health care delivery to Indigenous peoples. Health care delivery, patient satisfaction, and patient health are measured outcomes.

- 48. Kaufman CE, Whitesell NR, Keane EM, Desserich JA, Giago C, Sam A, et al. Effectiveness of Circle of Life, an HIV-preventive intervention for American Indian middle school youths: A group randomized trial in a Northern Plains tribe. American Journal of Public Health. 2014;104(6):e106–12.
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The following programs are examples of these three types of intervention strategies.

San'yas: Indigenous Cultural Safety Training (www.sanyas.ca), is a program developed by Chervl Ward, Kwakwaka'wakw and member of the 'Namgis First Nation, and delivered by the Provincial Health Services Authority in British Columbia (43). This program is an example of education and/or training of health professionals, though it can be for anyone who directly or indirectly works with Indigenous peoples. This cultural safety training was developed in response to Action Item 19 in the Transformative Change Accord: First Nations Health Plan: "First Nations and the Province will develop a curriculum for cultural competency in 2007/08 for health authorities" (46). Skilled facilitators guide learners through interactive course materials in an online format that cover topics such as culture, stereotyping, and colonization (47). There are now five core Indigenous Cultural Safety (ICS) training programs: Core ICS Foundations, Health, Mental Health, Child Welfare, and Justice (47).

Circle of Life is an example of a **culturally specific program** developed specifically for American Indian and Alaska Native youths (48, 49). Originally conducted in schools of a Northern Plains tribe, Circle of Life is an HIV prevention intervention in the format of a 30-hour curriculum that is based on learning approaches and traditional symbols (e.g. the Medicine Wheel) of the American Indian and Alaska Native peoples (48). This group randomized trial was delivered by qualified community members to 635 youth in middle school. Authors found that the intervention successfully delayed onset of sexual activity; greatest reductions were evident when Circle of Life was delivered to younger participants. Authors also noted that community partnership was essential to successful project design, implementation, and analysis; working closely with tribal partners built trust and collaboration (48).

A second example of a **culturally specific program** is NATIVE – It's Your Game, an online sexual health curriculum tailored to American Indian and Alaska Native youth (50). A 2017 study discussed how this standalone 13-session Internet-based sexual-health life skills curriculum was adapted from an existing curriculum called It's Your Game – Tech. The adaptation included three phases: a preadaptation needs assessment and usability testing; adaptation; and post-adaptation usability testing. Authors note the ethical imperative of developing a sexual health program for American Indian and Alaska Native youth that is culturally sensitive and relevant. The adaptation process was guided by community-based participatory research, and protocols were designed to maximize community ownership of the project (50). While a five-year efficacy trial was funded by the Centers for Disease Control and Prevention (51), no findings appear to have been published as of yet.

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Finally, Condoman is an internationally recognized culturally specific campaign that uses health promotion messages tailored to Aboriginal and Torres Strait Islanders in Australia (52). Condoman was conceived in 1987, three years after AIDS became a public health issue in Queensland (53). A 2014 article discussing the Australia response to AIDS notes that education campaigns utilized targeted messaging to different populations, and this included Aboriginal and Torres Straight peoples (53). Enter Condoman, an Indigenous male character who wears the colours of Indigenous Australia (53, 54), utilizes Indigenous humour (54), and spreads a message of safe sex and male responsibility for condom use (52). Condoman was well-received, attending community events and distributing safe-sex materials (53). Today, Condoman is an iconic figure within Aboriginal and Torres Strait communities, attending pride events in Australia (54).

Two-Eyed Seeing/Etuaptmumk

This review demonstrates the need for programs that address health disparities among Indigenous peoples that are driven by Indigenous worldviews and ways of knowing, which include a holistic concept of health and its interrelated dimensions (11). Indigenous communities have called for the development of programs where their worldviews and protocols are prioritized in each program's design, composition, testing, and implementation (13).

The programs, interventions, and campaigns described in the previous section demonstrate that mainstream biomedical approaches to health care can coexist with traditional Indigenous healing, a notion supported elsewhere (55). Two-Eyed Seeing (utilized in an aforementioned study) describes the idea that both these types of knowledge are compatible:

"...it refers to learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing, and to using both these eyes together, for the benefit of all" (56).

Etuaptmumk requires an openness towards learning about other perspectives and ways of knowing, as opposed to viewing one way of knowing as superior (36). While the scientific approach to addressing HIV has undoubtedly had an immense impact, the traditional indigenous approach continues to provide benefits above and beyond antiretroviral medication (55).

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Factors That May Impact Local Applicability

The term 'Indigenous peoples' is a collective name referring to the original peoples of North America (i.e. Canada and the U.S.) and their descendants (15). This name can also be used to describe the Aboriginal peoples and Torres Strait Islander peoples of Australia (57). While this review uses the term 'Indigenous peoples' to broadly identify the first inhabitants of these lands and territories, it also acknowledges that unmet healthcare needs of Indigenous people in Canada (58) and abroad (30) differ. Therefore, the Indigenous needs discussed in this review are not representative of all Indigenous peoples.



What We Did

We searched Medline (including Epub Ahead of Print, In-Process & Other Non-Indexed Citations) and PsycInfo using a combination of text term HIV and (text terms [Indigenous or Aboriginal or Torres Strait Islander* or Inuit* or Metis or Native American*] or MeSH terms [exp Indians, North American/ or First nation*]). Searches were conducted on May 29, 2019 and results limited to English articles published since 2009. Reference lists of identified review articles were also searched. Google searches using various combinations of the above listed terms were also conducted. The search yielded 657 references from which 58 were included. Sample sizes of primary studies ranged from 18 to 11,492.

Rapid Response: Evidence into Action

The OHTN Rapid Response Service offers quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a review summarizing the current evidence and its implications for policy and practice.

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