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Addressing Strengths and Disparities in Indigenous Health

As an Indigenous person, I came into the world of Indigenous health scholarship in the 1990s with a personal view that focused on the strength and solutions of our peoples and our cultures. Over the next two decades in research and clinical environments, I observed how biomedicine remained firmly entrenched as the dominant model of care for Indigenous individuals and communities, with traditional knowledges and medicines as an aside or non-existent entirely. I have built my life's work as a researcher and clinician in centering Indigenous knowledges and healing in both research and health care. Yet today in 2020, biomedicine and Western academic research still dismiss Indigenous knowledges and remain mostly in command of Indigenous health. There are wonderful pockets of Indigenous researchers and practitioners, supported by Indigenous communities that continue to have very little real autonomy or self-determination from colonialism, who are making a difference in Indigenous health by reducing health disparities, using our strengths such as culture, spirituality, medicines, the land, Elders, youth, and more. This issue highlights some of the work by researchers that are making a strong impact on Indigenous health, uplifting our communities.

Furthermore, this issue showcases the balancing act of Western health care and Indigenous strengths as it is reified in both health research and practice. The balance is precarious as the stakes are high if a tipping point is reached. Indigenous people's lives are at stake in the current COVID-19 pandemic, as Indigenous individuals are more vulnerable to communicable diseases due to the overburden of chronic illnesses, mental health issues, and social determinants of health (as determined by Western and not Indigenous science). One of our greatest challenges as Indigenous peoples is to continue to fight for our autonomy and self-determination in all aspects of our lives. This issue highlights efforts towards autonomy in areas of both health and wellbeing. Specifically, the communities and researchers working with children, youth, women, families in foster care, the land, environmental health justice, and strengths-based healing are honored in this issue—celebrate them with me in this dark and uncertain time. Join me in finding the light and healing where we can and while we can, as we are strong and loving peoples who live, work, and support each other regardless of who or what try to stop us.

Dr. Suzanne L Stewart
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INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

The Survival of Aboriginal Australians through the Harshest Time in Human History: Community-Strength

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Aboriginal People have inhabited the Australian continent before time began, but archaeologists and anthropologists state there is evidence for approximately 51,000 to 71,000 years of continual habitation. During this time, the Australian continent has experienced many environmental and climatic changes, which have contributed to mass animal extinction. The skeletal remains of Aboriginal Australians were examined for evidence, which may be indicative of fast running which would assist survival. The skull and mandible bones of the Kaurna People were examined for signs evolutional traits related to survival. Aboriginal culture, knowledge of medical treatment and traditional medicines were also investigated. Oral storytelling of factual events, passed down unchanged for millennia, contributed to survival. The Kaurna People exhibited evolutionary facial features that would have assisted survival. Kaurna People had excellent knowledge of medicine and the capacity to heal their community members. The process of mobility and relocation may have embedded the need to be mobile in some Aboriginal Australian cultures, and why many Aboriginal tribes did not invest too much time and resources in building permanent structures and dwellings. Navigating these extremely harsh, rapidly changing conditions is an incredible story of survival of Aboriginal Australians. The findings of this investigation suggest that Aboriginal Australians' survival methods were complex and multi-faceted. Although this paper could not examine every survival method, perhaps Aboriginal Peoples' knowledge of flora and fauna, (for nourishment and medicine) living in clans, and avoiding mass cohabitation was paramount to our survival.

Keywords: A*boriginal, Australia, survival, history, community-strength*

Disclaimer

In some instances, in this paper the term 'Aboriginal' will be used. This will occur when the author is specifically referring to Aboriginal Australians.

Warning

Aboriginal and Torres Strait Islander Peoples: This paper has images of bones from deceased Aboriginal (Kaurna) People; however, it should be noted the images are copies of pictures, and not the original photographs.

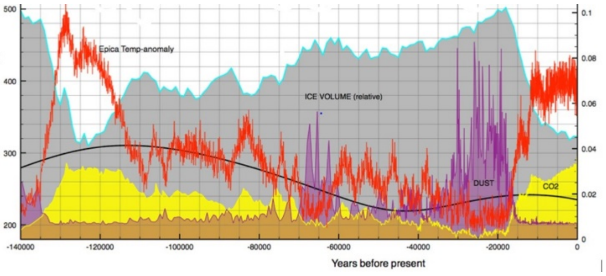
Acknowledgements

I would like to acknowledge several Aboriginal communities and their representatives below for their support and contribution to this paper. The Awabakal, Worimi, Kaurna, Biripi, Darug, Paakantji, Ngiyampaa and the Mutthi Aboriginal communities.

Introduction

Aboriginal People have a sacred connection to our land and we have inhabited the Australian continent before time began, and this has been expressed by Aboriginal Australians in our Dreaming stories, songlines, dance, and artworks (Brazil, 2000; Charles, 2015; Mountford, 1981; Taçon, 1991). Archaeologists and anthropologists estimated that Aboriginal People have inhabited the Australian continent for approximately 51,000 to 71,000 years (Malaspinas et al., 2016) during the Pleistocene period (Barker, Jones, McKay, & McLeod, 2001). During this time, there has been many extended periods of stability and plentiful food supply. However, the Australian continent has experienced many environmental and climatic changes (i.e., fluctuating temperatures, ice ages, fluctuating CO_2 levels, extremely high dust levels, high ice volume, high winds, large scale bush fires, glacial movement, low rain fall, extreme arid conditions, limited plant growth, evaporation of fresh water lakes, and dramatic sea level fluctuations. Please see Figure 1) All of these events have contributed to mass animal extinction (Bowler, 1976; Fielding, 2008; Johnson, 2006; Malaspinas et al., 2016; Monroe, 2011).

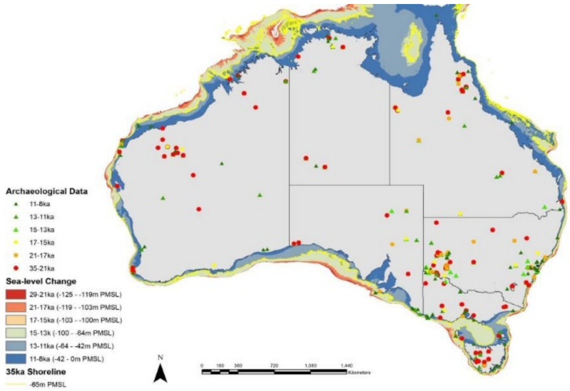
Figure 1



Note. Red graph (temperature), Purple graph (dust level), Grey graph (ice volume), Yellow graph (CO2 level) x-axis is time in years and y-axis is volume (Best, 2016).

The very shape of the continent has changed dramatically with the drop and rise of sea levels, where approximately 8,000-10,000 years ago the continent was much larger with sea levels 100-150m lower than the current sea levels in 2018 (please see Figure 2) (Monroe, 2011; Voris, 2000). At this time of low sea levels, the Australian state of Tasmania to the south and the nation of Papua New Guinea to the north created land bridges to mainland Australia. The Great Barrier Reef on Australia's east coast was above sea level, the land mass at that time was much greater than today, and created an ancient super continent i.e., Sahul (Malaspinas et al., 2016).

Figure 2



Note. Map of Australia showing sea level changes and archaeological sites for selected periods between 35,000 and 8,000 year ago (Ulm, 2016).

Surviving in Australia over the millennia, over some extended periods, would have been relatively easy with food sources and fresh water plentiful. However, over some extended periods it would have been incredibly difficult, where some of the environmental and climatic changes would have been catastrophic for many Aboriginal tribes and unimaginably difficult by today's relative mild environmental conditions. The incredible speed of climate change would have required great adaptability of our ancestors (Voris, 2000), and many would have found it extremely difficult to cope with these drastic and sudden changes (Monroe, 2011).

This paper focuses on the incredible survival story of Aboriginal Australians through a period from approximately 32,000 to 17,000 years ago which would have been difficult for all forms of life on the continent to survive (please see Figure 1). This paper will also examine Aboriginal Australian knowledge, Dreaming stories, and cultural practices to investigate links with modern scientific facts. During this time period (32,000 to 17,000 years ago) the temperature would have been approximately 10-20 degrees Celsius lower than today, likely linked to extremely low CO_2 levels at that time. The depletion of plant life from low temperature, high winds, bush fires, and low rainfall and consumption of plants from large herbivores would have contributed to the extremely high dust levels and low visibility also seen at this time. This reduction of plant life may have contributed to mass extinction of large herbivores inhabiting Sahul at this time and the domino effect that would have also contributed to extinction of large carnivores and impacted on Aboriginal Peoples' food source (Johnson, 2006). One of the most challenging times to survive on Sahul was approximately 25,000 years ago at the last ice age (Williams, Ulm, Cook, Langley, & Collard, 2013). When the continent became incredibly arid, CO_2 levels were at a low point, plant life would have struggled to grow, temperature was at its lowest point for millennia, dust levels reached its peak, visibility was low and fresh water lakes emptied (Figure 1-3) (Williams et al., 2013). Conditions were extremely harsh and it is thought that the population of Aboriginal Australians declined by approximately 60% (Williams et al., 2013). Although there were many extended difficult periods to survive on Sahul, it is this period approximately 25,000 years ago which would have required the knowledge passed down from our ancestors about environmental change, and adaptability, and it is a truly incredible feat of resilience by the Aboriginal People of Australia. These conditions were far harsher conditions than those experienced when Neanderthals became extinct 70,000 to 50,000 years ago (Shea, 2008), although there is some evidence Neanderthals survived up until approximately 28,000 years ago (Finlayson et al., 2006). This paper will investigate the incredible survival story of Aboriginal People, through some of the harshest conditions in human history, the link between scientific evidence, and the strength of Aboriginal cultural knowledge and oral history.

Methods

Scientific and Aboriginal evidence was collected for comparison. Footprints from Lake Mungo (Mungo National Park, NSW Australia) were examined to predict foot arch height and approximate the speed in which some Aboriginal men were running. The skeletal remains from Karraundo-ngga (Kaurna language for Hindmarsh area in Adelaide SA Australia) including the broken femur bone of a Kaurna (Aboriginal) man was examined for treatment and therapy. The skull and mandible bones were examined for signs of evolutional traits related to survival in tough environmental conditions. Aboriginal culture, and knowledge of medical treatment, therapies, and traditional medicines were investigated that may have contributed to survival.

Relationship

The authors are Kaurna (Aboriginal) men from the Adelaide Plains in South Australia and have community, cultural, and ancestral connections to the Kaurna People examined in this paper. The Kaurna People are the traditional owners of the Adelaide Plains and we still maintain our cultural heritage, beliefs, and connection to our land and waterways. The authors also have relationships with many Aboriginal and Torres Strait Islander communities around Australia. Written approval from the Willandra Lakes Region World Heritage Area Technical and Scientific Advisory Committee and the Community Management Council (TSAC and CMC), representing the Paakantji, the Ngiyampaa, and the Mutthi Mutthi Aboriginal Peoples was provided to visit their country and inspect the 21,000-year-old fossil footprints. In addition, the first author was given access to data previously collected by these communities. 103 Kaurna People were removed in the 1950s from a gravesite in Karraundo-ngga and were housed in the South Australian museum archives. Approval was given from Uncle Lewis Yerloburka O'Brien (Kaurna Elder) and the South Australian Museum to inspect skeletal remains of the author's ancestors.

Limitations

This project examined skeletal remains of Aboriginal People for possible links to survival methods and techniques. The skeletal remains examined were also of relatively small number and the extent of generalizability of the characteristics of these bones to the greater Kaurna community is unknown. The scope of this research was restricted and not every aspect or survival method was investigated. Nevertheless, the authors believe these findings make a valuable contribution to the current understanding of survival of Aboriginal People through one of the toughest environmental conditions in human history.

Results

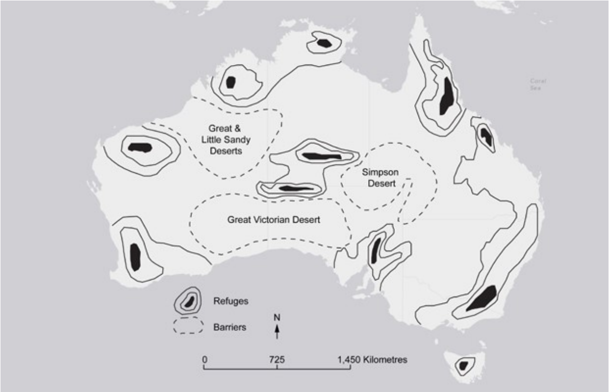
Aboriginal Oral History

Interestingly, Aboriginal Australians are sometimes undermined for not having written documented history, but it may have been oral story telling of factual events, passed down unchanged for millennia which contributed greatly to our survival. Many Aboriginal tribes have been practising survival education for millennia with Dreaming stories, songlines, dance, paintings, and carvings (Broome, 1982; Charles, 2015; Isaacs, 1980). Many Dreaming stories are about creation, but many are also about teaching and learning as some of this educating is designed to assist survival. Many Dreaming stories are often set in conflict between right and wrong, jealousy, arguments, and disagreements where listeners are able to learn from the mistakes made by animals, creators, and ancestors in these songlines, dance, stories, and paintings (Broome, 1982; Charles, 2015). Traditional lifestyles were able to be guided by Dreamtime stories, designed to keep people safe and well (e.g., eating the right foods and using medicines in the right amount, prepared in the right way, and at the right time of year (season), which is like modern day health promotion) (Broome, 1982; Charles, 2015; Isaacs, 1980). There are many Aboriginal oral Dreaming stories which record that sea levels were much lower than they are today (Barker et al., 2001; Campbell, 1967). This is of course is a true geological environmental fact about the Australian continent and it is incredible that this Aboriginal oral history has been shared down approximately 320 generations accurately for at least 8,000 years (Campbell, 1967). These historic stories were kept intact and unchanged, reflecting precisely geological facts of the Australian continent cooperated by many different Aboriginal tribes in the same geographical area (Barker et al., 2001). The ancestors of the Gunaikurnai People, the traditional owners of Gippsland area in Victoria, Australia, have Dreaming stories of their country extending further south which is now covered by the ocean today (Fison & Howitt, 1880; Fison & Howitt, 1880). The Wurundjeri and "Wannadrung" (Note: name may have been misinterpreted by colonists, it may be Wadawurrung) tribes around what is currently Port Phillip Bay in Victoria, were reported as stating to the colonists that there was previously plenty of kangaroo and possum in the Port Phillip Bay, obviously referring to a time when the sea level was much lower (Barker, 1854). Similar Aboriginal Dreaming stories were told by nearby tribes of the Mornington Peninsula, the Bunurong People, stating the low lands (Port Phillip Bay) became flooded very quickly following a violent storm and the earth shaking (earthquake) (Rogers, 1966). The Ngarrindjeri tribe of South Australia also had oral history passed down generations, of being able to walk to Kangaroo Island, which is currently several kilometres of the coast of South Australia (Campbell, 1967) but the track to Kangaroo Island would have been above sea level and part of mainland Australia 8,000 – 10,000 years ago.

Refuges for Survival

There is research that suggests that surviving the very harsh conditions of the last ice age in Australia approximately 25,000 years ago was to seek refuge where there was still fresh drinkable water, cover, and plant life (Williams et al., 2013). It is believed that all Aboriginal and Torres Strait Islander people of Australia at that time migrated to 11 distinct refugia (please see Figure 3) and abandoned approximately 80% of the Australian landscape temporarily because it was uninhabitable (Williams et al., 2013). Although this theory seems plausible, it should be noted that this study could not investigate every part of the continent or other possible populations and refugia. Interestingly, based on Williams et al 2013 theory, the main population centres are several hundred kilometres inland or possibly even thousands of kilometres inland with sea levels being much lower at that time, which seems counterintuitive to survival considering the sources of sustainability the ocean could provide, so perhaps it was a fear of potential fast rising oceans that led to inland settlement.

Figure 3



Note. Refuges of survival during the last ice age in Australia (Williams et al., 2013).

Athleticism and Survival

Aboriginal Australians have demonstrated great intelligence and knowledge of our environment, which have developed over the millennia (Watkins et al., 2006; Webb, Cupper, & Robins, 2006). Some of this ability to adapt to environmental conditions has been an evolutionary process (Webb, 2007) as a knowledge and understanding of flora and fauna would have been fundamental to survival (Westaway, 2010). Physical ability would have been paramount to survival and integral to many Aboriginal cultures (Robert, 1878; Taplin, 1879; Watkins et al., 2006). Successful hunting would have required great intellect, knowledge of the fauna and the environment, but obviously athleticism was essential for hunting (Grubb, 2011). Sahul had megafauna e.g., giant kangaroo and emu 3 metres tall, and giant wombat weighing over 1tonne. Although approximately 85% of megafauna became extinct about 50,000 years ago and most disappeared 25,000 years ago, around the time of the last ice age (Miller et al., 1999; Roberts et al., 2001; Wroe & Field, 2006) there is evidence of giant kangaroo and emu surviving 21,000 years ago in Southern Sahul, with paw prints found at Lake Mungo in the Willandra Lakes World Heritage area of NSW, Australia (Johnston, 2014).

Skeletal Anatomical Features

The Kaurna People of the Adelaide Plains area in South Australia exhibit very large nasal cavities (please see Figure 4) which may have assisted with extremely harsh ice age temperatures via warming very cold air before entering the sinus passages, throat, and lungs. These large nostrils would have also limited entry of pathogens like bacteria, fungi, and viruses (Barberán et al., 2015; Dutkiewicz, 1978; Kellogg & Griffin, 2006) preventing infection(s) that may have been life threatening, as these large nostrils and hair would have captured pathogens (Gonzalez-Martin, Teigell-Perez, Lyles, Valladares, & Griffin, 2013). The Kaurna People also exhibited a very broad and pronounced brow and large eye sockets useful for protecting the eyes in extremely dusty, windy, and smoky (from bush fires) conditions experienced 15,000 to 35,000 years ago, helping with visibility and limiting eye infection(s) carried in dust (Vismer, Marasas, Rheeder, & Joubert, 2002).

Figure 4

Skull of 60-year-old Kaurna Man

The skull and accompanying mandible (please see Figure 5) of an approximately 60-year-old Kaurna man show the teeth to be in excellent condition with no decay, which was the case with all 103 skeletal remains. This is an indication that the Kaurna People, despite the difficult environmental conditions, managed to maintain a healthy, balanced diet, which included adequate calcium levels, which is known to improve bone (Fonseca & Ward, 2004) and strength (Kornegay & Thomas, 1981). These skeletal facial features and bone health would likely have contributed to the Kaurna Peoples survival in harsh environmental conditions.

Figure 5

Mandible of 60-year-old Kaurna Man

Figure 6

Compound Fracture of Right Neck and Shaft of Femur

Culture, Medicine and Treatments

Figure 6 contains the right and left femur of a Kaurna man with the right femur having a completely healed compound fracture at the neck and shaft of the femur. These types of injuries are very difficult to heal, even for modern medical professionals (Davidovitch, Jordan, Egol, & Vrahas, 2010) and usually require fixation surgery (Christie, Court-Brown, Kinninmonth, & Howie, 1988; Mackenzie, 1971). Even with the best modern surgical practices and medicines, the rate of non-union and necrosis with these compound fractures is approximately 50% (Davidovitch et al., 2010). The fact that this Kaurna man had this injury completely healed is strong evidence the Kaurna People were in good health, had excellent knowledge of medicine and therapies, with the capacity to heal our community members, including from serious medical emergencies. The sizable calcification around the fracture suggests this 60 year old man lived for at least 5 years after the incident which caused the fracture (likely to be a fall from a great height) (Bourque, Gross, & HAll, 2004).

