HIV-Associated Neurocognitive Disorders within Indigenous Communities in Canada: Can connection to culture, land, and cultural continuity, promote aging in a good way for First Nations, Métis, and Inuit peoples living with HIV and AIDS in Canada?

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Brittany is a fourth-year undergraduate student pursuing a Bachelor of Science in Psychology with a minor in Indigenous studies. Brittany is a Mississauga-Nishinaabekwe, and a member of the Mississauga's of the Credit First Nation. However, she was not born or raised there and is working towards reconnecting with her culture and family. Research has been a major part of this journey. Brittany has some experience working in HIV/AIDS community-based and community-led research with Indigenous communities and has learned from and worked alongside several Indigenous health researchers. In her undergraduate research thesis, Brittany is investigating how formal and informal helping (i.e., peer mentorship and leadership) helps to promote well-being for Indigenous peoples living with HIV/AIDS. In the future, she hopes to continue her research and education by pursuing a master's degree and Ph.D. in clinical psychology.

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Abstract

With the advent of life-saving medications, many people living with HIV/AIDS are living longer. However, HIV-associated neurocognitive disorders remain a challenge to living with long-term HIV/AIDS. While there is no available prevalence data for HIV-associated neurocognitive disorders, Indigenous peoples are at an increased risk for all-cause dementia (i.e., Alzheimer's Disease). Several modifiable risk factors for HIV-associated neurocognitive disorders exist, such as diabetes and physical activity. Addressing these modifiable risk factors among First Nations, Métis, and Inuit living with HIV/AIDS may help to reduce the risk and prevalence of HIV-associated neurocognitive disorders. In this short literature review, I broadly consider how a connection to culture and land, and cultural continuity may help promote healthy brain aging for First Nations, Métis, and Inuit peoples living with HIV/AIDS in Canada by reducing the prevalence of several modifiable risk factors for HIV-associated neurocognitive disorders. I found that previous research suggests that cultural continuity and connection to culture and land may help to reduce the modifiable risk factors of physical activity, diabetes, obesity, and education. However, this relationship has not been experimentally studied. Therefore, future research should directly investigate how these factors contribute to healthy brain aging for First Nations, Métis, and Inuit living with HIV and AIDS in Canada.

With the advent of life-saving antiretroviral therapy, the number of people aging with HIV/AIDS is steadily increasing. For instance, Sok (2019) estimated that by 2025, one in six of all people living with HIV/AIDS in Canada will be aged 50 and over. Many people living with HIV/AIDS are at risk for HIV-associated neurocognitive disorders (HAND) (i.e., HIV-associated dementia) (Goodkin et al., 2017; Namagga et al., 2019; Valcour et al., 2004). There are three categories of HAND that increase in severity and prevalence, including asymptomatic neurocognitive impairment, HIV-associated mild neurocognitive disorder, and HIV-associated dementia (Montoya et al., 2021). These disorders are characterized by impairments in attention, memory, and executive functioning (Montoya et al., 2021). While 50% of all people living with HIV/AIDS experience some form of neuropsychological impairment, 12% experience mild forms, and up to 2% experience severe forms (Wing, 2016). Moreover, the risk of developing HAND increases with age, which poses significant challenges to quality of life and well-being (Jones et al., 2019; Valcour et al., 2004). Consequently, HAND remains a major complication of aging with HIV (Namagga et al., 2019), and a significant public health concern.

First Nations, Métis, and Inuit (FNMI) communities are widely diverse and represented by 1.6 million FNMI peoples in Canada. FNMI communities each have their own worldviews, values, beliefs, and knowledge systems that are specific to place (Pidgeon, 2019; McGuire Adams, 2020, Wilson, 2008).

Due to the ongoing effects of colonialism, FNMI peoples in Canada experience significant health inequities. Describing the effects of colonialism on health, Adelson (2005) states that "a history of colonialist and paternalistic wardship, including the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions or far away from their families and communities; inadequate services to those living on reserves; inherently racist attitudes towards Aboriginal peoples and a continued lack of vision in terms of the effects of these tortured relations – all of these factors underlie so many of the ills faced by Aboriginal peoples today (p. 46). For instance, while FNMI peoples represent 4.9% of the population in Canada, they represented 10.8% of new HIV diagnoses in 2020 where ethnicity was reported (Government of Canada, 2022; Statistics Canada, 2019).