The fall from a great height may have been while climbing a tree, perhaps for hunting (possum) or finding a scoping viewpoint, which the Kaurna and other tribes were known to do regularly (Lumholtz, 1889; Watkins et al., 2006). This suggests that at least part of the Kaurna survival strategy and perhaps part of our success was regular tree climbing. However, the most important evidence for the Kaurna Peoples ability to survive is the fact that this 60year-old man survived such a severe compound fracture of the neck and shaft of the femur bone. This would have been a life ending injury in many cases for people from other cultures without knowledge of treatment and therapies, certainly in the harsh environmental conditions of the time. For the Kaurna man who was in his 60s (an Elder), to survive such a horrific injury would have taken an extreme level of support from the Kaurna community i.e., “community-strength”, certainly from many members working together. This may be the most important aspect of survival in these harsh conditions -the culture of “community-strength” within tribes- and perhaps one of the earliest examples of "community-care" which many Aboriginal tribes are known for today (Berry et al., 2010; Rowley et al., 2000). This Kaurna man would have been in extreme pain, for a very long period of time, and would have been immobile for many months and would have required constant support (Fox et al., 2000). The recovery and rehabilitation from such an injury would have required knowledge of treatment, therapies, and medicines for serious injury. Indeed, the Kaurna People did have knowledge of medicine to reduce pain, a shrub (pituri plant) that produces an alkaloid which contains nicotine (Langley & Dickinson, 1890). The Kaurna people administered pituri in high doses to reduce pain (Langley & Dickinson, 1890; Watkins et al., 2006; Watson, 1983). Pituri would have been an important medicine (narcotic) (Johnston & Cleland, 1933) with a compound fracture, which would have been incredibly painful.

The possibility to die from blood loss would have been possible with an injury of this type. However, if the person did not bleed out, the possibility of contracting an infection would have been the greatest risk of a life-ending event. The Kaurna People had knowledge of medicine to prevent and/or treat infection and this would have been paramount to this man's survival. Honey has been used by Aboriginal Australians for thousands of years to treat wounds and a variety of skin complaints, including the Kaurna People (Boorn et al., 2010). Although it had been dismissed by many western medical professionals for many years, it is now commercially available for many purposes (e.g., MediHoney). MediHoney has been shown to be effective for a variety of wounds including those colonised or infected with multi-resistant staphylococcus aureus (MRSA) (Blaser, Santos, Bode, Vetter, & Simon, 2007). Other studies showed MediHoney to be effective against 58 strains of staphylococcus aureus and 20 strains of pseudomonas, and that honey dressing were able to produce sterile wounds in 3-10 days (Molan, 1999). It would have been likely that this man's wound would have been treated with Honey as an antibacterial. Tea Tree oil has also been used by many Aboriginal Australian tribes as a disinfectant against bacteria, fungi, and many other skin problems (Carson, Hammer, & Riley, 2006; Tong, Altman, & Barnetson, 1992), including an effective agent against MRSA (Caelli, Porteous, Carson, Heller, & Riley, 2000). This Aboriginal Australian traditional medicine was also ignored by western practitioners but is now commercially available and widely used. The knowledge of the properties of Tea Tree Oil, by the Kaurna and other tribes and its abundance, means it is very likely it would have been used to treat this Kaurna man's wound. The Kaurna People would have had this man lay in a bed of eucalyptus leaves and applied some leaves directly to the wound site as an antibiotic, as the leaves dry they will also absorbed fluid and cushion the wound site. There are many other traditional Aboriginal medicines and treatments used for wounds, pain, and injury that the Kaurna People would have likely used (Watkins et al., 2006). There was traditional knowledge of medicines for inflammation that were widely available to the Kaurna People and useful in the treatment of this man (Devanesen, 2000). Many modern surgical techniques involve surgical screws and internal braces to the bone for such a fracture this Kaurna man experienced (Christie et al., 1988). This injury and accompanying wound would have needed bracing of some form for it to heal and reduce pain and allow union of the bone (Herbert & Fisher, 1984) and the Kaurna People did have exceptional knowledge of human anatomy (Watkins et al., 2006). The amount of sizable calcification tells us that this man did in fact get back up and was weight bearing for several years, which is an incredible outcome and a credit to the Kaurna Peoples knowledge and community-strength.

Discussion

Aboriginal Oral History

The ancient historical geological knowledge held by these Aboriginal Peoples, of their country would have assisted their survival. Knowing the potential for massive sudden geological shift and potential rise and fall of sea levels and spread of disease would have likely influenced their decisions about where to live. Whether or not to have permanent settlement at one site and committing great time and resources in settling permanently on the coast, or low-lying land. It is well-documented that the Kaurna People of Adelaide Plains in South Australia would only have temporary dwellings and shift from near the coast to the shelter of the hills seasonally and main settlements that were several kilometres inland. The Kaurna People also spread out and lived in family groups and clans (Watkins et al., 2006). This regular rotation of dwelling was about flora and fauna regeneration and disease prevention i.e., leaving human and animal waste behind to decompose. Interestingly the permanent settlement at one single site, and rapid gathering of the masses in European cities led to the death of millions from disease (Scott, Duncan, & Duncan, 1996). Perhaps the culture of nomadic rotation of sites and dwellings of many Aboriginal Australian tribes, living separately of family groups and clans, but supporting the entire tribe was based on knowledge that was passed down from our ancestors to look after mother earth, allow regeneration, and preventing disease spread. This was also based on preservation of time and resources that could be lost with the fluctuation of sea level and climate change. This Aboriginal knowledge and culture of community-strength would have contributed to the survival of Aboriginal Australians.

Refuges for Survival

The mobility of these Aboriginal People over such long distances to reach refugia, through such incredibly difficult environmental conditions, is staggering. This mobility truly would have been a "survival of the fittest" and certainly many sacrifices would have had to been made to reach these destinations. One can only image the desperate journey to arrive at these refugia. This is a clear demonstration of the community-strength, adaptability, and resilience of the Aboriginal People of Australia. This process of mobility and relocation may have embedded the need to be mobile in some Aboriginal Australian cultures, and why many Aboriginal tribes did not invest too much time and resources in building permanent structures and dwellings and resisted cohabitation in one large group (Watkins et al., 2006).

Athleticism and Survival

To successfully hunt these very large and fast moving pre-historic animals it would have taken great skill, knowledge and athleticism by the Aboriginal People of this time (Charles, 2017, 2018). Modern day wombats have a top speed of 40km/hr, kangaroos have a top speed of 70 km/hr, and emu are one the fastest land birds on the planet at 50km/hr (Bennett, 1987; Garland, 1983; Heglund, Fedak, Taylor, & Cavagna, 1982). There is no evidence for the running speed of giant wombat, kangaroo and emu but because of their size, and similar ratio, they may have been even faster than their modern relatives. However, regardless of their speed, their size and strength alone would have made hunting these giant animals much harder and would have likely take great athleticism and teamwork from many members of the community. Despite their possible great speed and known size of these pre-historic animals, several studies reported that Aboriginal Australians were very successful hunters of megafauna (Miller et al., 1999; Roberts et al., 2001; Wroe & Field, 2006). This successful hunting style, relying on community-strength would have contributed to the survival of Aboriginal Australians.

In conjunction with the required knowledge of their environment, flora and fauna, Aboriginal Peoples have evolved foot structure and function that is conducive to athleticism, which would have improved hunting success and assisted their survival. The first author has recently demonstrated some aspects of foot and ankle morphology and function that are highly prevalent in modern day Aboriginal Peoples, including a high arched foot type and reduced ankle joint range of dorsiflexion (ankle equinus) (Charles, 2015, 2017). The author found ankle equinus was highly prevalent especially in males and most commonly affected the gastrocnemius muscle (Charles, 2015, 2017). This previous research indicated that both the foot arch type and the range of ankle joint dorsiflexion affected plantar pressures, with a tendency to increase the duration and degree of forefoot loading (Charles, 2017, 2018), and this is thought to have contributed to the athleticism of Aboriginal Australians. Although due to the cross-sectional nature of these studies, the findings are not generalizable to the total Aboriginal and Torres Strait Islander population.

Although not generalizable, it is possible both an ankle equinus and a high arch foot type are an evolutionary biomechanical development to increase running speed and thereby improve hunting ability and survival (Nigg, Cole, & Nachbauer, 1993). The great running speed of ancient Aboriginal Australians has been documented at Lake Mungo in the Willandra Lakes World Heritage area of NSW, Australia (Johnston, 2014). Some of the men running at Lake Mungo, are taking approximately 25 steps to travel an approximately 50 metres or if extrapolated 50 steps to travel 100m (Charles, 2018). This stride pattern is similar to some of the modern world's high performance athletes (Hanon & Gajer, 2009). If the Aboriginal men at Lake Mungo are taking 50 steps to travel 100m this would be an estimated sub 11 seconds to run 100m (Faccioni, 2016). Using a pace calculator (Net, 2016) this is an estimated top speed of 35km/h. It must also be considered that these men were running barefoot, in soft ground (mud), and likely carrying a weapon(s) and/or other item(s) (Charles, 2018). However, these calculations of the ancient Aboriginal men running 100m, is an estimate based on an extrapolation of a 50m run, and there is no way of knowing if these men could have maintained this stride pattern. This athleticism would have been a key component of survival of Aboriginal Australians. Especially having to travel vast distances to reach refuges and escape unviable land and unliveable environmental conditions (Williams et al., 2013). However, athleticism and the ability run fast would have only been part of the survival though the last ice age.

Culture, Medicine and Treatments

It could be argued that the Kaurna Peoples knowledge and use of traditional medicines, therapies, and treatments would have certainly contributed greatly to our survival through difficult environmental conditions.

Conclusion

The Australian continent has experienced many environmental and climatic changes over the millennia that would have been an extremely challenging for the Aboriginal People of Australia. However, a period of two thousand years, approximately 24,000 to 26,000 years ago which would have been especially tough to survive through. Navigating these extremely harsh, rapidly changing conditions is an incredible story of survival of Aboriginal Australians. The findings of this investigation suggest that Aboriginal Australians survival methods were complex and multi-faceted. There is evidence of an evolutionary component to survival, including facial features and biomechanics that would have contributed to survival. Aboriginal Australians have demonstrated incredible endurance and fitness for mobility and a strong "will" to survive. However, perhaps our community mindedness and community-strength is a very powerful tool of resilience and resistance. Our culture, knowledge, and understanding of flora and fauna for nourishment and medicine and other medical treatments was paramount to the survival of Aboriginal Australians. The benefits of living in family groups or clans and avoiding mass cohabitation, knowledge was passed down from ancestors and was a key aspect of preventing the spread of disease, seen in other continents like Europe. The potential for rapid change to earth's environment and its impact on all inhabitants experienced by Aboriginal Australians is perhaps a lesson for modern Aboriginal and non-Aboriginal people of our earth.

References

Barberán, A., Ladau, J., Leff, J. W., Pollard, K. S., Menninger, H. L., Dunn, R. R., & Fierer, N. (2015). Continental-scale distributions of dust-associated bacteria and fungi. *Proceedings of the National Academy of Sciences*, 201420815. https://doi.org/10.1073/pnas.1420815112

Barker, J. E., Jones, F. F., McKay, H. F., & McLeod, P. (2001). *Gadi mirrabooka : Australian Aboriginal tales from the dreaming* (H. F. McKay Ed.). Englewood, Colo: Libraries Unlimited.

Barker, W. (1854). *Report from the Select Committee of the Legislative Council on the Claims for the Discovery of Gold in Victoria: together with the proceedings of Committee, minutes of evidence and appendix*. Melbourne: John Ferres, Government Printer.

Bennett, M. (1987). Fast locomotion of some kangaroos. *Journal of Zoology, 212*(3), 457-464. https://doi.org/10.1111/j.1469-7998.1987.tb02916.x

Berry, H. L., Butler, J. R., Burgess, C. P., King, U. G., Tsey, K., Cadet-James, Y. L., . . . Raphael, B. (2010). Mind, body, spirit: co-benefits for mental health from climate change adaptation and caring for country in remote Aboriginal Australian communities. *New South Wales Public Health Bulletin, 21*(6), 139-145. https://doi.org/10.1071/NB10030

Best, C. (2016, October 08). When is the next Ice Age due? Retrieved from http://clivebest.com/blog/?p=7344

Blaser, G., Santos, K., Bode, U., Vetter, H., & Simon, A. (2007). Effect of medical honey on wounds colonised or infected with MRSA. *Journal of wound care, 16*(8), 325-328. https://doi.org/10.12968/jowc.2007.16.8.27851

Boorn, K., Khor, Y. Y., Sweetman, E., Tan, F., Heard, T., & Hammer, K. (2010). Antimicrobial activity of honey from the stingless bee Trigona carbonaria determined by agar diffusion, agar dilution, broth microdilution and time-kill methodology. *Journal of applied microbiology, 108*(5), 1534-1543. https://doi.org/10.1111/j.1365-2672.2009.04552.x

Bourque, W. T., Gross, M., & HAll, B. K. (2004). Expression of four growth factors during fracture repair. *International Journal of Developmental Biology, 37*(4), 573-579.

Bowler, J. M. (1976). Aridity in Australia: Age, origins and expression in aeolian landforms and sediments. *Earth-Science Reviews, 12*(2), 279-310. https://doi.org/10.1016/0012-8252(76)90008-8

Brazil, J. (2000). Dreamtime superstore: Encountering Australian aboriginal beliefs. *Third Text, 14*(50), 61-72. https://doi.org/10.1080/09528820008576837

Broome, R. (1982). *Aboriginal Australians*: Allen & Unwin Sydney.

Caelli, M., Porteous, J., Carson, C., Heller, R., & Riley, T. (2000). Tea tree oil as an alternative topical decolonization agent for methicillin-resistant Staphylococcus aureus. *Journal of Hospital Infection, 46*(3), 236-237. https://doi.org/10.1016/S0195-6701(00)90830-2

Campbell, A. H. (1967). Aboriginal traditions and the prehistory of Australia. *The Australian Journal of Anthropology, 6*(10), 476. https://doi.org/10.1111/j.1835-9310.1967.tb01351.x

Carson, C., Hammer, K., & Riley, T. (2006). Melaleuca alternifolia (tea tree) oil: a review of antimicrobial and other medicinal properties. *Clinical microbiology reviews, 19*(1), 50-62. https://doi.org/10.1128/CMR.19.1.50-62.2006

Charles, J. (2015). An evaluation and comprehensive guide to successful aboriginal health promotion. *Austr Indigen Health Bull, 16*(1), 1-8. Retrieved from http://healthbulletin.org.au/articles/an-evaluation-and-comprehensive-guide-to-successful-aboriginal-health-promotion

Charles, J. (2017). *An investigation into ankle joint dorsiflexion, musculoskeletal injury, arch height, foot pressure and diabetes in association with poor foot health outcomes in an Aboriginal population*. (Research Doctorate - Doctor of Philosophy (PhD) By Publication), University of Newcastle, Newcastle. Retrieved from http://hdl.handle.net/1959.13/1353477 (uon:31102)

Charles, J. (2018). Musculoskeletal injury and the correlation with foot plantar pressure in an Australian Aboriginal population. *Australian Indigenous Health Bulletin, 18*(1). Retrieved from http://healthbulletin.org.au/articles/musculoskeletal-injury-and-the-correlation-with-foot-plantar-pressure-in-an-australian-aboriginal-population

Christie, J., Court-Brown, C., Kinninmonth, A., & Howie, C. (1988). Intramedullary locking nails in the management of femoral shaft fractures. *The Journal of bone and joint surgery. British volume, 70*(2), 206-210. https://doi.org/10.1302/0301-620X.70B2.3346289

Davidovitch, R. I., Jordan, C. J., Egol, K. A., & Vrahas, M. S. (2010). Challenges in the treatment of femoral neck fractures in the nonelderly adult. *Journal of Trauma and Acute Care Surgery, 68*(1), 236-242. https://doi.org/10.1097/TA.0b013e3181c428ce

Devanesen, D. D. (2000). Traditional Aboriginal medicine practice in the Northern Territory.

Dutkiewicz, J. (1978). Exposure to dust-borne bacteria in agriculture. Environmental studies. *Archives of Environmental Health: An International Journal, 33*(5), 250-259. https://doi.org/10.1080/00039896.1978.10667344

Faccioni, A. (2016). Complete Sprinting Technique. Retrieved from http://www.adriansprints.com/2011/03/complete-sprinting-technique-charlie.html

Fielding, C. R., Frank, T. D., Birgenheier, L. P., Rygel, M. C., Jones, A. T., & Roberts, J. (2008). *Stratigraphic record and facies associations of the late Paleozoic ice age in eastern Australia (New South Wales and Queensland).* https://doi.org/10.1130/2008.2441(03)

Finlayson, C., Giles Pacheco, F., Rodríguez-Vidal, J., Fa, D. A., María Gutierrez López, J., Santiago Pérez, A., . . . Sakamoto, T. (2006). Late survival of Neanderthals at the southernmost extreme of Europe. *Nature, 443*, 850. https://doi.org/10.1038/nature05195

Fison, L., & Howitt, A. (1880). Kamilaroi andKurnai. In: George Roberston, Melbourne, Sydney, Adelaide and Brisbane.

Fison, L., & Howitt, A. W. (1880). *Kamilaroi and Kurnai: Group Marriage and Relationship, and Marriage by Elopement... Also the Kurnai Tribe: Their Customs in Peace and War*: George Robertson.

Fonseca, D., & Ward, W. E. (2004). Daidzein together with high calcium preserve bone mass and biomechanical strength at multiple sites in ovariectomized mice. *Bone, 35*(2), 489-497. https://doi.org/10.1016/j.bone.2004.03.031

Fox, K., Magaziner, J., Hawkes, W., Yu-Yahiro, J., Hebel, J., Zimmerman, S., . . . Michael, R. (2000). Loss of bone density and lean body mass after hip fracture. *Osteoporosis International, 11*(1), 31-35. https://doi.org/10.1007/s001980050003

Garland, T. (1983). The relation between maximal running speed and body mass in terrestrial mammals. *Journal of Zoology, 199*(2), 157-170. https://doi.org/10.1111/j.1469-7998.1983.tb02087.x

Gonzalez-Martin, C., Teigell-Perez, N., Lyles, M., Valladares, B., & Griffin, D. W. (2013). Epifluorescent direct counts of bacteria and viruses from topsoil of various desert dust storm regions. *Research in microbiology, 164*(1), 17-21. https://doi.org/10.1016/j.resmic.2012.08.009

Grubb, P. L. (2011). Persistence Hunting and the Evolution of Human Endurance Running. *Graduate Student Journal of Anthropology, 33*.

Hanon, C., & Gajer, B. (2009). Velocity and Stride Parameters of World-Class 400-Meter Athletes Compared With Less Experienced Runners. *The Journal of Strength & Conditioning Research, 23*(2), 524-531. https://doi.org/10.1519/JSC.0b013e318194e071

Heglund, N. C., Fedak, M., Taylor, C., & Cavagna, G. (1982). Energetics and mechanics of terrestrial locomotion. IV. Total mechanical energy changes as a function of speed and body size in birds and mammals. *Journal of Experimental Biology, 97*(1), 57-66. https://doi.org/10.1146/annurev.ph.44.030182.000525

Herbert, T. J., & Fisher, W. E. (1984). Management of the fractured scaphoid using a new bone screw. *The Journal of bone and joint surgery. British volume, 66*(1), 114-123.

https://doi.org/10.1302/0301-620X.66B1.6693468

Isaacs, J. (1980). *Australian dreaming: 40,000 years of Aboriginal history*: Lansdowne Press Sydney.

Johnson, C. (2006). *Australia's Mammal Extinctions : A 50,000 year history*. Port Melbourne: Cambridge University Press.

Johnston, H. (2014). The Willandra Lakes Region World Heritage Area, New South Wales, Australia: Land Use Planning and Management of Aboriginal and Archaeological Heritage. In *Archaeological Dimension of World Heritage* (pp. 39-55): Springer. https://doi.org/10.1007/978-1-4939-0283-5_4

Johnston, T. H., & Cleland, J. B. (1933). The history of the Aboriginal narcotic, pituri. *Oceania, 4*(2), 201-223. https://doi.org/10.1002/j.1834-4461.1933.tb00101.x

Kellogg, C. A., & Griffin, D. W. (2006). Aerobiology and the global transport of desert dust. *Trends in ecology & evolution, 21*(11), 638-644. https://doi.org/10.1016/j.tree.2006.07.004

Kornegay, E., & Thomas, H. (1981). Phosphorus in Swine. II. Influence of Dietary Calcium and Phosphorus Levels and Growth Rate on Serum Minerals, Soundness Scores and Bone Development in Barrows, Gilts and Boars 1. *Journal of animal science, 52*(5), 1049-1059. https://doi.org/10.2527/jas1981.5251049x

Langley, J. N., & Dickinson, W. L. (1890). Pituri and nicotin. *The Journal of physiology, 11*(4-5), 265-306. https://doi.org/10.1113/jphysiol.1890.sp000332

Lumholtz, C. (1889). *Among cannibals: an account of four years' travels in Australia and of camp life with the Aborigines of Queensland*: London: J. Murray.

Mackenzie, D. B. (1971). Simultaneous ipsilateral fracture of the femoral neck and shaft: report of 8 cases. *South African Medical Journal, 45*(4), 459-467.

Malaspinas, A.-S., Westaway, M. C., Muller, C., Sousa, V. C., Lao, O., Alves, I., . . . Willerslev, E. (2016). A genomic history of Aboriginal Australia. *Nature, 2016*(538), 207. https://doi.org/10.1038/nature18299

Miller, G. H., Magee, J. W., Johnson, B. J., Fogel, M. L., Spooner, N. A., McCulloch, M. T., & Ayliffe, L. K. (1999). Pleistocene Extinction of Genyornis newtoni: Human Impact on Australian Megafauna. *Science, 283*(5399), 205-208. https://doi.org/10.1126/science.283.5399.205

Molan, P. C. (1999). The role of honey in the management of wounds. https://doi.org/10.12968/jowc.1999.8.8.25904

Monroe, M. H. (2011). Australia: The Land Where Time Began. In. Australia: M. H. Monroe.

Mountford, C. P. (1981). *Aboriginal conception beliefs*: Hyland House Melbourne.

Net, C. (2016). Pace Calculator. Retrieved from http://www.calculator.net/pace-calculator.html?ctype=pace&ctime=00%3A00%3A10&cdistance=100&cdistanceunit=Meters&cpace=00%3A08%3A10&cpaceunit=tpm&printit=0&x=53&y=9

Nigg, B. M., Cole, G. K., & Nachbauer, W. (1993). Effects of arch height of the foot on angular motion of the lower extremities in running. *Journal of biomechanics, 26*(8), 909-916.

https://doi.org/10.1016/0021-9290(93)90053-H

Robert, B. (1878). *The Aboriginies of Victoria* (Vol. 1).

Roberts, R. G., Flannery, T. F., Ayliffe, L. K., Yoshida, H., Olley, J. M., Prideaux, G. J., . . . Smith, B. L. (2001). New Ages for the Last Australian Megafauna: Continent-Wide Extinction About 46,000 Years Ago. *Science, 292*(5523), 1888-1892. https://doi.org/10.1126/science.1060264

Rogers, H. (1966). *The early history of the Mornington Peninsula*: Hallcraft Publishing Company.

Rowley, K. G., Daniel, M., Skinner, K., Skinner, M., White, G. A., & O'Dea, K. (2000). Effectiveness of a community-directed 'healthy lifestyle'program in a remote Australian Aboriginal community. *Australian and New NZeland Journal of Public Health*, *24*(2), 136-144. https://doi.org/10.1111/j.1467-842X.2000.tb00133.x

Scott, S., Duncan, C. J., & Duncan, S. (1996). The plague in Penrith, Cumbria, 1597/8: its causes, biology and consequences. *Annals of human biology, 23*(1), 1-21. ttps://doi.org/10.1080/03014469600004232

Shea, J. J. (2008). Transitions or turnovers? Climatically-forced extinctions of Homo sapiens and Neanderthals in the east Mediterranean Levant. *Quaternary Science Reviews, 27*(23), 2253-2270. https://doi.org/10.1016/j.quascirev.2008.08.015

Taçon, P. S. (1991). The power of stone: symbolic aspects of stone use and tool development in western Arnhem Land, Australia. *Antiquity, 65*(247), 192-207. https://doi.org/10.1017/S0003598X00079655

Taplin, W. J. G. (1879). *The Native Tribes of South Australia*. London: E. S. Wigg.

Tong, M. M., Altman, P. M., & Barnetson, R. S. (1992). Tea tree oil in the treatment of tinea pedis. *Australasian Journal of Dermatology, 33*(3), 145-149. https://doi.org/10.1111/j.1440-0960.1992.tb00103.x

Ulm, S. (2016, January 16). Map showing sea level changes over time. Retrieved from https://www.abc.net.au/news/2018-01-16/map-showing-sea-level-changes-over-time/9333538?nw=0

Vismer, H., Marasas, W., Rheeder, J., & Joubert, J. (2002). Fusarium dimerum as a cause of human eye infections. *Medical mycology, 40*(4), 399-406. https://doi.org/10.1080/mmy.40.4.399.406

Voris, H. K. (2000). Maps of Pleistocene sea levels in Southeast Asia: shorelines, river systems and time durations. *Journal of Biogeography, 27*(5), 1153-1167. https://doi.org/10.1046/j.1365-2699.2000.00489.x

Watkins, C., Gale, M. A., Adelaide, S. I. o., & School, K. P. (2006). *Kaurna Alphabet Book: With an Introduction to the Kaurna Language*: Kaurna Plains School.

Watson, P. (1983). *This precious foliage: A study of the Aboriginal psycho-active drug pituri*: University of Sydney.

Webb, S. (2007). Further research of the Willandra Lakes fossil footprint site, southeastern Australia. *Journal of human evolution, 52*(6), 711-715. https://doi.org/10.1016/j.jhevol.2007.02.001

Webb, S., Cupper, M. L., & Robins, R. (2006). Pleistocene human footprints from the Willandra Lakes, southeastern Australia. *Journal of human evolution, 50*(4), 405-413.

https://doi.org/10.1016/j.jhevol.2005.10.002

Westaway, M. (2010). Footprints of the First Australians. *Australasian Science (2000), 31*(2), 14.

Williams, A. N., Ulm, S., Cook, A. R., Langley, M. C., & Collard, M. (2013). Human refugia in Australia during the Last Glacial Maximum and Terminal Pleistocene: a geospatial analysis of the 25–12 ka Australian archaeological record. *Journal of Archaeological Science, 40*(12), 4612-4625. https://doi.org/10.1016/j.jas.2013.06.015

Wroe, S., & Field, J. (2006). A review of the evidence for a human role in the extinction of Australian megafauna and an alternative interpretation. *Quaternary Science Reviews, 25*(21), 2692-2703. https://doi.org/10.1016/j.quascirev.2006.03.005

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Insights from a Jordan's Principle Child First Initiative in Alberta: Implications for Advancing Health Equity for First Nations Children

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In 2016, Canada was ordered to implement Jordan's Principle by the Canadian Human Rights Tribunal. In response to the order, Canada created the Child First Initiative to provide federal funding for provincial and territorial organizations supporting First Nations children's health, education, and social service needs, including service coordination. In the shifting national landscape of Child First Initiative funding, there is a lack of evidence on how pediatric healthcare services are addressing the serious health and healthcare inequities experienced by many First Nations children. This paper describes the implementation of a Child First Initiative by the First Nations Health Consortium in the Alberta region and research findings that provide insights into the complexity and challenges of advancing First Nations children's health and health equity within the current federal Child First Initiative mandate in this province. This paper highlights the need for transformative pediatric healthcare approaches that expand beyond an individual and demand-driven system and orient towards practices and policies that are socially-responsive. Also, this paper highlights that First Nations leaders and Jordan's Principle initiatives play a leading role in the design and delivery of all pediatric healthcare services with First Nations communities, families, and children across Canada.

Keywords: *Indigenous, First Nations Health Consortium, pediatric healthcare, early intervention, substantive equality, social determinants, structural inequities*

Glossary

AW: Access Worker
CFI: Child First Initiative
ESC: Enhanced service coordination
FNHC: First Nations Health Consortium
RSC: Regional Service Coordinator

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Introduction

Jordan's Principle is a legal requirement that Canada ensures all First Nations children have access to education, social, health services, supports, and products without denials, delays or disruptions (First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada, 2016). Jordan's Principle is named in honor of Jordan River Anderson, a little boy from Norway House Cree Nation in Manitoba who was born with a rare genetic disorder that required specialized care from birth. Jordan was denied the basic health supports necessary to leave the hospital and return home due to lengthy jurisdictional funding disputes between provincial and federal governments. Jordan spent his life in hospital until he passed away in 2005 at the age of five (First Nations Child & Family Caring Society, 2020). Jordan's Principle was created and championed by First Nations organizations and advocates. In 2007 Jordan's Principle was introduced as a motion in the House of Commons where it received unanimous support. However, meaningful steps towards the implementation of Jordan's Principle did not occur until a landmark 2016 ruling by the Canadian Human Rights Tribunal (CHRT) which ordered the federal government of Canada to immediately implement the full meaning and scope of Jordan's Principle (Caring Society v. Canada, 2016).

Following the CHRT ruling the federal government initiated a Jordan's Principle Child First Initiative (CFI) to provide federal funding for organizations supporting First Nations children's health, education, and social service needs. The CFI included funds for Enhanced Service Coordination (ESC) initiatives that were intended to help maximize First Nations children's access to existing health, social, and educational services. The CFI also included funds for requests for individual children and group requests to address service gaps affecting large numbers of children. These funds were originally approved for three years and have recently been renewed for an additional three years (Sangster et al., 2019). In January 2017, a newly-formed First Nations Health Consortium (FNHC) in Alberta received CFI funding for all First Nations children living on- and off-reserve and initiated a research partnership with the Children's Services Policy Research Group at McGill University in order to document the organizational development of their ESC model.

This paper focuses on the implementation of a CFI initiative to implement Jordan's Principle and advance First Nations children's health and healthcare equity. The paper highlights the FNHC in the Alberta region as an exemplar of an ESC model and research findings that provide insights into the complexity and challenges of advancing First Nations children's health and health equity within the current federal CFI mandate. This paper also explores the implications of these findings for informing the transformation of pediatric healthcare services and systems in partnership with Jordan's Principle initiatives in Canada.

This paper uses the concept of health equity as meaning that "all people (individuals, groups, and communities) have a fair chance to reach their full health potential and are not disadvantaged by social, economic, and environmental conditions" (National Collaborating Centre for Determinants of Health, 2015, p. 2). In Canada, health equity is enshrined in Canadian public health practices and policies (Pauly et al., 2013; Public Health Agency of Canada, 2014). Orienting pediatric healthcare towards equity in Canada and similar wealthy countries is starting to emerge in response to concerns about widening social inequalities (Gerlach & Varcoe, 2020; Wood & Goldhagen, 2013), and increasing scientific evidence on the impacts of early childhood adversity on health and wellbeing across the life course (Boyce & Hertzman, 2018; Goldblatt et al., 2015). While the concept of health equity is used in public health discourses, policy discussions and legal rulings around services for First Nations children in Canada are increasingly using the term 'substantive equality' (Caring Society v. Canada, 2016). Despite being two distinct discourses, a primary indicator and intent of both of these concepts is equitable outcomes. Equitable outcomes cannot be measured in a single fiscal year as achieving equitable outcomes often requires examining and interrupting routine approaches and restructuring deeply rooted systems and practices so that they are inclusive of and responsive to individuals, groups, and communities' social contexts and circumstances (Browne et al., 2018; Goldblatt et al., 2015). For example, the funding, organization and delivery of pediatric healthcare for a family and child living in a northern rural community may need to be very different from those provided in an urban centre.

The Structurally Determined Nature of First Nations Children's Health

First Nations children's health is inextricably tied to past and present colonial violence. From the late 19th century until today, despite continued resistance from their families and communities, many First Nations children have been removed from their homes through state-sanctioned legislation and policies in the form of residential schools, the Sixties scoop, and the contemporary child welfare system (McKenzie et al., 2016; Truth and Reconciliation Commission of Canada, 2015). A legacy of this state-sanctioned violence is that First Nations families can delay accessing child-related services because of deep-seated fears that it will result in their children being removed from their care (Gerlach, et al., 2017). Colonial violence and historically-rooted structural inequities continue to directly contribute towards First Nations children experiencing a greater risk of poor health outcomes compared to non-Indigenous children in Canada (Allan & Smylie, 2015; Greenwood & de Leeuw, 2012; Smylie et al., 2010). This structurally-rooted vulnerability is manifested in many First Nations children lacking access to basic determinants of health including family income, parental education and employment, safe drinking water, food security and safe housing (Smylie & Adomako, 2009). Importantly, health inequities are potentially avoidable or remediable (Marmot, 2007). However, in the Canadian context instead of creating policies that aim to remediate structural inequities, the federal government continues to enact policies that underfund or rely on short-term funding for needed services, while actively resisting legal requirements that would support improved outcomes for First Nations children (Sinha et al., 2018; The Canadian Bar Association, 2019).

An Enhanced Service Coordination Model for First Nations Children in Alberta

In Alberta, there are an estimated 137,000 First Nations Peoples, with a young, fast growing population (Statistics Canada, 2017). There are 46 First Nations, encompassing 140 communities of varied sizes with distinct cultural traditions. The languages currently spoken include Blackfoot, Cree, Chipewyan, Dene, Sarcee, and Stoney (Indigenous and Northern Affairs Canada, 2010). Recognizing the enormous diversity within and between First Nations in the Alberta region, the FNHC was formed with the goal of serving all First Nations families and children across this province. The FNHC is a collaboration between Bigstone Health Commission, Kee Tas Kee Now Health Commission, Maskwacis Health Services, and Siksika Health Services which are located in Treaty 6, 7, and 8.

In 2017, the FNHC initiated an ESC model based on their mandate to fulfill First Nations children's 'inherent rights to holistic services and supports' by connecting families and children to health, social, education services, supports, and products (First Nations Health Consortium, 2020). This ESC model operates within shifting federal and legal directives surrounding the eligibility, provision, and administration of Jordan's Principle, and with no clear directives on the long-term funding or implementation of Jordan's Principle, or the gap this funding is intended to fill (Sangster et al., 2019). The federal government's 'Standard Operating Procedures' for Jordan's Principle specifies that Jordan's Principle requires case reviewers to consider requests on a case-by-case basis, focusing on how the request will address the immediate need of the child, rather than long-term systemic change (Indigenous Services Canada, 2019). Group requests do provide a means for extending beyond a case-by-case approach. However, there is currently insufficient information or guidance around group requests for this to serve as a mechanism for systemic change (Sinha et al., 2018).

The ESC model developed by the FNHC is typically accessed by families or service providers initiating contact with a Jordan's Principle Access Worker (AW) through a 1-800 number, who then conducts an initial interview in order to determine if a child's needs can be met by referrals to pre-existing services. When services are unavailable, a case file is opened, and the AW connects the family and/or service provider(s) with a FNHC Regional Service Coordinator (RSC). RSCs gather the necessary and often extensive documentation for a Jordan's Principle request, which is then submitted to the Alberta based federal government focal point workers who determine whether the request is approved, denied, or forwarded to a national office in Ottawa for further review and outcome determination (Sangster et al., 2019). From Fall 2017 to Spring 2019, 739 First Nations children accessed the ESC, 57% of whom were children living on-reserve. During this time period, the FNHC opened cases for approximately 1 in every 85 First Nations children in the Alberta region. The FNHC also supported 21 Jordan's Principle group requests from organizations and First Nations across this region who successfully identified a gap in services for a group of children. Examples of approved group requests include early intervention therapy programs, diabetes care, and psychosocial assessments (Sangster et al., 2019).

Methods

This research was initiated by the FNHC. Informed by a participatory research approach, the research team co-developed the study objectives, design, methods of data collection, and knowledge translation activities with the leadership and staff of the FNHC and their invited advisors from October 2017 to April 2019. A research agreement between the FNHC and the Children's Services Policy Research Group at McGill University was grounded in a framework based on OCAP® (ownership, control, access, and possession) principles (First Nations Information Governance Centre, 2007). Ethics was approved by McGill University. For a detailed summary of the methods see Sangster et al., 2019.

The findings in this paper are based on data generated through: (1) participant observation of weekly staff meetings, staff retreats and visioning sessions, and monthly meetings between the FNHC staff and federal government focal point workers, and (2) in-depth, semi-structured individual interviews with the FNHC Board (n=5) and staff (n=13) members following informed, written consent. During the study, the researchers had no access to identifying information about the children or families accessing ESC. All data were transcribed, coded, and analyzed by members of the research team and verified through an iterative member checking process with the FNHC staff and Board members over several months. Analysis was further informed by the literature and publicly available government and legal documents related to Jordan's Principle, First Nations of Alberta, and the Alberta health, education, and social service systems. The full findings from the study are summarized in a formative evaluation report (Sangster et al., 2019).

Results

In this paper, the findings centre on data generated from interviews with FNHC staff and Board members, and two 'family stories' that were compiled from interviews and discussions with FNHC staff and researchers' fieldnotes. There are two inter-related themes that are pertinent to advancing health equity: (1) 'It's complex – it's the needs of the entire family' and (2) 'We have to find a better way'.

'It's Complex - It's the Needs of the Entire Family'

In their interviews, FNHC staff (RSCs and AWs) frequently talked about the time it took to fully understand the circumstances of a family's life, including their family history, geographical location, housing situation, community infrastructure, and other factors impacting their child's unmet health, social, or educational needs. In connecting with families through the early intake and long-term case management process, staff described a relational and often emotional process that focused on developing trust with families who had been unable to access services for their children. As one RSC reflected:

> *This [case] was complex because it was also emotional. You know, the mom cried, I cried. You know you're dealing with people's lives, and little children, and I'm a mom myself.... It wasn't just a medication - it was medical supplies, it was medical equipment, it was renovation of a house, it was a lack of transportation, it was the medical needs of the entire family.*

Staff described a process of 'walking with' families in gathering extensive amounts of information and documentation that were required to advance children's access to health-related supports, services, or products.

The following family story illustrates the complex nature of this work.

Through her conversations with local public service providers, a RSC at the FNHC became aware of a family whose living situation was severely compromising their ability to continue caring for their child at home. The family consisted of two grandparents, a mother who used a wheelchair, and her three children. One of the children required a wheelchair and a feeding tube as a result of complications from a surgery when she was much younger. Following this surgery, the grandparents had been told that they would be unable to bring the child home because they did not have the supports necessary to meet her needs. Rejecting this, the grandparents sought the training needed to care for their granddaughter while they were residing in the city where the surgery took place. After about a month, the family returned home.

The family home was approximately 900 square feet with poor ventilation, mold, and one wheelchair accessible exit. In an emergency, the mother and daughter would not be able to get out at the same time. The living room had sunken floors, making much of the house inaccessible to the mother and daughter in their wheelchairs. The isolated location of the home made it difficult for the family to arrange for purified water delivery, which they needed to clean the daughter's feeding tubes. Minor renovations on the house were supported by the family's Band, which had a housing budget of $80,000 for the entire community. These renovations were not enough to adapt the home to the family's needs.

The RSC joined with local service providers to advocate for a safe and wheelchair-accessible home for this family. At that time, the RSC was informed that because the CFI federal funding was due to end in March 2019, there was no funding available for services, renovations, or equipment beyond this date. Thus, funding could only be provided if a new home was built in less than a year. With this tight timeline in mind, the RSC gathered the documents required for the application to the focal point in Alberta for Indigenous Services Canada. The family's pediatrician wrote a letter explaining the granddaughter's health issues. The Chief wrote two letters: one confirming that land was available to the family for a new house and another detailing the community's insufficient housing budget. An occupational therapist met with contractors and reviewed plans for wheelchair accessibility. In addition, the RSC met with an environmentalist to inspect the home for mold and document the findings in a letter. The RSC also worked with the Band administrator to gather three quotes to build a new home or purchase a prefabricated home that could be moved to the site.

This RSC submitted an initial request for house modifications for this family in March 2018 and communicated regularly with the focal point regarding the required documentation. In June 2018, the Alberta focal point informally confirmed that the federal government would fund major renovations to the family's existing home to make it wheelchair accessible but would not fund the building of a new home under Jordan's Principle. After a series of partial approvals, the necessary major renovations were denied. In December 2018, the FNHC filed an appeal on behalf of the family. In January 2019, the appeal was approved and renovations to the home finally began.