Although there is no available data on the prevalence of HAND among FNMI peoples living with HIV/AIDS in Canada, other research has suggested that FNMI peoples are at a greater risk for all-cause dementia (e.g., Alzheimer's Disease) (Jacklin et al., 2013; Warren et al., 2015). For example, Walker and Jacklin (2019) predicted that the prevalence of dementia on First Nation's reserves will increase 4.5 times by 2031, whereas for non-Indigenous people it is expected to rise by 2 times. Consequently, First Nations people living with HIV/AIDS may be at a greater risk for age-related neurocognitive disorders, including HAND.

Several non-modifiable and modifiable risk factors contribute to the prevalence of HAND. Research among non-Indigenous people living with HIV/AIDS has identified aging, genetics,

ethnicity, and gender as non-modifiable risk factors (Kompella et al., 2021). Importantly, not everyone develops HAND as a consequence of aging. Modifiable risk factors, such as diabetes, obesity, cardiovascular health, physical activity, low education, hypertension, diet, HCV co-infection, and substance use disorders increase the risk of HAND, above normal aging (Heaton et al., 2015; Kompella et al., 2021; McCutchan et al., 2012, Valcour et al., 2005). Although no literature exists that investigates the modifiable risk factors for HAND among FNMI people living with HIV/AIDS, previous research suggests that similar modifiable risk factors, such as diabetes and low education, contribute to the increased prevalence of all-cause dementia among FNMI peoples (Petrasek MacDonald et al., 2018).

Among all-cause dementia research with non-Indigenous people who do not live with HIV/AIDS, lifestyle and behavioral interventions and programs have been developed to address modifiable risk factors to prevent the incidence and/or progression of dementia among at-risk older adults (Rosenberg et al., 2020). However, minimal research exists that investigates how to moderate the modifiable risk factors of HAND among FNMI peoples living with HIV/AIDS. Consequently, it is important to investigate how to moderate the modifiable risk factors of HAND among FNMI living with HIV/AIDS, as this may help to inform future programs and interventions that prevent the incidence and/or progression of HAND among FNMI peoples living with HIV/AIDS.

While recent research has begun to investigate how to promote healthy aging for FNMI peoples living with HIV/AIDS(Jackson et al., 2021; Ryan et al., 2020), there remains a lack of research that investigates how to prevent the incidence of HAND. To address this gap, I provide a brief narrative overview of how a connection to culture, land, and cultural continuity shape behaviors that may prevent HAND among FNMI peoples living with HIV/AIDS through the modifiable risk factors of physical activity, diabetes, obesity, and education.

Methodology

In this paper, I aimed to provide a broad and brief overview of how a connection to culture, land, and cultural continuity may help to moderate the modifiable risk factors for HAND among FNMI peoples living with HIV/AIDS. As there is no available research that investigates the specific modifiable risk factors for HAND among FNMI peoples living with HIV/AIDS, I drew on the common modifiable risk factors for all-cause dementia that exist among FNMI peoples generally and the HAND modifiable risk factors for non-Indigenous people living with HIV/AIDS. This review was founded on the assumption that despite the effects of colonialism, FNMI peoples have been resilient through practicing and revitalizing cultural traditions and that these traditions may help prevent the incidence of HAND. This is of particular importance as previous research conducted with First Nations Elders described a connection between colonization, including loss of culture, and the increased prevalence of age-related neurocognitive disorders (Hulko et al., 2010).

I utilized a brief and unsystematic narrative overview approach (Dekkers et al., 2022) and drew on peer-review literature gathered from Google Scholar and PsycINFO from February 2021 to

August 2022. Grey materials were utilized as needed. Because of the breadth and limited research in this area, utilizing other systematic approaches was not feasible. Rather, the aim was to provide a broad introduction and introduce several key themes, and signpost areas for future research. Research involving FNMI peoples that reflected a community-engaged, collaborative, and strengths-based approach was prioritized (Ranco, 2006). While most literature is focused on FNMI, research from Indigenous communities within the United States was utilized where gaps existed.

I acknowledge that my positionality and worldview implicated my approach to this narrative overview. Consequently, I provide a self-location to situate myself in this search (Kovach, 2009). I am a Mississauga-Nishinaabekwe and a member of the Mississauga's of the Credit First Nation. I belong to the Eagle Clan. I am Anishinaabe, German, Irish, and Danish on my father's side and Dutch on my mother's side. Due to the gender discrimination in the Indian Act, I was not raised in my culture or on reserve and have spent several years healing this disconnect by reconnecting to my culture and family. I am a two-time cancer survivor and have a family history conflated with chronic illnesses, including cancer, diabetes, Parkinson's disease, and stroke. I know that colonization, and the subsequent disconnection to culture and land, have had considerable impacts on my personal and family's health. Subsequently, these experiences have guided my research interests in culture, community, and chronic illness in FNMI communities. While I do not live with HIV/AIDS, I continue to be an ally to the community by contributing to efforts that address the health inequities experienced by FNMI peoples living with HIV/AIDS.