The findings in this theme highlight the extent of intersectoral coordination and collaboration between multiple health and social service stakeholders, including federal focal point workers, to advance a child's health and quality of life within families and communities that are impacted by discriminatory chronic federal underfunding. The social and often complex nature of 'needs' identified and addressed by the FNHC is also highlighted by the organization's statistics. Over an 18-month period from, October 2017 to April 2019, there were 447 requests categorized as 'outside of health' including 121 related to education, 78 for food and/or income, and multiple categories including transportation, housing and infrastructure, status or treaty, respite and social supports, and cultural supports and services. Of the families requesting services 558 had one need, 121 had two needs, 46 had three needs, and 14 families had four or more needs. During this same time period, the FNHC identified 551 requests for health needs including 169 for dental care, 107 for glasses and/or vision needs, 62 for medication needs, and many others including but not limited to mental health, medical equipment and occupational therapy (Sangster et al., 2019).

‘We Have to Find a Better Way’

The FNHC staff and Board members described how the current federal directive for Jordan’s Principle requests was predominately based on the premise that individual parents/caregivers or service providers will identify what service a child needs. Staff noted that caregivers were often hesitant to initiate a request due to their prior experiences of discriminatory or ineffective professional intervention, fears of racism or dismissal, and conflicting opinions within families about whether to ask for help. Moreover, some staff voiced their frustration about the individualistic framework established by the federal government, while broader systemic concerns were left unaddressed. This tension is reflected in the following family story.

The FNHC received a call from a social worker at the Stollery Children’s Hospital in Edmonton requesting service coordination for a family. The mother, accompanied by her own mother, had travelled from their home community to Edmonton with her severely malnourished infant. The family lived in an isolated northern community only accessible by plane or by ice road. Children under the age of two made up 10% of the community’s population. However, as in many northern communities, the cost of food created a significant burden for families. For example, in the spring 2018 a gallon of milk cost $70. The price of baby formula was also exorbitant. Furthermore, a permanent boil water advisory made it difficult for parents to prepare powdered formula, which was the only formula officially approved through NIHB. Despite widespread and sometimes permanent boil water advisories in First Nations communities throughout Alberta, NIHB did not cover bottled water. In the hospital, a social worker informed the Jordan’s Principle AW that the baby would be discharged in a few days, and would require liquid formula when returning home. Two days before the baby was to be discharged home, the Jordan’s Principle AW started gathering information about the family. She learned that the grandmother’s first language was Cree and that the hospital lacked a Cree translator, which created a barrier when communicating with hospital staff. The Jordan’s Principle AW then phoned a nurse in the family’s home community to gather information about the process of shipping supplies North. She was told that doctors completing rotations in the community often brought medications and prescriptions, but that access to these resources was weather-dependent, with up to three weeks between shipments.

After gathering this information, the AW started the process of securing liquid formula for the family. She asked the hospital nurse to have the attending doctor write a prescription for the liquid formula and take it to the pharmacy immediately. The pharmacy tried to charge NIHB for the prescription but received an immediate denial. The doctor completed a form explaining why the medical team requested a formula prescription and faxed this documentation to NIHB. At this point, the Jordan’s Principle AW was advised it could take 24 to 48 hours for an answer from NIHB; time the family did not have, because the baby was soon to be discharged. The AW anticipated, based on past experience, that the liquid formula prescription would be denied by NIHB. She developed a contingency plan with the focal point - if the family did not receive NIHB approval by Friday, they would apply to fund the formula under Jordan’s Principle. The family received a second denial for liquid formula coverage from NIHB, after which the focal point approved funding.

In the interim, the doctors decided to keep the child in hospital over the weekend. During this observation period, doctors prescribed a different liquid formula in order to better meet the child's medical and developmental needs. The AW was told by a focal point that this change in prescription meant she had to again complete the process of documentation gathering and NIHB denial. The secondary submission process required taking the new prescription to the pharmacy and getting another immediate denial from NIHB, after which the doctor wrote another letter to explain why the prescription was changed. This was followed by a fourth submission to NIHB, which received another denial. At this point, the AW submitted a second Jordan's Principle application, which was deemed complete by the focal point.

The mother, baby, and grandmother returned home with a prescription for a year's worth of liquid formula. The family later contacted the AW to confirm the compensation process for purchase of additional formula. The AW contacted the focal point and learned that, after four NIHB denials and two Jordan's Principle applications, NIHB had agreed to fund the medically necessary liquid formula for the family. The community and AW were concerned by the family's experience and submitted a successful group request so that all parents in the community could have access to liquid formula for their infants under the age of two. According to the RSC, this cost more than $700,000. The entire group application process took about 2½ months. The community continues to have no access to safe drinking water.
This family story highlights the increased vulnerability of First Nations infants for health inequities as a result of a lack of access to a basic determinant of health – safe drinking water. As of February 2020, there are 60 long-term drinking water advisories in First Nations across Canada (Government of Canada, 2020). Efforts towards adequate funding, infrastructure and human resources to resolve drinking water advisories remain inadequate despite significant commitments from provincial and federal governments (Lukawiecki, 2018).

Several FNHC Board members also expressed concerns about a system based primarily on responding to individual children's needs, including the following in relation to speech therapy:

> *A major issue is the lack of speech language therapy. So, we have to change [the] regulation so speech language therapy is an automatic approval process. Then you don't have to go through a Jordan's Principle system. We used to have allied health services as part of NIHB that include occupational therapy, physio, speech language therapy and chiropractic. We have to be able to, through our data, we have to tell people... that there is a better way of delivering services.*

The findings in this second theme highlight the challenges and limitations of a predominately individual identification and request driven system that operates within the status quo of underlying structural inequities and a fragmented pediatric healthcare system.

Limitations

A limitation of this study is that it did not include interviews with First Nations families, children, or youth or First Nations community-based healthcare providers or Elders. Their experiences and perspectives would have further enhanced our understanding of the lived realities of navigating Jordan's Principle and the ESC model delivered by the FNHC in Alberta.

Discussion

Currently there is a lack of evidence on how pediatric healthcare systems, organizations and professionals are addressing the serious health and healthcare inequities experienced by many First Nations children in the midst of shifting federal responses to the CHRT rulings on Jordan's Principle (Assembly of First Nations, 2018; Sinha & Wong, 2015). In the following section, we explore how the findings in this paper can inform greater dialogue on transforming pediatric healthcare in partnership with Jordan's Principle initiatives in Canada.

Expanding Beyond Individual and Demand-Driven Systems

The findings in this paper provide insights into an individualistic and demand-driven system for Jordan's Principle funding in the Alberta region. This system requires that caregivers or professionals in a child's life can identify an unmet need and recognize which specialized supports, services, or products exist to resolve the unmet need. This responsibility is compounded by unclear and shifting federal procedures for the approval of services that exceed normative provincial standards in order to advance equitable health outcomes for First Nations children. For example, the current federal guidelines for assessing whether a Jordan's Principle funding request is approved for a pediatric healthcare service rely heavily on the capacity of caregivers and FNHC staff to describe the social disadvantages that are impacting a child's health. A reliance on individual caregivers or service providers making a request and being approved for Jordan's Principle funding risks that an unknown number of First Nations children continue to experience unmet needs (Sangster et al., 2019). The lack of systemic federal and provincial reform of funding for, and provision of pediatric healthcare services for First Nations children, and the federal government's failure to address the deficits in on-reserve resources and services, severely limits the capacity of the current CFI funding to ensure that all First Nations children can achieve health outcomes equitable to other children in Canada.

Thus, pediatric healthcare providers working with First Nations can find themselves in a landscape that continues to be characterized by fragmented healthcare funding, inadequate responses, and individual remedies. This landscape aligns with the constant pull of healthcare funding and delivery towards neoliberal and biomedical individualism that often fails to attend to how broader social and structural factors can profoundly shape children's health, development and life trajectory (Gerlach, Teachman, et al., 2017). This approach to children's health is in sharp contrast to the work of the FNHC frontline staff as described in this paper. A common thread in this work is the frequency with which staff are having to respond to, and navigate through colonial structural inequities that result in communities and/or families' lacking access to basic determinants of health such as safe drinking water and housing (Vives & Sinha, 2019; Woodgate, 2013).

Orienting towards Socially-Responsive Pediatric Healthcare

The findings in this paper point to the importance of broadening the scope of pediatric healthcare beyond a focus on an individual child's health and development to services and practices that are socially-inclusive and responsive. This transformation requires a shift in focus towards building authentic relationships with each First Nation community and family in order to learn *from* them about their everyday lives, social circumstances, resources and priorities. Allocating the time to build genuine relationships is central to avoiding the imposition of interventions and approaches that are informed by non-First Nations' perspectives and settings. This relational approach also broadens the scope of routine practices to be inclusive of, responsive to, and directed by communities and families' realities and self-identified priorities surrounding their children's health and wellbeing (Gerlach et al., 2018; Gerlach & Elliott, 2017). Unfortunately, at an organizational and system level, the reductionist tendencies of how pediatric healthcare services are structured and evaluated means that spending time building relationships to learn from a community or family about their social history, resources and circumstances are not typically prioritized or legitimized. Doing this form of relational work can also be compromised by the short-term or limited nature of current Jordan's Principle funding that does not allow healthcare professionals the time to work with communities and families in a trusted and meaningful way.

Healthcare professionals who are collaborating with First Nations on the implementation of Jordan's Principle may also experience uncertainty or moral distress as they question their agency and responsibility in orienting their care to be socially-inclusive and responsive. Central to this approach is the expectation that healthcare providers engage in a process of ongoing reflexivity and dialogue with First Nations community members and leaders (Canadian Pediatric Society, 2016; Sinha & Wong, 2015). This process can include questioning - *'What am I/we doing to build authentic relationships?' 'Is my/our service relevant and useful?' 'How have I/we sought to understand the social and historical context of this community or family?' 'How have I/we created space and mechanisms for engaging with community members and First Nations colleagues so that they can direct the work I am/we are doing?'*

Ultimately, orienting towards socially-responsive pediatric healthcare requires a fundamental structural change, in which First Nations lead, design, and deliver services. In this context, respectful, responsive and effective programs and services are predicated on close and equitable relationships between pediatric organizations and First Nations organizations in order to ensure that pediatricians, family physicians, and allied pediatric healthcare professionals are fully informed about and collaborating effectively on Jordan's Principle initiatives (Canadian Pediatric Society, 2016; Sinha & Wong, 2015). Central to this endeavor is the need for a greater investment in human resources to support the full implementation of Jordan's Principle.

Conclusion

Historically-rooted inequitable power relations, that are the hallmark of colonization, continue to endanger First Nations children's health and wellbeing with potentially lifelong consequences. This paper contributes further evidence on the need for the federal government to address the chronic underfunding of services, resources and infrastructure in First Nations communities in order to advance health equity for all First Nations children (Sangster et al., 2019). Federal reforms are also necessary to create long-term funding that adequately provides for the sustained implementation of Jordan's Principle and allow healthcare programs and services to mature and be effectively implemented. A federal and provincial response that shifts the provision of pediatric healthcare beyond a demand driven approach focused on the needs of individual children to policies that create long-term, equitable funding for First Nations communities is necessary in order to advance First Nations children's equity in health and healthcare. Finally, it is imperative that First Nations leaders and Jordan's Principle initiatives play a leading role in the design and delivery of all pediatric healthcare services with First Nations communities, families, and children in Canada.

References

Allan, B., & Smylie, J. (2015). *First peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada*. Retrieved June 5, 2015 from http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Report-First-Peoples-Second-Class-Treatment-Final.pdf

Assembly of First Nations. (2018). *Support for the long-term implementation of Jordan's Principle*.

Boyce, W. T., & Hertzman, C. (2018). Early childhood health and the life course: The state of the science and proposed research priorities. In N. Halfon, C. B. Forrest, R. M. Lerner, & E. M. Faustman (Eds.), *Handbook of life course health development* (pp. 47-93). Springer https://doi.org/10.1007/978-3-319-47143-3

Browne, A. J., Varcoe, C., Ford-Gilboe, M., Wathen, C. N., Smye, V., Jackson, B. E., Wallace, B., Pauly, B., Herbert, C., Lavoie, J., Wong, S., & Blanchet-Garneau, A. (2018). Disruption as opportunity: Impacts of an organizational health equity intervention in primary care clinics. *International Journal for Equity in Health*, *17*(154). https://doi.org/10.1186/s12939-018-0820-2

Canadian Pediatric Society. (2016). Are we doing enough? A status report on Canadian public policy and child and youth health: Jordan's Principle. http://www.cps.ca/en/status-report/jordans-principle-2016-report

First Nations Child & Family Caring Society. (2020). *Honouring Jordan River Anderson*. https://fncaringsociety.com/honouring-jordan-river-anderson

First Nations Health Consortium. (2020). *About us*. https://www.abfnhc.com/index.php/about

First Nations Information Governance Centre. (2007). *OCAP: ownership, control, access and possession*.

Gerlach, A. J., Browne, A. J., Sinha, V., & Elliott, D. (2017). Navigating structural violence with Indigenous families: The contested terrain of early childhood intervention and the child welfare system in Canada. *International Indigenous Policy Journal*, *8*(3). https://doi.org/10.18584/iipj.2017.8.3.6

Gerlach, A. J., Browne, A. J., & Suto, M. J. (2018). Relational approaches to fostering health equity for Indigenous children through early childhood intervention. *Health Sociology Review*, *27*(1), 104-119. https://doi.org/10.1080/14461242.2016.1231582

Gerlach, A. J., & Elliott, D. E. (2017). Prioritizing relationships and relational practices with families experiencing social marginalization. *Childcare Exchange November/December*, 84-89.

Gerlach, A. J., Teachman, G., Laliberte Rudman, D., Huot, S., & Aldrich, R. (2017). Expanding beyond individualism: Engaging critical perspectives on occupation. *Scandinavian Journal of Occupational Therapy*, *25*(1), 35-43.

https://doi.org/10.1080/11038128.2017.1327616

Gerlach, A. J., & Varcoe, C. (2020). Orienting child- and family-centred care towards equity. *Journal of Child Health Care*. https://doi.org/10.1177/1367493520953354

Goldblatt, P., Siegrist, J., Lundberg, O., Marinetti, C., Farrer, L., & Costongs, C. (2015). *Improving health equity through action across the life course: Summary of evidence and recommendations from the DRIVERS project. Report produced as part of the 'DRIVERS for Health Equity' project*. EuroHealthNet. Retrieved April 9, 2015 from http://health-gradient.eu/wp-content/uploads/2015/02/DRIVERS_Recommendations_rel2.pdf

Government of Canada. (2020). *Ending long-term drinking water advisories*. https://www.sac-isc.gc.ca/eng/1506514143353/1533317130660

Greenwood, M., & de Leeuw, S. (2012). Social determinants of health and the future wellbeing of Aboriginal children in Canada. *Paediatric Child Health*, *17*(7), 381-384.

Indigenous and Northern Affairs Canada. (2010). *First Nations in Alberta*. https://www.aadnc-aandc.gc.ca/eng/1100100020670/1100100020675 [Record #3343 is using a reference type undefined in this output style.]

Lukawiecki, J. (2018). Reconciling promises and reality: Clean drinking water for First Nations. The David Suzuki Foundation. https://davidsuzuki.org/science-learning-centre-article/reconciling-promises-and-reality-clean-drinking-water-for-first-nations/

Marmot, M. (2007). Achieving health equity: From root causes to fair outcomes, Commission on Social Determinants of Health. *Lancet*, *370*, 1153-1163. https://doi.org/10.1016/s0140-6736(07)61385-3

McKenzie, H. A., Varcoe, C., Browne, A. J., & Day, L. (2016). Disrupting the continuities among residential schools, the Sixties Scoop, and child welfare: An analysis of colonial and neocolonial discourses. *The International Indigenous Policy Journal*, *7*(2). https://doi.org/10.18584/iipj.2016.7.2.4

National Collaborating Centre for Determinants of Health. (2015). English glossary of essential health equity terms. http://nccdh.ca/images/uploads/comments/Glossary_EN.pdf

Pauly, B., MacDonald, M., Hancock, T., Martin, W., & Perkin, K. (2013). Reducing health inequities: The contribution of core public health services in BC. *BMC Public Health*, *13*. https://doi.org/10.1186/1471-2458-13-550

Public Health Agency of Canada. (2014). *Toward health equity: Canadian approaches to the health sector role - Protecting Canadians from illness*. Retrieved May 1, 2015 from http://en.healthnexus.ca/sites/en.healthnexus.ca/files/resources/towards-health-equity-en.pdf

Sangster, M., Vives, L., Chadwick, K., Gerlach, A. J., & Sinha, V. (2019). Advancing Jordan's Principle by realizing enhanced service coordination in the Alberta region. https://static1.squarespace.com/static/57320457ab48dea767e5e69f/t/5db34642a621353113c9ab79/1572030080205/final+report_FNHC_evaluation.pdf

Sinha, V., Vives, L., & Gerlach, A. J. (2018). Implementing Jordan's Principle service coordination in the Alberta Region: The First Nations Health Consortium. https://static1.squarespace.com/static/57320457ab48dea767e5e69f/t/5c97103eeef1a1538c20022e/1553403977185/2019-FNHC_InterimReport-WEB.pdf

Sinha, V., & Wong, S. (2015). Ensuring First Nations children's access to equitable services through Jordan's Principle: The time to act is now. *Paediatrics & Child Health 20*(2), 62-63. https://doi.org/10.1093/pch/20.2.62

Smylie, J., & Adomako, P. (2009). *Indigenous children's health report: Health assessment in action*. Centre for Research on Inner City Health. Retrieved December 18, 2010 from http://www.stmichaelshospital.com/crich/indigenous_childrens_health_report.php

Smylie, J., Fell, D., & Ohlsson, A. (2010). A review of Aboriginal infant mortality rates in Canada: Striking and persistent Aboriginal/Non-Aboriginal inequities *Canadian Journal of Public Health*, 143-148. https://doi.org/10.1007/BF03404361

Statistics Canada. (2017). *Focus on geography series, 2016 census*. https://www12.statcan.gc.ca/census-recensement/2016/as-sa/fogs-spg/Facts-PR-Eng.cfm?TOPIC=9&LANG=Eng&GK=PR&GC=48

The Canadian Bar Association. (2019). Executive summary Bill C-92, An act respecting First Nations, Inuit and Métis children, youth and families. https://www.cba.org/CMSPages/GetFile.aspx?guid=f70fcef1-519d-4da4-b316-ea326e6105b5

Truth and Reconciliation Commission of Canada. (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. http://nctr.ca/assets/reports/Final%20Reports/Executive_Summary_English_Web.pdf

Vives, L., & Sinha, V. (2019). Discrimination against First Nations children with special healthcare needs in Manitoba: The case of Pinaymootang First Nation *International Indigenous Policy Journal*, *10*(1). https://doi.org/10.18584/iipj.2019.10.1.4

Wood, D. L., & Goldhagen, J. L. (2013). Promoting child health equity: Family-centered care coordination is just one piece of the puzzle. *Pediatrics*. www.pediatrics.org/cgi/doi/10.1542/peds.2012-3248

Woodgate, R. (2013). Understanding the disability trajectory of First Nations families of children with a disability: Advancing Jordan's Principle. Retrieved August 12, 2015, from http://umanitoba.ca/faculties/nursing/research/media/Booklet_June_Summit.pdf

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Northwest Territories Residential Southern Placement Program: Dislocation and Colonization through 'Care'

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This research traces colonialism and neoliberalism as foundational architecture to health policy in Canada that seeks to erase Indigeneity and disability and secure the dominance of a White settler able-bodied state. This is accomplished through critical analysis of the Residential Southern Placement Program, a health policy from the Northwest Territories, Canada. Residential Southern Placements are contractual agreements made between the Northwest Territories Department of Health and Social Services and service agencies from southern provinces to provide care to territorial residents with a disability whose needs—according to the Department of Health and Social Services—cannot be met within the territory. We explore how the ostensibly neutral health policy Residential Southern Placements becomes enacted as a violent intervention of erasure that specifically targets Indigenous adults and children with cognitive disabilities – as evidenced through data collected by a Freedom of Information Request- through long-term and, at times, lifelong dislocation from families, communities, and land. In this analysis we position the Residential Southern Placement Program as an intervention that aims to uphold and safeguard a White settler able-bodied vision of Canadian society. This research highlights an ongoing colonial practice with important implications for disability studies and Indigenous health researchers.

Keywords: *Indigenous, colonization, trauma, disability, schooling, medical travel, dislocation, Northern, institutionalization*

Introduction

The formation and implementation of health policy cannot be separated from foundational sociopolitical contexts that govern how a policy is enacted. In Canada, the rise of neoliberalism and entrenchment of colonialism are central tenets to existing social and political architecture. These rationalities naturalize and perpetuate existing power structures and position the dominance of a White settler able-bodied State as natural and inevitable. As a result, ostensibly neutral health policies can serve to further cement the subordinate status of marginalized social groups, including Indigenous Peoples and peoples with disabilities.

In the case of health and social care, policies that appear, or are marketed as, benevolent in nature are often deployed as apparatuses of violence and oppression. Certainly, the relations between Indigenous and non-Indigenous, and able-bodied and disabled, are consistent with such policy interventions. From sterilizations to Residential Schooling to institutionalization and confinement, Indigenous and disabled bodies have similarly been positioned as the 'fortunate' recipients of benevolent State projects of education, reform, care, and rehabilitation. As interventions into the lives of Indigenous Peoples have intensified, so too has the harm and suffering of Indigenous Peoples, which has, strategically, further justified the 'help' these communities continue to require from White settler society. However, despite their benevolent branding, interventions to 'improve' the lives of disabled people and Indigenous Peoples have often translated to the violent erasure of Indigeneity and disability from a White settler, able-bodied vision of Canada.

This research explores the ways in which we can trace overarching eugenic and colonial imperatives aimed at erasing Indigeneity and disability in Canada to the enactment of a specific health policy from the Northwest Territories - the Residential Southern Placements. Residential Southern Placements are contractual agreements made between the Northwest Territories Department of Health and Social Services and service agencies from southern provinces to provide care to territorial residents with a disability whose needs—according to the Department of Health and Social Services—cannot be met within the territory. This research explores how the ostensibly neutral health policy of Residential Southern Placements becomes enacted as a violent intervention of erasure that specifically targets Indigenous Peoples[1] with cognitive disabilities[2] through long-term and, at times, lifelong dislocation from families, communities, and land. In this analysis, we position the Residential Southern Placement Program as an intervention that aims to uphold a White settler able-bodied vision of Canada and as a masked continuation of colonial projects of dislocation.

Northwest Territories Health System Background

An organizing logic of dislocation is embedded in the delivery of health and

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[1] Data retrieved from my Access to Information Request indicate that 100% of individuals in the Residential Southern Placement Program have some kind of cognitive disability and approximately 95% of residents sent south are Indigenous Peoples. Results from the Freedom of Information Request are discussed in detail in the "Results from Freedom of Information Request" section.

[2] In this paper, I adopt the terminology of "cognitive disability" as this is language utilized within the Department of Health and Social Services as it operates the Residential Southern Placement Program. In this case, cognitive disability broadly refers to a range impairment of the mind that fall under the categories of: intellectual disability, mental illness, and brain injuries, as defined by the Department of Health and Social Services (2017a).

social service programming in the Northwest Territories, including the Northwest Territories Long Term Care Program, which governs Residential Southern Placements. The Northwest Territories Long Term Care Program is a division of the Northwest Territories Department of Health and Social Services that operates to meet the needs of territorial residents whose care needs surpass what can be provided in the home environment (NWT Department of Health and Social Services, 2015a). This program delivers care to a fraction of the 45,000 territorial residents, spread across a landmass of 1.3 million square kilometers and divided into 33 communities (Moffit & Mercer, 2015). Approximately 50% of these 33 communities are remote and inaccessible by all-season road and most have a population fewer than 1,000 people (Moffit & Mercer, 2015). Wide geographic dispersal, low population size, and limited infrastructure development within communities are defining features of health-care delivery in the Northwest Territories. A centralized service model has been the predominant government response to these challenges. Within this framework, long-term care and health services are delivered through regional centres, to which residents from surrounding smaller communities must travel (Young & Chatwood, 2011). That said, the range of services offered within the territory, even in more largely populated regional centers like the territorial capital, remain highly limited (Young & Chatwood, 2011). In response to this, the Northwest Territories has established and become heavily reliant on contracted health and social care from southern provinces in Western Canada, particularly Alberta (Young & Chatwood, 2011). In this system, territorial residents are sent on medical travel from the Northwest Territories to health and social care facilities in provinces to the south where their health needs can be met. Residents with lifelong or long-term care needs that cannot be met in the Northwest Territories are those who become subject to Residential Southern Placements.

Residential Southern Placements are deployed within a context of long-term care service configuration. Since 2009, a single-entry point for all Long-Term Care services exists through a unified Territorial Admissions Committee (TAC) that reviews all applications and makes an offer of a support scheme for each applicant (Fraser, 2011). Limited information about the TAC exists publicly, however, membership on the TAC includes two representatives from Seniors and Continuing Care Services Division, a public representative who serves a two-year term, and one representative from each of the three Health and Social Services Authorities who are nominated by their CEO for a two-year term, and appointed by the Deputy Minister of Health and Social Services. With this change, region-specific health authorities were replaced by a centralized system operating out of Yellowknife. The TAC receives every application for long-term care and holds absolute authority over the provision of services to Northwest Territories residents both within the territory and in care arrangements made with out-of-territory agencies. In the decision-making pathway of the TAC, an application for long-term care is completed and received by a committee that decides whether long term care is necessary or not. If long-term care is deemed necessary, the TAC then decides where the applicant will receive support. If a suitable space—as determined only by the TAC—is available within an individual's region, they are automatically placed there. However, if no suitable space is available within the individual's region, the TAC offers the 'choice' of an alternate facility either within the territory or through a Residential Southern Placement. If the individual accepts the ‘choice’ given to them by the TAC, they gain priority access to that facility; however, if they decline this ‘choice’ they are put on the bottom of the waitlist for service in their region. Importantly, the territory only has 13 long-term care spaces within the purview of TAC are specifically for residents with cognitive disabilities. Given that these placements are virtually always full, these applicants find themselves uniformly funneled into Residential Southern Placements.

Methods

This research began with answering the ostensibly straightforward question of how people with cognitive disabilities from the Northwest Territories are sent to another province for years on end to receive care. However, after an initial investigative process, the research purpose evolved from that of quasi-investigative journalism, describing precisely *what* Residential Southern Placements are and the ways in which they are imposed, to a more critical scholarly question of *how* this policy is rationalized and enacted onto very specific bodies; namely Indigenous adults and children with cognitive disabilities.

To gather more information about the demographics of individuals subjected to Residential Southern Placements, a Freedom of Information Request (FIR) was submitted to the Access to Information and Health Privacy Officer at the Northwest Territories Department of Health and Social Service. The request was submitted on December 12, 2018 and requested data regarding the age, disability type, community of origin, and race (broken down to Indigenous or non-Indigenous status) for adult placements in the Residential Southern Placement Program. This FIR provided additional data including length of placements, contracted agencies, and contract amounts that were utilized, however, not all of which are addressed in this paper. Public government financial documents were also consulted throughout the analysis to contextualize and supplement data.

Based on the data received from the FIR request, it became clear that the overwhelming overrepresentation of Indigenous Peoples within the program demanded specific attention. This oriented the research to the position of de Leeuw et al. (2010)—originally taken with reference to the Child Welfare System in Canada—that asserts that even though health or social programs, such as the Residential Southern Placement Program, may not explicitly address Indigenous Peoples in their mandate or policies, the fact that the vast majority of individuals in the program are Indigenous means their deployment is “invariably implicitly aimed at Indigenous people” (Leeuw et al., 2010, p. 290). By acknowledging the foundational role of race in the operation of the Residential Southern Placement Program, researchers can explore how this health policy functions as an apparatus of colonialism that advances Indigenous erasure through: the reproduction and perpetuation of dislocation from land imposed onto Indigenous Peoples; disruption of natural connectedness of Indigenous Peoples through the forced separation of families and communities; and disruption of knowledge transmission that impedes the acquisition of traditional languages and cultural expression. The authors of this study come to this work with their own unique worldviews and experiences that has helped to inform this research. McKee is a white settler living with a disability who relocated from southern Ontario to the Northwest Territories as a young child and has lived there with her family ever since. Hillier is a queer mixed Mi’kmaw / settler person who grew up economically disadvantaged in a small isolated community in rural

Newfoundland whose work focuses on how system level issues impact Indigenous Peoples health.

As the data from the FIR substantially represented Indigenous Peoples, Indigenous community organizations in the Northwest Territories were approached to share and discuss the findings. During the outreach process, ten Indigenous organizations were provided with an infographic of key research findings and demographic data, and representatives from these organizations were invited to set up a time to call or meet about the results. Discussion with organizations included any questions they had regarding the research or the data uncovered, how these findings may impact their organization or the communities they represent, and what action they would like to see in response to the findings. Over the course of May and June 2019, outreach with the ten Indigenous organizations in the Northwest Territories took place. From this, a phone call with four of these organizations and an in-person meeting with one organization was coordinated, whose scope encompassed First Nation, Metis, and Inuit residents from all regions of the territory.

In addition to presenting data gathered with Indigenous organizations, there was a discussion about the ways they would like to see this information mobilized. From these conversations, additional data was requested regarding the number of children in Residential Southern Placements and a breakdown of all individuals in placements by region and First Nation, Inuit, and Metis status. These data sets were requested as a secondary FIR on May 27, 2019 to the Access to Information and Health Privacy Officer at the Northwest Territories Department of Health and Social Service. Responses to this request were received on June 28, 2019 and July 15, 2019. It was requested by the community organizations that any new data be provided to them so that they may use it as evidence in their own requests for funding or to redistribute control and autonomy over the delivery of health and social services from the Government of the Northwest Territories to Indigenous organizations. This information sharing was completed after each of the discussions.

Results

Data received through FIR indicate that 162 Northwest Territories residents are in Residential Southern Placements, as of June 2019. Of these, 56 individuals are children (<18 years of age) and 106 are adults (>18 years of age). 89% of children in Residential Southern Placements have registered Indigenous status and 90% of adults in Residential Southern Placements have registered Indigenous status, as detailed in Table 1. It should be noted that the FIR request received indicated that, “while the table demonstrates that six children/youth are non-Indigenous this should be interpreted cautiously. The siblings and/or parents of these children/youth are Indigenous. Therefore, based on the ethnicity of siblings and/or parents, some children may not have applied for their Nunavut Inuit Enrolment Card (NTI), Metis Status Card, or First Nation Status Card.” The FIR received for adult placements gave no specification on the Indigenous relations of those codified as ‘non-Indigenous’.

Table 1

Breakdown of Individuals in the Southern Residential Placement Program by Ethnicity as of June 2019

Ethnicity	**Number of Children (<18 yrs.) in Placement**	**Number of Adults (> 18yrs.) in Placement**
First Nation	35	56
Inuit	10	38
Metis	5	1
Non-Indigenous	6	11
Total	**56**	**106**

As of October 2019, data on the length of Residential Southern Placements had only been received for adult placements. Data received indicate that placements were predominantly long-term and, in some cases, lifelong. Only 15% of adult residents in placements had been outside of the territory for less than one year; 32% of adults had been in their placement for 4-10 years; and 23% had been in their placement for over 10 years, as outlined in Table 2.

Table 2

Length of Residential Southern Placement for Adults as of December 2018

Length of Placement Range	**Approximate Number of Adults in Range**	**Percentage of Adults in Range**
Less than 1 year	16	15.2%
1-2 years	10	9.5%
2-4 years	21	20.0%
4-10 years	34	32.4%
10-15 years	8	7.6%
15-20 years	14	13.5%
Greater than 20 years	2	1.9%

Review of the 2017 Request of Proposals for the Residential Southern Placement Program from the Northwest Territories Department of Health and Social Services indicate that 100% of individuals in the program had some form of cognitive disability, including intellectual disabilities, psychiatric disabilities, and brain injuries, as outlined in Table 3.

Table 3

Distribution of Residential Southern Placements by Disability Type as of 2017

Disability Category	Percentage of Placements
Intellectual disability	66%
Psychiatric disability	31%
Brain injury	3%

According to Northwest Territories Department of Finance budgets, the budget for the Residential Southern Placement Program has increased steadily, such that between 2011 and 2017, government investment in these placements increased from 16.1 million dollars to 28.5 million dollars (a 77% increase), and now accounts for over 50% of the Northwest Territories Department of Health and Social Services' total spending on residential care (NWT Department of Finance, 2017a, 2017b; NWT Department of Health and Social Services, 2013, 2014, 2015, 2016, 2017b).

Discussion

Settler Colonialism and Indigenous Elimination

Given that a majority of the Northwest Territories population (50.7%) is Indigenous, analysis of any of its health policies would be incomplete without consideration of historic and ongoing colonialism that shape the lived experiences of Indigenous Peoples and govern the social landscape where health policy operates (NWT Bureau of Statistics, 2016).

The relationship between the Canadian State and Indigenous Peoples has been, and continues to be, shaped by policy with an unchanging goal to "ensure the eventual disappearance of Indians" (Palmater, 2014, p. 27). This goal of eliminating Indigenous Peoples from what is now Canada has been enacted through the violent intervention of the State into nearly every aspect of Indigenous People's bodies, lives, communities, and lands. While this attempted erasure has taken on innumerable manifestations since initial contact between Indigenous Peoples and White settlers—from outright state-sanctioned killing through incentivized scalping of Indigenous Peoples, to involuntary sterilization, to violent and aggressive assimilative projects— the rationality driving this elimination, in all adopted methodologies, continues to fall back to the domination and ownership of land (Milloy, 2008; Palmater, 2011; Palmater, 2014). Settler colonialism is a violent enterprise of erasure that asserts the natural domination and ownership of settlers over land and resources controlled by a preceding, and still present, sovereign peoples; in essence, as described by Wolfe (2006), "settler colonialism destroys to replace" (p.388). In this formulation, Indigenous Peoples, with preceding ownership and connection to land, embody a permanent contestation towards the existing domination of the White settler State and, furthermore, an obstacle to the unobjectionable assertion of settler dominion over stolen land. Wolfe (2006) theorizes the settler response to this tension as taking on a particular form of elimination that negatively seeks to destroy Indigenous society through the dissolution of social structures, culture, and political power, and positively seeks to erect a new colonial society (i.e., the White settler state) on its stolen territory.

In Canada, the attempted elimination of Indigenous societies for the purposes of securing permanent access to Indigenous lands and resources by the settler population has arisen from violently assimilative policies and projects that seek to erase Indigeneity through "absorption into the general population" for purposes of "overcoming lingering native custom and tradition" (Duncan Campbell Scott, as cited in Palmater, 2014, p. 31). From this vantage point, the Canadian State positioned—and continues to position through the present-day enactment of historic policy—Indigenous Peoples and cultures as a threat to the actualization of the settler State. This perceived threat is neutralized by the State through heinous colonial projects that are often not advertised as such publicly, at least not explicitly. Since the enactment of the Indian Act in 1869, the violent intervention of the State into the bodies, lives, communities, and lands of Indigenous Peoples has been rationalized as social projects of benevolent transformation that aim to 'help' and 'improve' Indigenous Peoples.

Projects of Elimination in the Northwest Territories

In northern Canada, and the Northwest Territories specifically, social projects of 'improvement' often rely on a model of dislocation that necessitates the movement of Indigenous Peoples from their home communities to regional centres where care is delivered. Moreover, for people with long-term care needs, particularly those with cognitive disabilities, this dislocation of people from the Northwest Territories is intense, with placements for care outside the territory in southern provinces.

The legacy of trauma faced by people with cognitive disabilities sent south for care can be traced back to historical patterns of dislocation during the era of institutionalization. Once institutionalized in the south, northern people with cognitive disabilities faced increased barriers to remain connected with their home communities and families due to the sheer extent of physical separation, which would have required a high level of independent wealth to overcome. While families of southern people with cognitive disabilities relocated to institutions within their home province may be able, with difficulty, to save enough money to make a trip by road or rail, it is doubtful that families of northern people sent south can ever save enough money to make such a journey, considering the significant cost of transportation by plane and already high cost of living in the north (Menzies & Palys, 2006). In addition to the increased isolation and emotional devastation experienced by northern people with cognitive disabilities in general, it is also crucial to recognize that the interlocking social identity of Indigeneity would have greatly influenced the experience of southern institutionalization for Indigenous Peoples with cognitive disabilities. Upon institutionalization, Indigenous Peoples with cognitive disabilities became subjected to an additional level of segregation, surveillance, and attempted erasure through the entrenched colonialism of Canada's health system. Segregation of Indigenous persons in medical institutions was commonplace in Canada, especially western and northern Canada, into the 1960s. In Yellowknife's own hospital, where some people with cognitive disabilities were held for a time before being relocated to institutions in the provincial south, Indigenous patients were relegated to 'Indian Wards' until at least 1965 (Lux, 2016). Considering the pervasiveness of the residential school system in the Northwest Territories, with the last school closing in 1994, it is likely that at least some Indigenous Peoples living in the north with cognitive disabilities were subjected to the abovementioned process of dislocation and re-traumatization, having been forced out of their communities to attend residential schools and then, again, forced into segregate health institutions in the south. Beyond the already morbid prospects of displacement, illness, poor living conditions, and abuse faced by all people with cognitive disabilities, being institutionalized as an Indigenous person would have also been a profoundly alienating experience (Menzies & Palys, 2006). Once confined to an institution, it was not uncommon for a patient to discover that they were the only Indigenous person in their ward, or in an entire facility (Menzies & Palys, 2006). Not only would this have created a significant barrier to cultural expression and sense of belonging, but day to day social life of Indigenous residents may have also been impacted by the fact that English was very often not their first spoken language—if it was spoken at all—and, as such, basic communication was impeded (Menzies & Palys, 2006). As well, outside the walls of institutions, colonialism and medicalization interlocked in other eugenic projects, such as sexual sterilization, increasing the vulnerability of Indigenous Peoples with cognitive disabilities from the Northwest Territories housed in institutions of the south. For example, from 1969-1972 in Alberta, First Nations people accounted for 25% of patients sterilized through the Sexual Sterilization Act, despite only representing 3% of the province's population (Stote, 2012). Together, these factors contributed to an especially violent and painful experience of southern institutionalization for Indigenous Peoples from the north with cognitive disabilities, who not only faced significant geographical separation, but also cultural repression and greater levels of subjugation, isolation, and attempted erasure (Roman et al., 2009).

Importantly, this should not be understood as an issue of the past. Physical distance between families separated through southern placements continues to be an insurmountable barrier for many. This is especially true for Indigenous Peoples, given that the Northwest Territories has the second highest rate of poverty in Canada at 16.3%, and particularly for Indigenous Peoples and those in smaller and remote communities, where the rate of family poverty ranges from 22% to 50% (NWT Bureau of Statistics, 2016b). It is difficult to conceptualize the degree of isolation imposed onto northern people with cognitive disabilities, who, during this era of institutionalization, have been treated as limitlessly portable and depersonalized sites of medical management, relegated to unfamiliar lands and climates, a world away from their families and homes with no end in sight.

Residential Southern Placements and Indigenous Elimination through Dislocation

Given the legacy of dislocation imposed onto Indigenous Peoples in general, it is no surprise that the data from the FIR reveal a disproportionate number of Indigenous Peoples with cognitive disabilities being subjected to Residential Southern Placements. Despite accounting for 50.7% of the population of the territory, Indigenous residents account for at least 90% of persons placed outside of the territory for care. It is also clear that this figure is under-representative of the true proportion of individuals in Residential Southern Placements, given that at least 4% of placements outside the territory are codified 'non-Indigenous' by the Department of Health and Social Services despite a known Indigenous parent or sibling. Of the Indigenous persons in the Residential Southern Placement Program, 100% of them had some form of cognitive disability. Despite a policy that does not specifically address Indigenous Peoples or cognitive disability, it is critical to understand how almost all individuals in these placements fall into both categories. We posit that dislocation is a mechanism of erasure with shared historic and contemporary deployment onto Indigenous Peoples and persons living with cognitive disabilities in Canada.