Connection to Culture, Land, Cultural Continuity, and Aging in a Good Way

Connection to culture, land, and cultural continuity have been described as determinants of FNMI people's health (Auger, 2016; Lines et al., 2019; Reading and Wien, 2009), and may help to promote healthy brain aging among FNMIpeoples living with HIV/AIDS. Cultural connectedness is often defined as engagement with cultural identity, traditional and cultural activities, and spirituality (Auger, 2016). In comparison, Reading and Wien (2009) state that cultural continuity emphasizes the importance of "intergenerational cultural connectedness, which is maintained through intact families and the engagement of elders, who pass traditions to subsequent generations" (p. 18). Connection to land can be widely conceptualized, such as building relationships with the land through cultural and traditional activities (Lines et al., 2019). Recent research has found that connection to culture, spirituality, relationships with community and Elders, and connection to land help to promote healthy aging among FNMI peoples living with HIV/AIDS (Jackson et al., 2021; Ryan et al., 2020). Moreover, research from other Indigenous cultures, namely Northern Okinawan Indigenous women, suggests that connection to culture, land, and cultural continuity help support successful aging, including cognitive functioning, during aging (Willcox et al., 2007).

Physical Activity

Previous research indicates that increased physical activity is positively associated with improved cognitive functioning and reduced likelihood of neurocognitive impairment (Dufour et

al., 2013; Fazeli et al., 2015; Ortega et al., 2015). More specifically, physical activity improves cognition by promoting brain plasticity and neurogenesis and reducing hippocampus apoptosis and chronic inflammation (Montoya et al., 2021). Notably, chronic inflammation may contribute to increased neurocognitive impairment across the lifespan of people living with HIV/AIDS (Montoya et al., 2021).

Previous research suggests that increased physical activity is positively associated with a connection to culture, land, and cultural continuity among First Nations peoples. For example, Lévesque et al. (2015) conducted a study to identify the factors associated with increased physical activity among on-reserve First Nations youth in 216 northern reserves. Results evidenced that physical activity was highest amongst participants who identified as male, had one chronic condition, attended school, spoke a First Nations language, and identified as living in balance spiritually (Lévesque et al., 2015). Moreover, physical activity was more prevalent among youth who had relatives help them understand their culture, compared to youth who did not (Lévesque et al., 2015), which suggests a role of cultural continuity. Furthermore, the loss of culture and the destruction of natural resources were identified as barriers to physical activity. Collectively, this study provides evidence of the role of cultural continuity and connection to culture and land in increasing physical activity and moreover, that a loss of culture and land may influence a major risk factor of HAND.

Engagement in dance has been identified as a physical activity that can reduce the risk of dementia (Rolland et al., 2008), and is a component of many FNMI cultural traditions and activities (Archibald & Dewar, 2010). Previous research has found that connection to culture and cultural continuity promotes engagement in dance. Burnette et al. (2020) sought to investigate how cultural traditions promote well-being, cultural continuity, family resilience, and enculturation among two Indigenous communities in the United States. Data were collected from 436 participants from two tribal communities through focus groups, family and individual interviews, and observation. A thematic analysis was conducted, and the data were returned to participants for review and amendments. They found that family involvement in powwows influenced lifelong participation in powwows among the participants. Specifically, powwows were viewed as family traditions that help foster a sense of community and cohesiveness. This was illustrated through a participant who described:

> Ever since I was real little, my uncle-I have cousins that are the same age as me and one's older-a year older, but he had started when we were 4 or 5 a-a dance group, traditional dance group, and I've been dancing with them. I still do (Burnette et al., 2020, p. 14).

Accordingly, family relationships and cultural traditions influence participation in physical activities that may help moderate the risk of HAND. Moreover, participating in traditional activities fosters the development of social relationships, which has also been identified as a preventative mechanism for cognitive impairment, all-cause dementia, and HAND (Cornect-Benoit et al., 2020; Dobbins, 2022; Kuiper et al., 2015). However, research has not been conducted on the long-term cognitive health benefits of participating in traditional physical

activities, such as dance, and should be further explored. Moreover, no research exists that investigates how engagement in dance, or other forms of culturally-grounded physical activity, moderates the prevalence of HAND among FNMI peoples living with HIV/AIDS.