Projects of erasure that impact people with cognitive disabilities and Indigenous Peoples in settler-colonial Canada have been similarly predicated on an overarching rationality that some persons are better served through the external management of worthy citizens with power (read as White and able-bodied). Institutionalization of people with cognitive disabilities in Canada arose from eugenic thinking that aimed to protect the nondisabled population from the threat of feeblemindedness and was legitimized through a subtext of care and medicalization of disability (Walmsley & Johnson, 2017). Through eugenic rationality, people with cognitive disabilities were viewed through a moralistic lens and positioned as sites of risk that needed to be addressed through segregation, surveillance, confinement, and management by nondisabled people and, in particular, the State. To legitimize these interventions by the State, people with cognitive disabilities had to be positioned as inherently inferior and non-autonomous objects of management; sites for improvement and transformation towards hegemonic understandings of rationality and intellectual capacity (Walmsley & Johnson, 2017). In other words, people with cognitive disabilities ought to be 'cared' for by people without disabilities, who are best suited to define and address their needs. In the Residential Southern Placement Program, this organizing logic remains embedded in a pathway of care distribution that places full autonomy with an external governing body (i.e., the TAC), to make decisions about the lives and bodies of persons with cognitive disabilities. Likewise, since contact, Indigenous Peoples and societies have been similarly characterized as inherently deviant and inferior to that of settler society. Through this logic, White settlers strategically positioned themselves as the rightful and natural trustees of Indigenous Peoples and communities and justified an array of violent and intrusive projects into the lives of Indigenous Peoples (de Leeuw et al., 2010, p. 290). Not unlike the interventions aimed at persons with cognitive disabilities, colonial projects including Residential Schooling and the Sixties Scoop that aimed to erase Indigeneity, have similarly organized around dislocation from family and community.

Dislocation is central to the functioning of the Residential Southern Placement Program. In this program, Indigenous Peoples with cognitive disabilities find themselves subjected to displacement from their families, communities, and land for extended periods of time. As indicated from FIR, these placements are by no means short-term and, for most adults, last from years to a lifetime. As such, it is helpful to understand the Residential Southern Placement Program as a current iteration of a colonial legacy of dislocation for the purposes of elimination, that operates under a guise of 'caring for' Indigenous Peoples through medicalization. In what has been described by some scholars as "medical colonialism", Western medical practices and conceptions of health are deployed and imposed onto Indigenous bodies in ways that undermine the integrity of Indigenous communities by disrupting traditional Indigenous social structures and ways of knowing through enforced assimilation and acquiescence to Western systems (Brown et al., 2012, p. 45). This is especially pronounced in the enforcement of Western medical interventions and by making basic medical care contingent on dislocation of Indigenous Peoples from their home communities. The fact that many Indigenous Peoples, particularly Indigenous Peoples living outside urban centres and especially those in northern communities, face a dilemma in health care access that forces them to choose between accessing care or staying in their home communities, is well supported in existing scholarship (see, for example: Allan & Smylie, 2015; Anderson et al., 2008; Czyzewski, 2006; Kolewaski et al., 2010; Martens, 2000; Moffit & Vollman, 2006; Reading & Wien, 2013; Salvalaggio & Miore, 2003). The disconnection that comes from Indigenous Peoples' need to relocate for access to health care engenders intense loneliness, isolation, alienation, and negative mental and physical health outcomes (Allan & Smylie, 2015; Auger, 2016; Kolewaski et al., 2010; Salvalaggio & Miore, 2003; Moffit & Vollman, 2006). In addition to the devastating impact this has on an individual level, separation from one's land, family, and community also have important implications for Indigenous societies, where fractured families and communities disrupt the intergenerational and lateral transmission of cultural knowledge, language, and identity formation (Reading & Wied, 2009). Of particular relevance to this paper is specific research identifying that Indigenous Peoples with cognitive disabilities dislocated for the purpose of accessing care are more highly represented in large institutional-like settings, less likely to return to their home communities, and have systemic challenges accessing and engaging with Indigenous language, culture, and community while living in residential settings (Auger, 2016; Rossow-Kimball et al., 2017). This is perhaps best captured through the words of Indigenous Peoples themselves, such as those of a 'Na̲mg̲is participant in a Brown et al.'s (2012) study of dispossession and health equity, who stated that living away from home territories has the impact of "undermining sacred connections that nourish the relationship between one and another" (p. 55). Where land is the lifeblood of culture and connectedness for Indigenous societies, dislocation serves as a direct attack on the existence of Indigenous societies, and, further, the resistance they pose to the actualization of the White settler State. By orchestrating the dislocation of Indigenous Peoples from their own land, the Canadian State engages in a violent assertion of dominance that implies White settlers have the inherent authority over this land, to choose who can go where, and erase Indigenous sovereignty and history altogether.

What also cannot be ignored is a trajectory towards further investment and dependence on placements of dislocation as a catch-all response for Indigenous adults and children living with cognitive disabilities. As evidenced in review of budgets from the Department of Finance and Department of Health and Social Services, the Government of the Northwest Territories continues to increase its spending on out-of-territory services such that the budget for out of territory placements has increased 77% in just 6 years between 2011 and 2016. A similar investment within the territory for non-institutional residential supports for persons with disabilities has been notably absent. Unrestricted and indefinite investment in southern agencies is an approach that has, and continues to, predictably lead to a continued need to move people out of the territory. Existing spending patterns indicate that this destructive system of care is only set to expand moving forward.

Conclusion

The Residential Southern Placement Program facilitates contractual care arrangements between the Government of the Northwest Territories and southern care agencies for individuals who, according to the TAC, cannot have their needs met within the territory. Placements are predominantly long-term and impose intense dislocation, literally thousands of kilometers, from one's and home community to agencies in the provincial south.

Although never naming Indigenous Peoples or persons with cognitive disabilities, available data establishes that the Northwest Territories Residential Southern Placement Program is deployed for Indigenous Peoples with cognitive disabilities at least 90% of the times it is utilized. To understand how Indigenous Peoples with cognitive disabilities became the primary target of this program, this research contextualizes Residential Southern Placements into a history of colonialism that seeks to eliminate cognitive disability and Indigeneity from a White settler, ablebodied vision of what is now Canada. This research highlights an ongoing colonial practice with important implications for disability studies and Indigenous health researchers. This research serves as a critical point of intersectional scholarship and provides a framework for disability communities and Indigenous Peoples to work in collaboration towards the redistribution of power, resources, and justice for all people that call the Northwest Territories home.

References

Allan, B. & Smylie, J. (2015). First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Toronto, ON: the Wellesley Institute.

Anderson, K., Yeates, K., Cunningham, J., Devitt, J., & Cass, A. (2009). They really want to go back home, they hate it here: The importance of place in Canadian health professionals' views on the barriers facing Aboriginal patients accessing kidney transplants. *Health & Place, 15,* 390-393. https://doi:10.1016/j.healthplace.2008.03.002

Auger, M. D. (2016). Cultural continuity as a determinant of Indigenous people's health: A metasynthesis of qualitative research in Canada and the United States. *The International Indigenous Policy Journal, 7*(4). https://doi:10.18584/iipj.2016.7.4.3

Brown, H. J., McPherson, G., Peterson, R., Newman, V., & Cranmer, B. (2012). Our land, our language: Connecting dispossession and health equity in an Indigenous context. *Canadian Journal of Nursing Research, 44*(2), 44-63.

Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *The International Indigenous Policy Journal, 2*(1), 1-14. https://doi:10.18584/iipj.2011.2.1.5

de Leeuw, S., Greenwood, M., & Cameron, E. (2010). Deviant constructions: How governments preserve colonial narratives of addictions and poor mental health to intervene into the lives of Indigenous children and families in Canada. *International Journal of Mental Health and Addictions, 8*, 282-295. https://doi:10.1007/s11469-009-9225-1

Fraser, S. (2011). *Northwest Territories health programs and services-2011 Department of Health and Social Services*. Report Prepared for Office of the Auditor General of Canada. Ottawa, Canada. https://www.fin.gov.nt.ca/sites/hss/fin/files/2017-18_budget_address_final_pdf.pf

Kolewaski, C. D., Paterson, M. L., Yeates, K. E. (2010). Relocation from the Mushkegowuk Territory for hemodialysis: The Cree illness experience and perceived quality of life. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health, 8*(3), 103-150.

Lux, M. K. (2016). Making Indian hospitals. In *Separate beds: A history of Indian hospitals in Canada, 1920s-1980s* (pp. 19-47). Toronto, ON: University of Toronto Press. https://doi.org/10.3138/9781442663114-004

Martens, C. (2000). Intellectual disability and Aboriginal people: An overview of current practice and process in institutionalization [Graduate thesis, University of Manitoba]. http://www.collectionscanada.gc.ca/obj/s4/f2/dsk1/tape3/PQDD_0022/MQ51760.pdf

Menzies, R., & Palys, T. (2006). Turbulent spirits: Aboriginal patients in the British Columbia psychiatric system, 1879-1950. In J. E. Morgan & D. Wright (Eds.), *Mental health and Canadian society: Historical perspectives* (pp. 149-175). Montreal, Quebec: McGill-University Press.

Milloy, J. (2008). Indian Act colonialism: A century of dishonour, 1869-1969. National Centre for First Nations Governance Website: http://fngovernance.org/ncfng_research/milloy.pdf

Moffit, P. & Mercer, A. (2015). Northwest Territories. In State of Rural Canada Report. http://sorc.crrf.ca/nwt/

Moffit, M. P., & Vollman, A. R. (2006). At what cost to health? Tlicho women's medical travel for childbirth. *Contemporary Nursing, 22*(2), 228-239. https://doi:10.5172/conu.2006.22.2.228

NWT Bureau of Statics. (2016a). Population projections. https://www.statsnwt.ca/population/community-projections/

NWT Bureau of Statistics. (2016b). Poverty indicators. https://www.statsnwt.ca/Poverty%20Indicators/index.html

NWT Department of Finance. (2017a). *Budget main estimates: 2017-2018*. https://www.fin.gov.nt.ca/sites/fin/files/2017-2018_main_estimates.pdf

NWT Department of Finance. (2017b). Annual business plan 2018-2019 Health and Social Services. https://www.fin.gov.nt.ca/sites/fin/files/2018-19_annual_business_plans_for_website.pdf

NWT Department of Health and Social Services. (2013). *Measuring success and focusing on results: NWT Health and Social Services System 2011-2012 Annual Report*. https://www.hss.gov.nt.ca/sites/hss/files/2011-2012-annual-report-measuring-success-and-focusing-results.pdf

NWT Department of Health and Social Services. (2014). *Measuring success and focusing on results: NWT Health and Social Services System 2012-2013 Annual Report*. https://www.assembly.gov.nt.ca/sites/default/files/td_42-175.pdf

NWT Health and Social Services. (2015a). *Northwest Territories long-term care program review: Final report*. https://www.hss.gov.nt.ca/sites/hss/files/nwt-long-term-care-program-review.pdf

NWT Department of Health and Social Services. (2015b). *Measuring success and focusing on results: NWT Health and Social Services System 2013-2014 Annual Report*. https://www.hss.gov.nt.ca/sites/hss/files

/2013-2014-annual-report-measuring-success-and-focusing-results.pdf

NWT Department of Health and Social Services. (2016). *Measuring success and focusing on results: NWT Health and Social Service System 2014-2015 Annual Report*. https://www.hss.gov.nt.ca/sites/hss/files/measuring-success-focusing-results-hss-annual-report-2014-15.pdf

NWT Health and Social Services. (2017a). *Request for proposals: Non-exclusive Out of Territory (OOT) placement program—youth, adult or family services*.

NWT Department of Health and Social Services. (2017b). *Caring for our people: Strategic plan for the NWT health and social services system 2017 to 2020*. https://www.assembly.gov.nt.ca/sites/default/files/td_328-182.pdf

Palmater, P. (2011). Stretched beyond human limit: Death by poverty in First Nations. *Canadian Review of Social Policy, 65/66*, 112-127.

Palmater, P. (2014). Genocide, Indian policy, and legislated elimination of Indians in Canada. *Aboriginal Policy Studies, 3*(3), 27-54. https://doi:10.5663/aps.v3i3.22225

Reading, C., & Wien, F. (2009). Health inequalities and social determinants of Aboriginal peoples' health [Report]. https://www.ccnsa-nccah.ca/docs/determinants/RPT-HealthInequalities-Reading-Wien-EN.pdf

Roman, L.G., Brown, S., Noble, S., Wainer, R., & Young, A. E. (2009). No time for nostalgia!: Asylum-making, medicalized colonialism in British Columbia (1859-97) and artistic praxis for social transformation. *International Journal of Qualitative Studies in Education, 22*(1), 17-63. https://doi.org/10.1080/09518390802581919

Salvalaggio, G., Len, K., & Miore, B. (2003) Perspective on health: Experiences of First Nations dialysis patients relocated from remote communities for treatment. *Canadian Journal of Rural Medicine, 8*(1), 19-24.

Stote, K. (2012). The coercive sterilization of Aboriginal women in Canada. *American Indian Culture and Research Journal, 36*(3), 117-150. https://doi.org/10.17953/aicr.36.3.7280728r6479j650

Walmsley, J., & Johnson, K. (2017). Institutionalizing rural life. In K. Soldatic & K. Johnson (Eds.), *Disability and rurality: Identity, gender and belonging* (pp. 53-68). New York, NY: Routledge. https://doi.org/10.4324/9781315577340-5

Wolfe, P. (2006). Settler colonialism and the elimination of the native. *Journal of Genocide Research, 8*(4), 387-409. https://doi:10.1080/14623520601056240

Young, T. K., & Chatwood, S. (2011). Health care in the North: What Canada can learn from its circumpolar neighbours. *Canadian Medical Association Journal, 183*(2), 209-214. https://doi:10.1503/cmaj.100948

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Decolonising the HIV Care Cascade: Policy and Funding Recommendations from Indigenous Peoples Living with HIV and AIDS

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Indigenous Peoples in settler colonial nations, like Canada, continue to experience intergenerational trauma, racism, socioeconomic disadvantages, and pervasive health disparities resulting from centuries of systemic oppression. Among these, is the disproportionate burden of HIV in Indigenous Peoples in Canada, coupled with a lack of access to care and services. One method of assessing systems-level gaps is by using the framework of the HIV care cascade, which focuses attention on diagnosis of individuals, initiation of antiretroviral treatment, and achievement and maintenance of viral suppression. The cascade, as it stands today, does not yield positive outcomes for Indigenous Peoples living with HIV. In order to close existing gaps, the authors sought to decolonise the HIV care cascade by rooting it in funding and policy recommendations provided directly by Indigenous Peoples living with HIV. This research presents 29 recommendations that arose when First Nations participants living with HIV partook in traditional storytelling interviews to share their life's journey and offer suggestions for improving access to care and services. Said recommendations are to localize testing and diagnosis (while upholding confidentiality), improve access to culturally-appropriate care and services, provide targeted programming for Indigenous women and heterosexual men, and increase funding for provincial disability benefits; important steps in decolonising the HIV care cascade.

Keywords: *Indigenous, First Nations, HIV, AIDS, care cascade, policy, health equity*

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Introduction

Colonialism has a long history of violently intervening into the life of Indigenous Peoples in Canada (a collective term for those who are First Nations, Inuit, or Métis) through policies such as the *Indian Act (1985)*, the construction of residential schooling, the 60's scoop, theft of lands, the reserve system, and the overrepresentation of Indigenous Peoples in Canadian prisons (Oliver et al., 2015). Colonial policies have produced inequities across the social determinants of health tied to intergenerational trauma and a persistent lack of funding and services for Indigenous Peoples. Indigenous Peoples continue to resist the processes of colonisation all while remaining resilient to significant adversity and a continued systemic effort to eradicate them as a people. However, socioeconomic disparities are seen across every facet of health, including: heavy infectious disease burdens, significantly shortened life expectancy; diseases and death associated with cigarette smoking; illnesses and deaths linked to misuse of alcohol and other drugs; intimate partner violence; homicide and suicide; obesity, diabetes, hypertension, cardiovascular, and chronic renal disease; and diseases caused by environmental contamination (National Collaborating Centre for Aboriginal Health, 2013, p. 4). Yet another disproportionate health burden facing Indigenous Peoples of Canada and their communities is that from Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). The estimated HIV prevalence rate for Indigenous Peoples in Canada in 2016 was 362 per 100,000 population which is two times higher than in the general population (Public Health Agency of Canada, 2018). Despite Indigenous Peoples making up only 4.9% of the Canadian population (in 2016; Statistics Canada, 2017), Indigenous women accounted for 30.9% of new HIV cases in Canadian women and Indigenous men accounted for 16.3% of new HIV cases in Canadian men (in 2017; Haddad et al., 2019). However, given significant issues with HIV data collection and reporting, there is limited data on the true impact of HIV and AIDS on this population.

One way to assess gaps in current HIV care and engagement is by using the HIV care cascade, a tool that outlines the stages of care people living with HIV encounter, starting from testing and diagnosis, to initiating antiretroviral treatment, and finally, treatment adherence to maintain viral suppression (Ontario Advisory Committee on HIV/AIDS, 2017). In theory, if everyone living with HIV were able to access and engage with care at each stage of the cascade, the virus would no longer be transmitted. However, individuals can encounter barriers at each step of the cascade due to poor service access, lack of HIV education, stigma and discrimination, poverty, food insecurity, homelessness, and mental health and substance use (Hull et al., 2012), all of which are faced by Indigenous Peoples today. As a result, there is a substantial disconnect between the priorities of the HIV care cascade and the real experiences of Indigenous Peoples living with HIV (Jongbloed et al., 2019).

Concerted efforts are required to decolonise the HIV care cascade, or rather, close the health, discriminatory, and socioeconomic barriers faced by Indigenous Peoples. This large study explored the policies and funding arrangements for HIV/AIDS prevention and treatment in First Nations communities in Ontario, Canada. Particular attention was given to the origin of funding and service delivery, how health and social services are utilized, and the specific role each level of government played in the funding and delivery of services. In this research, 29 First Nations people living with HIV and AIDS in Ontario provided, through storytelling, their first-hand experiences of the pervasive effects of colonial trauma and how the intersection of racism and HIV stigma has affected their ability to seek confidential, localized, culturally-competent care. Storytelling allows for unmediated sharing of Indigenous experiences and knowledges, and is a pedagogical tool for learning about life (Iseke, 2013). Through participant stories arose a set of 29 recommendations for action at various levels of government and by First Nations communities to re-evaluate current practices of funding and service delivery and diminish Indigenous health inequities across the HIV care cascade.

Methods

This research was conducted alongside Indigenous Peoples living with HIV and followed the Tri-Council Policy Statement on research involving First Nations people, it was approved by the Ryerson University Research Ethics Board (REB 2015-343). Given the legacy of traumatic research conducted upon Indigenous Peoples, it was essential to be respectful of, and give agency to, the knowledge conveyed by participants to researchers. Therefore, this research was developed, directed, and overseen by two Indigenous HIV organisations and a comprehensive reciprocal research agreement was entered into by all parties. Twenty-nine diverse First Nations people living with HIV and AIDS who were or had been living in remote/isolated First Nations in Northern Ontario participated. Due to issues of confidentiality, interviews took place in six cities (Toronto, Thunder Bay, North Bay, and Sudbury, Hamilton, and Chatham) where participants were either now living or visiting in order to receive treatment/services. Participants identified as male (n=13), female (n=12), or Two-Spirit (n=4). The average age of participants was 48 years, with an average monthly income of $1,362 CAN. All participants identified as recipients of the Ontario Disability Support Program. Education varied across participants, with 38% (n=11) not attaining higher than grade 9, 10% (n=3) completing grade 10 or 11, 17% (n=5) completing high school, 10% (n=3) completing some college, and 24% (n=7) completing a college or university degree (for a full breakdown of participant demographics, please see [Hillier et al., in press]).

Data were obtained through the Indigenous method of storytelling (Iseke, 2013), which places oral history and ceremony at the forefront. Participants were offered tobacco as a form of consent and paid a $50 honorarium. The use of tobacco was a cultural connection to traditional medicines, which are critical to storytelling. The storytelling and re-storying process was explained to participants along with their options to withdraw at any point of the research process. Participants were asked six open-ended questions about the impact of HIV and AIDS on their lives, their access to services and treatment, and mitigating factors related to their HIV status that may have forced them to move from their northern communities to urban centres. After transcription, data were de-identified using pseudonyms (chosen by the participant or assigned by the researcher), and six undergraduate students re-storied the transcripts by removing the facilitators' questions and comments. Participants were given the ability to review and change/withdraw their completed stories upon completion of this process, no participants did so. The data were then formatted and edited by the lead author into a set of uniform first-person stories of each participant's life's journey.

Story transcripts were uploaded into the software program NVivo 2017 and coded. This process was chosen at the request of the two Indigenous HIV organisations, as to better understand, organize, and ascertain patterns in the issues facing First Nations people living with HIV and AIDS. This process uncovered 17 major themes, representing some 143 individually-coded nodes. These themes have been presented, contextualized, and discussed previously in (Hillier et al., 2020). Participants were asked to provide recommendations for improving access to services and treatment for First Nations people living with HIV and AIDS. Twenty-six participants gave recommendations, which have been collated and presented in this research paper. Prior to finalizing the list, it was sent back to participants who consented to be re-contacted by our two Indigenous research partners for feedback and approval. The recommendations each begin with ‘we’, as they represent a collective request of the individuals and partner organisations who contributed. Our aim was to capture the voices of Indigenous Peoples living with HIV and AIDS and incorporate them into a larger body of knowledge and literature to inform their overall depth. The authors of this study come to this work with their own unique worldviews and experiences that has helped to inform this research. The principal author is a queer mixed Mi’kmaw / settler person who grew up economically disadvantaged in a small isolated community in rural Newfoundland. Co-author Lavallée is an Anishinaabek Qwe registered with the Métis Nation of Ontario and served as the doctorial supervisor of this research, while Winkler is a queer settler who does community-based HIV research with a provincial HIV organisation and is currently a medical student intending to work with Indigenous Peoples.

Results

The recommendations are divided into five calls, each representing a different governing body or collective. First, there is one recommendation directed toward Indigenous Peoples living with HIV and AIDS. Second, recommendations are directed toward the federal government for the overall improvement of funding and access to HIV and AIDS treatment, care, and services amongst First Nations communities. Third and critically, recommendations are directed toward the provincial government who are responsible for many of the services and programs accessed by Indigenous Peoples living with HIV off-reserve. Fourth, recommendations are provided for First Nations communities and political organisations (i.e., Chiefs of Ontario) who can improve the conditions of their people in relation to stigma, education, and access to services within their communities. Fourth, recommendations are provided for non-Indigenous HIV and AIDS community organisations who act as a main resource for many Indigenous Peoples unable to access Indigenous-specific resources. Finally, recommendations are provided for Indigenous HIV and AIDS service organisations to help improve service delivery to their clients.

Indigenous People living with HIV and AIDS

1. We call on all Indigenous Peoples living with HIV and AIDS to seek testing, treatment, services, and programs. We call on them to continue their treatment so as to achieve and maintain an undetectable viral load.

Federal Government

2. We call upon the federal government to resolve jurisdictional confusion surrounding Indigenous HIV and AIDS funding by creating a clear policy that details its responsibility for funding HIV

and AIDS care and services for First Nations people living on reserves in Canada. This policy can take the form of a ministerial directive that will clearly provide direction to the bureaucracy regarding funding allocation to First Nations communities for delivery of programs and services related to HIV and AIDS. This will provide clear guidance so First Nations communities can understand what funding they can access and where they can access it.

3. We call on the federal government to provide sustainable and adequate funding for HIV and AIDS care, treatment, programming, and services in First Nations communities. This funding should be stable and long-term, to avoid creating unnecessary work for communities in having to apply and re-apply for funding on an annual or semi-annual basis.
4. We call on the federal government to continue its commitment to addressing the significant issues affecting Indigenous Peoples across the north including poverty, lack of education, lack of adequate housing, lack of clean drinking water, addressing youth suicide, and the continued trauma experienced by Indigenous Peoples. Without tackling such underlying issues, the incidence of negative coping mechanisms will continue to drive up the incidence of HIV and AIDS within the Indigenous population.
5. We call on the federal government to provide a funding envelope that allows access to culturally-based healing treatment for Indigenous Peoples living with HIV and AIDS. This should include funding for culturally-based programming and services that can be accessed by both Indigenous and non-Indigenous organisations.
6. We call on the federal government to provide a dedicated funding envelope for services and programming, both culturally-based and not, to meet the unique needs of Indigenous women living with HIV and AIDS. This recognizes that Indigenous women face high rates of violence by males in our society and urgently require dedicated space and services to address the high incidence rates of HIV in this sub-population.
7. We call on the federal government to provide a funding envelope for services and programming, both culturally-based and not, to meet the needs of heterosexual Indigenous males living with HIV and AIDS. HIV and AIDS affects Indigenous heterosexual males at higher rates than the general public, and most services and programming are directed toward men who have sex with men and women.
8. We call on the federal government to provide a funding envelope for HIV education in First Nations communities, with a focus on youth. We must remember that HIV prevention is a cost-saving endeavour for everyone. This funding should seek out culturally-based education programs that focus on the unique challenges and risks faced by Indigenous Peoples living in remote and non-remote communities.
9. We call on the federal government to work with provinces to increase access to HIV and sexually transmitted and blood borne infections (STBBIs) testing (including rapid and anonymous testing) along with access to specialists and treatment within First Nations communities. This should include more stringent accountability measures to ensure patient confidentiality.
10. We call on the federal government to provide a funding envelope to increase

access to harm reduction measures within First Nations communities across the north. This includes spaces like safe injection sites for individuals who use drugs.

11. We call on the federal government to do as people ask. Indigenous Peoples living with HIV and AIDS must grapple through bureaucracy to access care, treatment, programming, and services required for survival. Indigenous Peoples must be able to access the care they need in a streamlined fashion, without daunting requirements that take time, resources, and significant effort, with no guarantee that their requests will not be declined. Having a clear policy that lays out what can and cannot be funded, and where to access that funding, can assist in solving this problem.

Provincial Government

This research focused on First Nations in Ontario; however, these recommendations are applicable for other provinces and territories.

12. We call on the provincial government to increase its funding of the Ontario Disability Support Program (ODSP) for people living with HIV and AIDS. Indigenous Peoples already struggle with homelessness; many think their benefits are too little to survive on, and this leaves them facing issues that exacerbate their health problems.
13. We call on the provincial government to provide a funding envelope for provincially-funded AIDS service organisations (ASOs) to provide access to culturally-based healing treatment for Indigenous Peoples living with HIV and AIDS. This should include funding for culturally-based programming and services that can be accessed by both Indigenous and non-Indigenous organisations. This is in recognition of the fact that many, if not most, Indigenous Peoples are forced to leave their communities for off-reserve treatment by provincially funded ASOs.
14. We call on the provincial government to implement Indigenous cultural safety training for all physicians and medical care professionals within the province. This is in recognition of the treatment participants have received by provincially-mandated and supervised physicians. This recommendation supports the call by the Truth and Reconciliation Commission of Canada to create an environment where culturally appropriate medical care is the standard, whereby all people are treated with respect and their cultural beliefs are acknowledged.

Indigenous Communities and Political Organisations

15. We call on Indigenous communities and political organisations to be receptive to HIV and AIDS education and harm reduction initiatives undertaken by other levels of government and ASOs. This includes actively seeking out funding and opportunities to support such work in their communities.
16. We call on Indigenous communities and political organisations to educate members of their council and respective healthcare teams about HIV and AIDS, issues of confidentiality, stigma, and the supports or services they can provide.
17. We call on Indigenous communities and political organisations to work with their communities to address the issue of HIV and AIDS stigma within their communities. Only by breaking the cycle of stigma and rejection can we begin to eradicate HIV within our communities.
18. We call on Indigenous communities and political organisations to work with

ASOs in accepting community members back after they have passed on to the spirit world. Communities should be prepared to receive their member and allow them a dignified burial in their home.

Non-Indigenous HIV and AIDS Community Organisations

19. We call on Non-Indigenous HIV and AIDS community organisations to undertake initiatives to educate members of their staff about colonisation and the unique issues faced by Indigenous Peoples living with HIV and AIDS.
20. We call on Non-Indigenous HIV and AIDS community organisations to work with Indigenous groups and ASOs to implement culturally-based, competent programming and services for Indigenous Peoples.
21. We call on Non-Indigenous HIV and AIDS community organisations to implement culturally-based, competent programming and services for Indigenous women. This may include dedicated space and time for women's-only programming, in recognition of the disproportionate violence Indigenous women face.
22. We call on Non-Indigenous HIV and AIDS community organisations, especially those in the north, to implement programming and services for heterosexual Indigenous males. This is in recognition of the growing incidence of HIV in this group and a lack of specific resources available to them.

Indigenous HIV and AIDS Organisations

23. We call on Indigenous HIV and AIDS organisations to seek funding to implement programming and services for Indigenous Peoples. This should include education about the cultural healing practices of their clients and advocating for culturally-based care in accordance with their clients' wishes.
24. We call on Indigenous HIV and AIDS organisations to implement culturally relevant and competent HIV education in First Nations communities and urban areas with a particular focus on Indigenous youth.
25. We call on Indigenous HIV and AIDS organisations to implement culturally relevant and competent HIV harm reduction practices that can be deployed in remote or hard to access First Nations communities alongside urban centres.
26. We call on Indigenous HIV and AIDS organisations to partner with non-Indigenous ASOs to assist in the implementation of culturally-based, competent programming and services for Indigenous People.
27. We call on Indigenous HIV and AIDS organisations to ensure targeted programming and services for women. This may include dedicated space and time for women's-only programming, in recognition of the disproportionate violence Indigenous women face.
28. We call on Indigenous HIV and AIDS organisations to ensure targeted programming and services for heterosexual males, especially in the north. This is in recognition of the growing incidence of HIV in this group and a lack of specific resources available to them.
29. We call on Indigenous HIV and AIDS organisations to work with First Nations communities to assist them in receiving their [deceased] members for burial.

Limitations

A number of limitations are reflected in this research study. Given the timeframe and availability of resources, it was only possible to conduct storytelling interviews with 29 participants. However, given the target population, the authors believe this was an appropriate sample size to produce the robust recommendations included in this research study.

There were community engagement issues throughout the study, which caused this study to go three years over its anticipated duration. Both community agencies experienced significant staff changes and internal governance challenges throughout, which had a significant impact at the start of the research process and in being able to recruit participants. The loss of multiple executive directors from both organisations was overcome by continued engagement with the new executive directors or the organisation's board of directors.

Discussion

Decolonising the HIV Care Cascade

Recommendations related to Indigenous Peoples are often presented as an act of reconciliation, or a new way forward. The authors reject this approach due to the problematic implication that Indigenous Peoples were once whole, experienced a rift, and can, through reconciliation efforts, become whole again (Stanton, 2011). Indigenous Peoples were never approached as equals, and instead, systematically oppressed, marginalized, and silenced by settler colonialism. This has produced widespread health and socioeconomic inequities and continues to contribute to the disproportionate HIV burden facing Indigenous Peoples. Despite this, Indigenous Peoples have demonstrated persistent strength and resilience in the face of adversity. In their interviews, participants shared a desire to create a better life for younger people and others living with HIV, which can only be achieved with new policy and funding efforts. The recommendations in this paper, rooted in Indigenous voices, address the inequities faced by Indigenous Peoples living with HIV when seeking confidential testing and diagnosis, sustaining access to antiretroviral treatment, and maintaining viral suppression.

Uptake of Testing and Diagnosis

Decolonising the HIV care cascade must begin with localized rapid diagnostic testing in Northern and remote communities and increased cultural competency towards Indigenous Peoples in urban testing centres. Participants recommended "increased access to HIV and sexually transmitted and blood borne infections (STBBIs) testing (including rapid and anonymous testing) along with access to specialists and treatment within First Nations communities." Indeed, the largest cohort study of people living with HIV in Ontario placed Indigenous participants at a higher risk for very late diagnosis compared to other populations and concluded that an unmet need is access to HIV testing (Wilton et al., 2019). This recommendation also emphasizes the "stringent accountability measures to ensure patient confidentiality", as a lack of anonymity in communities is a barrier to testing and diagnosis. Concerns around confidentiality and discrimination towards one's status have been documented in other Canadian research (Woodgate et al., 2017), ultimately pushing Indigenous Peoples living with HIV out of their communities for care. In order to combat the stigma and discrimination experienced within communities, HIV education for "members of their council and respective health care teams about HIV and AIDS, issues of confidentiality, stigma, and the supports or services they can provide" is required alongside a "funding envelope for HIV education in First Nations communities with a focus on youth." This can be achieved by empowering and supporting peer educators, as demonstrated in the Taking Action II study, where eighteen Indigenous youth leaders from across Canada shared their stories and promoted change by facilitating peer-led, community arts-based programs and sexual health outreach initiatives (Monchalin et al., 2016).

Access to Treatment and Services

Following testing and diagnosis, people living with HIV require continuous, reliable treatment and care. As recommended, funding for treatment should be stable and long-term so there is no "unnecessary work for communities in having to apply and re-apply for funding on an annual or semi-annual basis." Indigenous Peoples being treated outside their community should have access to safe, culturally-competent care. These recommendations call for the "implementation of Indigenous cultural sensitivity training for all physicians and medical care professionals" as well as "culturally-based and competent programming and services" at all Indigenous and non-Indigenous HIV and AIDS organisations. Indigenous medicine differs from Western medicine, extending beyond the physical domain to a wholistic (cultural, spiritual) approach grounded in knowledge, belief, and ceremonies. The Western health care system is not always prepared to provide these comprehensive services (Lewis & Myhra, 2018). However, mounting evidence suggests that the integration of Western medicine and traditional medicine is feasible both in communities and larger, urban centres. Traditional medicine has been successfully integrated in a Northern community health centre on Manitoulin Island (Manitowabe & Shawande, 2013), in a rural hospital in Sioux Lookout, where an Elders advisory council provides governance and decision-making around culturally-safe palliative care treatment (Pierre-Hansen et al., 2010), and an urban primary care clinic in British Columbia, where a culturally-informed, chronic care model for HIV patients has reduced all-cause mortality rates (Klakowicz et al., 2016).

Targeted programming is required for "heterosexual males, especially across the north. This is in recognition of their growing incidence of HIV in this group and a lack of resources available to them." In a recent analysis of a large cohort of people living with HIV, compared to gay and bisexual men, heterosexual men were more likely to have lower socioeconomic status, a history of injection drug use, greater incidence of Hepatitis C co-infection, and to be Indigenous (Wheeler et al., 2017). Efforts should be made by Indigenous and non-Indigenous service organisations to create programming directed at heterosexual men (in addition to the programming that exists for men who have sex with men or women).

Indigenous women living with HIV should have "dedicated space and time for women's-only programming, in recognition of the disproportionate violence Indigenous women face." A history of colonial abuse has left Indigenous women living in poverty and often disconnected from their family and communities (Varcoe & Dick, 2008). Analysis of a cohort of 1,425 women living with HIV found that Indigenous women had higher adjusted odds for a lack of access and delayed access to HIV care (Kronfli et al., 2017). Disproportionate rates of HIV, violence, and involvement in sex work maintain the case that Indigenous women require specific, culturally-safe programming where they feel empowered to access care.

Achieving and Maintaining Viral Suppression

Recommendations call on Indigenous Peoples living with HIV "to continue their treatment so as to achieve and maintain an undetectable viral load." Medication adherence can only be maintained with sustained access to antiretroviral therapy and consistent funding for medications. Therefore, these recommendations call on the provincial government to "increase its funding of the Ontario Disability Support Program (ODSP) for people living with HIV and AIDS." Adherence remains a challenge for those facing precarious housing and addictions issues. As ODSP has only recently extended support to those facing addictions (in the last decade), this recommendation goes hand in hand with "increase[d] access to harm reduction measures within First Nations communities across the north. This includes having spaces such as safe injection sites for individuals to access." Access to programs like Maximally-Assisted Therapy (MAT), an interdisciplinary care intervention for HIV-positive individuals with a history of addictions and homelessness, has been associated with optimal medication adherence amongst Indigenous participants (Barker et al., 2018) and should be implemented wherever possible.

Unfortunately, as the recommendations highlight, adherence can be complicated by any of the significant issues affecting Indigenous Peoples across the north including:

> "poverty, lack of education, lack of adequate housing, lack of clean drinking water, addressing youth suicide, and the continued trauma experienced by Indigenous Peoples. Without tackling [these] underlying issues, the incidence of negative coping mechanisms will continue to drive up the incidence of HIV and AIDS within the Indigenous population."

Coupled with the racism, stigma, and discrimination faced by Indigenous Peoples living with HIV, the barriers to maintaining adherence are numerous and require support from all parties outlined in our recommendations. Although Indigenous Peoples display a tremendous amount of resilience in the face of adversity, federal and provincial governments must address the widespread socioeconomic disparities, rooted in colonialism, that persist today. Indigenous communities and Indigenous HIV and AIDS organisations should work hand in hand to ensure communities are educated about HIV and that Indigenous Peoples living with HIV are accepted and have access to treatment. These recommendations also provide a call to action for non-Indigenous HIV organisations to ensure staff are educated about colonisation and trained to provide culturally-competent services. Without changes to policy, funding, community support, and access to culturally-safe services and care, HIV transmission and progression will continue to affect Indigenous Peoples disproportionately, reinforcing the gaps in the HIV care cascade.

Conclusion

This set of recommendations acts as a resurgence of Indigenous voices to claim agency over the funding, cultural competency, and support needed to achieve wholistic well-being and engage in all levels of the HIV care cascade. Resurgence is a way to restore and regenerate Indigenous nationhood (Snelgrove et al., 2014). As such, these recommendations are a tangible collection of principles to stimulate and actualize said nationhood. Due to the colonialism that permeates Canadian society, these recommendations alone cannot impact change; the funding and support of government bodies, Indigenous leaders, Indigenous and non-Indigenous HIV and AIDS organisations is required across all provinces and territories. This is a call to action to create and sustain equitable access for Indigenous Peoples living with HIV; closing the gaps in the Indigenous HIV care cascade.

References

Barker, B., Adams, E., Wood, E., Kerr, T., DeBeck, K., Dong, H., ... & Milloy, M. J. (2019). Engagement in Maximally-Assisted Therapy and Adherence to Antiretroviral Therapy Among a Cohort of Indigenous People Who Use Illicit Drugs. *AIDS and Behavior*, *23*(5), 1258-1266. https://doi.org/10.1007/s10461-018-2226-y

Haddad, N., Robert, A., Weeks, A., Popovic, N., Siu, W., & Archibald, C. (2019). HIV: HIV in Canada—Surveillance Report, 2018. *Canada Communicable Disease Report*, *45*(12), 304. https://doi.org/10.14745/ccdr.v45i12a01

Hillier, S., Winkler, E., & Lavallée, L. (in press). Colonisation, Suicide, and Resilience: Storying with First Nations people living with HIV and AIDS. *Journal of Indigenous Wellbeing: Te Mauri – Pimatisiwin, 6(1)*.

Hillier, S., Winkler, E., Lavallée, L.F. (2020) Barriers to Accessing Care and Services: Consequences for Indigenous Peoples living with HIV and AIDS in a Settler Colonial State [Manuscript submitted for publication].