Type 2 Diabetes

Type 2 Diabetes and prediabetes are associated with poorer cognitive abilities among people living with HIV/AIDS, and this relationship is stronger among older adults (Dufouil et al., 2015; McCutchan et al., 2012), and includes combination antiretroviral therapy treated people living with HIV/AIDS (Dufouil et al., 2015; Yu et al., 2019). Moreover, Type 2 diabetes increases the risk of all-cause dementia twofold (Petrasek MacDonald et al., 2018). The prevalence of diabetes is also increasing among FNMI communities (Statistics Canada, 2016). The prevalence of diabetes in First Nation reserves ranges widely from 1.2% to 18.3% across Canada (Oster et al., 2014). Importantly, previous research supports the role of cultural continuity in the prevention of diabetes among FNMI peoples. For example, a study conducted with Cree and Blackfoot participants living on First Nations reserves in Alberta, Canada revealed a positive association between "being who we are" (Oster et al., 2014, p. 8), which was measured by traditional language use, and the prevalence of diabetes. Qualitative semi-structured interviews coupled with quantitative data revealed that among the variables of income, unemployment, education, and cultural continuity, only cultural continuity was a predictor of diabetes. Moreover, most communities with the highest rates of Indigenous language knowledge reported the lowest rates of diabetes (Oster et al., 2014). Although similar trends may exist amongst HAND prevalence, this has not been explicitly studied.

Obesity

Obesity has also been identified as a risk factor for HAND (McCutchan et al., 2012). Recent research provides support for a relationship between a connection to culture, land, and cultural continuity with the prevalence of obesity (Big-Canoe & Richmond, 2014). Big-Canoe and Richmond (2014) conducted a study with 19 Anishinaabe youth from Pic-River First Nation, Ontario, to determine the effects of land dispossession on health. The youth described that Anishinaabe peoples were traditionally exceptionally healthy and that the cumulative effects of residential schools and the subsequent loss of culture led to a rise in obesity and chronic health conditions. Moreover, land dispossession was identified as contributing to these lifestyle changes through increased pollution and nearby resource extraction in their home territories.

Furthermore, other First Nations have also experienced negative health consequences due to land dispossession. A qualitative study conducted by Richmond et al. (2005) with 19 members of the Namgis First Nation in British Columbia sought to determine the effects of aquaculture on the health and well-being of their community. Participants described that the land and water serve as kitchen cupboards, that the health of their community was based on the health of the land, and that the availability of resources has been negatively affected by "environmental degradation, resource depletion, and reduced access to natural resources" (Richmond et al., 2005, p. 356). Moreover, changes to fishing legislation have created changes in their community that have led

to decreased fishing and gathering (Richmond et al., 2005), thereby risking cultural continuity and knowledge transfer to FNMI youth.

While land-based diets were once common among FNMI peoples and are increasing steadily through food sovereignty movements (Hill, 2021; Lowitt et al., 2019), colonization and settler colonialism have imposed obstacles to land-based diets. For example, the traditional Anishinaabe diet of corn, squash, beans, and berries became restricted due to the cessation and destruction of traditional lands and increased migration (Bodirsky & Johnson, 2008). First Nations peoples who were forced to attend residential schools were further restricted from eating land-based diets and were instead fed unhealthy diets of lard, sugars, and other 'empty' carbohydrates (Bodirsky & Johnson, 2008). These assimilative tactics have been connected to stunted growth, increased rates of diabetes, obesity, cardiovascular disease, stroke, cancers, cognitive health, and metabolic diseases (Jang & Serra, 2014; Mosby & Galloway, 2017a; Mosby & Galloway, 2017b; Tobias & Richmond, 2014).

Education and Learning

Increased education may also help to prevent the incidence of HAND for FNMI peoples living with HIV/AIDS (Kompella et al., 2021). Evidence that supports low education as a risk factor is based on the cerebral reserve hypothesis of dementia, which states that increased synaptic connections through learning results in a slower onset of neurocognitive impairment (Fratiglioni & Wang, 2007; Vance et al., 2019). While there is no available data that specifies the extent to which low education is implicated in HAND among FNMI peoples living with HIV/AIDS, low education was identified as the highest modifiable risk factor for Alzheimer's disease among First Nations peoples living on-reserve, contributing to 65.9% of modifiable risk (MacDonald et al., 2015). However, these data are collected based on Western academic education and may feature a narrow representation of education, through neglecting to survey the benefits of traditional learning, such as the intergenerational knowledge transfer experienced in land-based programs between Elders and youth (Danto et al., 2020). These programs are arguably bidirectionally beneficial, as both youth and Elders engage in learning and physical activity on the land. Indeed, researchers have identified the need to increase intergenerational knowledge transfer between youth and Elders to support healthy brain aging among FNMI peoples (Cornect-Benoit et al., 2020). Further research is necessary to determine the cognitive long-term health outcomes of these land-based learning programs for FNMI peoples living with HIV/AIDS.

The promotion of land-based learning within Western education systems may also help foster increased engagement in academic settings to improve engagement in education and prevent HAND later in life. For example, a primary school in Prince George, British Columbia recently introduced a land-based learning segment of the curriculum in response to some students struggling with learning from textbooks but flourishing when learning outdoors. The program features outdoor land-based based skills, such as ice fishing, directed by local Indigenous cultures (Fanshaw, 2021). Other schools in the Yukon have also adjusted their curriculum to reflect the context of local Indigenous cultures. For example, a lesson on sound

and pitch was modified to include a community Elder and lessons on moose calls. The Elder introduced the topic through a narrative approach, and students were then taught how to make moose callers out of construction paper. Changes to the learning curriculum led to significant improvements in applicable learning attributes such as effort, contribution, attentiveness, attitude, self-image, and problem-solving skills among First Nations and non-FNMI students (Lewthwaite et al., 2014). First Nations students were also described as being more willing to contribute to stories in class when they reflected on their life experiences and worldview. This illustrates the benefits of incorporating FNMI worldviews and traditions into the academic curriculum to improve engagement in learning, which may help to improve the rates of education among FNMI. It should be noted that cultural connectedness, cultural continuity, and land are requirements for inter-generational knowledge transfer and land-based programs in Western academic settings.

Conclusion

While ongoing colonialism negatively impacts health and well-being, FNMI peoples possess cultural traditions and practices that may help to prevent the incidence and progression of chronic illnesses, including HAND. In this narrative literature review, I investigated how a connection to culture, land, and cultural continuity may prevent HAND among FNMI peoples living with HIV/AIDS by addressing the modifiable risk factors of physical activity, Type 2 diabetes, obesity, and low education. While this review indicated that these factors may promote healthy brain aging among FNMI peoples living with HIV/AIDS, definite conclusions cannot be made.

There are several limitations to this narrative literature review. While the available research suggests that connection to culture, land and cultural continuity may promote aging well for FNMI peoples living with HIV/AIDS), this relationship has not been directly studied and therefore, definite conclusions cannot be made. Interestingly, there is a dearth of literature that investigates HAND among Indigenous populations living with HIV and AIDS worldwide, yet minority populations, including FNMI peoples, are at a greater risk for HIV/AIDS (Rivera Mindt et al., 2020). In addition, to my knowledge, there are no estimated prevalence data for HAND among FNMI peoples living with HIV/AIDS in Canada. Therefore, future research should investigate the prevalence of HAND for IPHA in Canada. Moreover, culturally-appropriate neurocognitive assessments for HAND among FNMI peoples living with HIV/AIDS are needed (e.g., Haddow et al., 2013) to assist with estimating HAND prevalence. Further, there is no available literature that empirically investigates the modifiable risk factors of HAND for IPHA. Accordingly, research is needed to identify these modifiable risk factors. However, my brief review demonstrates that HAND prevention may be supported by a connection to culture, Land, and cultural continuity. Future empirical research is needed to further investigate this relationship. Lastly, as I used an unsystematic literature review approach that centred First Nations research, future systematic reviews are needed with FNMI.

The risk of developing HAND increases with age and poses significant challenges to well-being and health-related quality of life (Jones et al., 2019; Valcour et al., 2004). As the population of

FNMI peoples living with HIV/AIDSages within Canada, lifestyle and behavioral interventions that address the modifiable risk factors will be needed to prevent the incidence and/or progression of HAND. For instance, future research and/or community-based organizations should identify, develop, and evaluate culturally-grounded and land-based interventions to prevent the incidence and/or progression of HAND among FNMI peoples living with HIV/AIDS.

Shawn Wilson (2008) states that "if research hasn't changed you as a person then you haven't done it right" (p. 135). This narrative literature review revealed many gaps in the literature that must be addressed through community-led research that embodies the Greater Involvement of People with HIV(GIPA) principles (King et al., 2017) in order to support FNMI peoples aging with HIV/AIDS. As an undergraduate student with the intention of furthering my education within clinical psychology with a focus on aging and neurocognitive disorders, I hope to contribute to addressing these gaps within the literature. Furthermore, I acknowledge my responsibility to widely share these findings and identified gaps within the literature with community organizations, including CAAN Communities, Alliances, & Networks, and aging researchers within the academy.

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