Hull, M. W., Wu, Z., & Montaner, J. S. (2012). Optimizing the engagement of care cascade: a critical step to maximize the impact of HIV treatment as prevention. *Current Opinion in HIV and AIDS*, *7*(6), 579-586. https://doi.org/10.1097/COH.0b013e3283590617

Iseke, J. (2013). Indigenous storytelling as research. *International Review of Qualitative Research, 6*(4), 559-577. https://doi.org/10.1525/irqr.2013.6.4.559

Jongbloed, K., Pooyak, S., Sharma, R., Mackie, J., Pearce, M. E., Laliberte, N., ... & Spittal, P. M. (2019). Experiences of the HIV Cascade of Care Among Indigenous Peoples: A Systematic Review. *AIDS and Behavior*, *23*(4), 984-1003. https://doi.org/10.1007/s10461-018-2372-2

Klakowicz, P., Zhang, W., Colley, G., Moore, D., & Tu, D. (2016). Declining mortality among HIV-positive indigenous people at a Vancouver indigenous-focused urban-core health care centre. *Canadian Family Physician*, *62*(6), e319-e325. ISSN: 1715-5258

Kronfli, N., Lacombe-Duncan, A., Wang, Y., de Pokomandy, A., Kaida, A., Logie, C., ... & Pick, N. (2017). Access and engagement in HIV care among a national cohort of women living with HIV in Canada. *AIDS Care*, *29*(10), 1235-1242. https://doi.org/10.1080/09540121.2017.1338658

Lewis, M. E., & Myhra, L. L. (2018). Integrated care with Indigenous populations: considering the role of health care systems in health disparities. *Journal of Health Care for the Poor and Underserved*, *29*(3), 1083-1107. https://doi.org/10.1353/hpu.2018.0081

Manitowabi, D., & Shawande, M. (2013). Negotiating the clinical integration of traditional Aboriginal medicine at Noojmowin Teg. *The Canadian Journal of Native Studies*, *33*(1), 97. ISSN: 0715-3244

Monchalin, R., Flicker, S., Wilson, C., Prentice, T., Oliver, V., Jackson, R., ... & Restoule, J. P. (2016). "When you follow your heart, you provide that path for others": Indigenous Models of

Youth Leadership in HIV Prevention. *International Journal of Indigenous Health*, *11*(1), 135-158. https://doi.org/10.18357/ijih111201616012

National Collaborating Centre for Aboriginal Health. (2013). *An Overview of Aboriginal Health in Canada*. https://www.ccnsa-nccah.ca/docs/context/FS-OverviewAbororiginalHealth-EN.pdf

Oliver, V., Flicker, S., Danforth, J., Konsmo, E., Wilson, C., Jackson, R., . . . Mitchell, C. (2015). 'Women are supposed to be the leaders': intersections of gender, race and colonisation in HIV prevention with Indigenous young people. *Culture, Health & Sexuality*, *17*(7), 906-919. https://doi.org/10.1080/13691058.2015.1009170

Ontario Advisory Committee on HIV/AIDS. (2017). *HIV/AIDS Strategy to 2026: Focusing Our Efforts – Changing the Course of the HIV Prevention, Engagement and Care Cascade in Ontario*. http://www.health.gov.on.ca/en/pro/programs/hivaids/docs/oach_strategy_2026.pdf

Pierre-Hansen, N. S., Kelly, L., Linkewich, B., Cromarty, H., & Walker, R. (2010). Translating research into practice: developing cross-cultural First Nations palliative care. *Journal of Palliative Care*, *26*(1), 41-46. https://doi.org/10.1177/082585971002600109

Public Health Agency of Canada. (2018). *Summary: Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2016*. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90.html

Snelgrove, C., Kaur Dhamoon, R., & Corntassel, J. (2014). Unsettling settler colonialism: The discourse and politics of settlers, and solidarity with Indigenous nations. *Decolonization: Indigeneity, Education & Society*, *3*(2), 1-32.

Stanton, K. (2011). Canada's Truth and Reconciliation Commission: Settling the Past? *The International Indigenous Policy Journal*, *2*(3). https://doi.org/10.18584/iipj.2011.2.3.2

Statistics Canada. (2017). *Aboriginal peoples in Canada: Key results from the 2016 census*. https://www150.statcan.gc.ca/n1/en/daily-quotidien/171025/dq171025a-eng.pdf?st=YMj1XzRU

Varcoe, C., & Dick, S. (2008). The Intersecting Risks of Violence and HIV for Rural Aboriginal Women in a Neo-Colonial Canadian Context. *Journal of Aboriginal Health*, 42-52. https://doi.org/10.18357/ijih41200812314

Wheeler, K. M., Antoniou, T., Gardner, S., Light, L., Grewal, R., Globerman, J., ... & OHTN Cohort Study Team. (2017). Sociodemographic and health profile of heterosexual men living with HIV in Ontario, Canada. *American Journal of Men's Health*, *11*(4), 855-862. https://doi.org/10.1177/1557988317696639

Wilton, J., Light, L., Gardner, S., Rachlis, B., Conway, T., Cooper, C., ... & Murray, J. (2019). Late diagnosis, delayed presentation and late presentation among persons enrolled in a clinical HIV cohort in Ontario, Canada (1999–2013). *HIV Medicine*, *20*(2), 110-120. https://doi.org/10.1111/hiv.12686

Woodgate, R. L., Zurba, M., Tennent, P., Cochrane, C., Payne, M., & Mignone, J. (2017). “People try and label me as someone I'm not”: The social ecology of Indigenous people living with HIV, stigma, and discrimination in Manitoba, Canada. *Social Science & Medicine*, *194*, 17-24. https://doi.org/10.1016/j.socscimed.2017.10.002

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Governmental Fiduciary Failure in Indigenous Environmental Health Justice: The Case of Pictou Landing First Nation

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From 1967 until 2020, Pictou Landing First Nation (PLFN) has had 85 million litres of pulp and paper mill effluent dumped every day into an estuary that borders the community. A federal government appointed Joint Environmental Health Monitoring Committee, mandated to oversee the health of the community, has never addressed PLFN concerns about cancer in the community. In this study we accessed the 2013 Canadian Cancer Registry microdata file, and using the standard geographical classification code, accessed the cancer data for PLFN, and provided comparable data for all Nova Scotia First Nations, as well as the county, provincial, and national populations. We determined that digestive organ cancers, respiratory organ cancers, male genital organ cancers, and urinary tract cancers are higher in PLFN than at all comparable levels. Female breast and genital organ cancers are lowest in PLFN than at all other comparable levels. A limitation of this study was not being able to capture cancer data for off-reserve members at the time of diagnosis and the lapse in availability of up-to-date Canadian Cancer Registry data. As this study demonstrates, when governmental regulatory agencies do not fulfill their mandates, First Nations can mobilize to get the data they need. Moreover, as Indigenous scholars acquire the statistical skills to work with quantitative data to address concerns in their own and other Indigenous communities, we can achieve environmental health justice for Indigenous nations, not only in Canada, but around the world.

Keywords: *First Nation, Indigenous, health, cancer; pulp mill, environmental health justice, Cancer Registries*

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Introduction

Pictou Landing First Nation (PLFN) is a Mi'kmaw community of approximately 490 on-reserve members located on the northern shore of Nova Scotia, Canada (Indigenous and Northern Affairs Canada, 2019). Since 1967, the provincial government of Nova Scotia has allowed a pulp and paper mill to pump 85 million litres of effluent per day into a lagoon that was once a culturally significant place known as *A'se'k,* and which borders the community (Castleden et al., 2017; Lewis et al., 2016; Pictou Landing Native Women's Group et al., 2016). The women in the community were concerned about the health of their families, and in 2010, the Pictou Landing Native Women's Group (NWG) initiated a research collaboration with researchers at Dalhousie University that would help them determine whether the health of their community has been impacted. Of the many health concerns addressed by the research collaboration (see Castleden et al., 2017; Lewis et al., 2016, 2020; Pictou Landing Native Women's Group et al., 2016), the NWG were concerned about what they perceived to be an increase in the incidence of cancer in the community since 1967, possibly as a result of the effects from air emissions from the mill's stacks and exposure to the waters and sediments of the Boat Harbour Effluent Treatment Facility (BHETF) (Pictou Landing Native Women's Group, 2010). This concern has also been raised in several other public venues (Andreatta, 2013; Hoffman et al., 2015).

Investigating potential health impacts from the mill and the BHETF has been the responsibility of a Joint Environmental Health Monitoring Committee (JEHMC), comprised of representatives from Indigenous and Northern Affairs Canada (INAC), Health Canada, the Department of Justice, and Environment Canada, and representatives of PLFN. The JEHMC was structured in 1993 after PLFN sued the federal government for breach of fiduciary duty to safeguard the community members by allowing the effluent treatment facility to be built on its' shores (Lewis et al., 2020). The federal government settled for $35 million, and the PLFN *Indian Band Agreement Act (The Act),* ratified in Parliament in 1995, formalized the PLFN *Indian Band Settlement Agreement* (1993) to ensure that the Government of Canada could never be held liable for damages related to the BHETF again (Parliament of Canada, 1995). The JEHMC, established by *The Act*, has been mandated since then to establish and implement programs that would be "reasonably required to monitor the health of the band members, and the extent of environmental contamination on reserve lands and in Boat Harbour..." (Joint Environmental and Health Monitoring Committee, 1996, p. 1), but maintains that the health of PLFN has not been impacted.

In their first report in 1996, JEHMC noted that concerns of community members would be investigated by specialists in assessment of environmental health risks and would be compared to other communities (Joint Environmental and Health Monitoring Committee, 1996, p. 5). In 1997, JEHMC hired CanTox, a consulting company specializing in environmental health risks, which determined that no measurable adverse effects would occur as a result of current exposures, or the lowering of water levels in the lagoon. A future scenario which saw the effluent no longer pumped into Boat Harbour, and the return of the lagoon to a tidal estuary, "would not be expected to result in measurable adverse health effects with the exception of exposures to chlorinated dioxins and furans...but only under the assumption that PLFN residents would catch and eat fish on a daily basis from the lagoon" (Joint Environmental and Health Monitoring Committee, 1998, p. 6).

Many other studies were conducted over the years and in 2008, Dillon Consulting was hired to review all of the existing studies (*n* = 106) conducted under the auspices of JEHMC, to hold community consultations to identify concerns, and to identify the types of information that would be required to address those concerns (Joint Environmental and Health Monitoring Committee, 2015). The study concluded that a human health risk assessment was not recommended (Joint Environmental and Health Monitoring Committee, 2015).

For over 25 years, the JEHMC never gathered baseline health data in the community (Lewis et al., 2020). Had they done so, the federal government representatives on JEHMC, who have access to data held at Statistics Canada, could have compared the health outcomes in PLFN to other populations that might have signaled whether further investigation was warranted (Lewis et al., 2020). Despite the fact that health concerns were raised frequently by community members over the decades, the JEHMC has never addressed any of these concerns (Pictou Landing Native Women's Group, 2010), including those about the perceived increase in cancers. The PLFN representatives on the JEHMC seemingly have had little influence in changing that stance (Lewis et al., 2020).

It is suggested that cancer is understudied among Indigenous Peoples because there are no ethnic identifiers in the Canadian Cancer Registry (CCR) (Mazereeuw et al., 2017, 2018; Withrow et al., 2017). The Alberta First Nation Information Governance Centre (2015), Chiefs of Ontario (2016), and Institut National de Santé Publique Québec (2009) report that the lack of identifiers in the CCR leads to gaps in information, which hamper the ability of these organizations to effectively plan to reduce cancer risks and burdens in their communities.

There are, however, a few studies that have used First Nation identity to look at cancer rates. One such study linked the CCR to adults age 25 years and older from the 1991 Long Form Census who self-reported First Nation identity (reported North American Indian ancestry, reported registration under the Indian Act, and/or were a member of an Indian Band or First Nation) (Mazereeuw et al., 2018). The issue with this study, however, is that the relationship to government, and their efforts to conduct censuses, has been marked by resistance, avoidance, and suspicion on the part of Indigenous communities, mainly because of the legacy of the colonial relationship with Canada, and therefore, the likelihood of underreporting is very real (Hamilton, 2007). In the early 1990s, Statistics Canada launched three major national longitudinal surveys – the Survey of Labour and Income Dynamics (1993), the National Longitudinal Survey of Children and Youth (1994), and the National Population Health Survey (1994) (Picot et al., 2006) – that "specifically excluded First Nation people living on-reserve" (First Nations Information Governance Centre, 2019, p. 1). Further, Statistics Canada (2009) reported they continued to have issues in conducting the 1996, 2001 and 2006 census processes with some Indian reserves and settlements refusing to participate or being interrupted before the processes were complete.

One study conducted in Manitoba was able to compile a First Nation cohort to compare cancer incidence, morbidity, and survival in First Nation children versus non-First Nation children by using data from the Cancer in Young People in Canada Registry (CYPCR), a national population-based registry which tracks data using self-reported racial origin (Stammers et al., 2014). The CYPCR records if patients are First Nation, and those with formal treaty numbers are assigned to a First Nation category, while those without formal treaty numbers are assigned as Aboriginal (excluding Métis, Inuit, and mixed ancestry from the sample), both categories then making up the First Nation cohort (Stammers et al., 2014). This is an excellent method to track cancer among First Nation children and youth. Another study linked records in the Alberta cancer registry using the postal codes associated with 140 reserves and linked those to the Alberta provincial health registry, which has First Nation identifiers (Erickson et al., 2015). Postal codes boundaries, however, do not delineate along reserve boundaries, so First Nation identifiers may be capturing patients who live outside of reserve boundaries as well.

Other studies have tracked First Nation patients through the use of the Indian Registry List, the official record of persons registered as status Indians under the *Indian Act* and maintained by Indigenous and Northern Affairs Canada or the British Columbia First Nations Health authority (Decker et al., 2015, 2016; Marrett & Chaudhry, 2003; McGahan et al., 2017; Nishri et al., 2015). This is the most efficient way to extract data on registered Indians in Canada, however, the registry does not track location of status Indians and whether they are in their home reserve when a cancer diagnosis is made. Further, access to the registry is limited to INAC employees responsible for the registry, or Band employees given authority to act on behalf of the Indian Registrar (Government of Canada, 2018).

In our approach, we recognized that while it is true that the CCR does not include ethnic identifiers, and the data that we were given access to did not include patient names or street addresses, we were still able to get to the data at the First Nation level in order to assess the incidence of cancer for PLFN. This paper presents the approach we took to conduct the study that gave PLFN data on cancer for the first time, considering that the INAC representative on the JEHMC did not facilitate access to link the CCR to the Indian Registry List.

To assist the NWG, which included members sitting on the JEHMC, to determine whether their concerns were warranted, we set out to access data to determine if the empirical evidence supported the anecdotal evidence of cancer prevalence in PLFN. Moreover, the approach we took in our study demonstrates what can be accomplished when a community advocates for its' own health, despite governmental oversight, and mobilizes to engage researchers to get their questions answered. What follows is the approach that was taken in order to do so.

Methods

We accessed the 2013 CCR through the Atlantic Research Data Centre (ARDC), a member of the Canadian Research Data Centre Network (CRDCN), a partnership between 38 universities and Statistics Canada whereby each university can provide a secure laboratory setting for researchers to access confidential census, surveys, and administrative data (Canadian Research Data Centre Network, n.d.). Researchers wishing to access any of the Research Data Centres across Canada will submit a proposal to Statistics Canada. Once approved, the researcher will proceed through a federal government security clearance, sign a contract with Statistics Canada for a specific research study, take an Oath or Affirmation of Office and Secrecy, and then will be deemed an employee of Statistics Canada for the duration of the contract (Statistics Canada, 2020). A research data analyst in the centre controls the data output that is released only to the contracted researcher to ensure confidentiality is not breached. In these secure locations, detailed individual/household/business responses to surveys (microdata) is available, depending on the survey, and this level of data is significantly more detailed than publicly available aggregate data and public use microdata files (Statistics Canada, 2019).

The CCR is a patient-oriented administrative database that the Canadian Council of Cancer Registries maintains to provide data on cancer diagnoses since 1992, and to help track patients who have been diagnosed with neoplasms, or tumours (Statistics Canada, 2017b). Administered through Statistics Canada, the CCR links to each provincial and territorial CCR which tracks individual cancer patient data (Statistics Canada, 2017a). The CCR reports place of residence at diagnosis for patients (Statistics Canada, 2017c). The address is coded using the standard geographical classification (SGC), an official classification used by Statistics Canada for all addresses throughout Canada (Statistics Canada, 2017c). Each province is broken down using the SGC system into census geographic divisions, further subdivided into census geographic subdivisions. These subdivisions are defined as municipalities, or the equivalent, such as an Indian reserve or settlement (Statistics Canada, 2011).

Taking the First Nation profiles maintained by INAC, we extracted the names of each of the thirteen Nova Scotia First Nations, and each of their respective reserves, settlements, and villages (Indigenous and Northern Affairs Canada, 2019). For example, PLFN is comprised of five reserves, settlements, or villages: Boat Harbour West 37, Fisher's Grant 24, Fisher's Grant 24G, Franklin Manor No. 22 (co-owned with Paq'tnkek First Nation), and Merigomish Harbour 31 (Indigenous and Northern Affairs Canada, 2019). Of the five, only two have residents, Fisher's Grant 24 and Merigomish Harbour 31, both being assigned their own census subdivision codes. We were then able to extract data for each subdivision code. To access the data for all thirteen Nova Scotia First Nations, we did the same for each of the other twelve Nova Scotia First Nations.

Each cancer patient is given a unique number that is used throughout their registration in the CCR (Statistics Canada, 2017b). The CCR file provided through the ARDC removes the name and street address of the patient to ensure privacy. We were able to extract gender, age, SGC including census, and census subdivision, year of diagnosis, and histology for each patient record, at the PLFN, Pictou County, Nova Scotia First Nation, provincial, and national levels. The histological description of a neoplasm is coded according to the World Health Organization International Classification of Diseases for Oncology, Third Edition (ICD-O-3) (Statistics Canada, 2017b).

We have grouped human cancers sites using the International Agency for Research on Cancer (IARC) classification system, which groups human cancer sites according to digestive organ cancers, respiratory organ cancers, breast and female genitalia cancers, male genital organ cancers, urinary tract cancers (Fritz et al., 2000), cancers that were present in PLFN. Other cancer sites listed in the IARC classification system, such as lip, oral cavity and pharynx cancers, skins cancers, or thyroid and other endocrine gland cancers, were grouped into the category of 'All other cancers', as they did not occur in PLFN, or were at an incidence rate in PLFN that could not be released for use in this study for confidentiality reasons. Gender and age are not reported to protect the confidentiality of individuals in PLFN.

Relationship

The NWG is comprised of a collective of women from PLFN who approached the first author, a Mi'kmaq woman from a neighboring First Nation, who had just earned a master's degree in Resource and Environmental Management at Dalhousie University in the spring of 2010

(Lewis et al., 2016). The first author invited the fourth author, a community-based participatory researcher (CBPR) with years of experience working with other Indigenous communities on environment and health studies, to meet with the NWG to explore the possibility of a research partnership (Lewis et al., 2016). This research formed part of a multi-year CBPR project, co-led by the second author, who at the time was the President of the NWG, and the fourth author (for further details on the research partnership that ensured research was pertinent to and respectful of PLFN needs, see Castleden et al., 2017; Lewis et al., 2016, 2020; Pictou Landing Native Women's Group et al., 2016). The research received both Dalhousie University Health Sciences Research Ethics Board and the Mi'kmaq Ethics Watch approval. The latter is the Mi'kmaw Ethics Committee appointed by the Sante' Mawio'mi (Grand Council) in 1999 to establish principles and protocols to protect the integrity and cultural knowledge of the Mi'kmaq and ensures Mi'kmaq control and ownership of the data collected.

Results

The data presented in Table 1 has been taken from the 2013 CCR and compares the proportion of cancer diagnoses for the period 1992-2013 at the PLFN, Pictou County, Nova Scotia First Nation, provincial, and national levels, using the International Agency for Research on Cancer (IARC) classification system, as mentioned above. As noted in every broad category, PLFN experiences the highest rates of cancer, with the exception of breast and female genital organ cancers. Compared to all thirteen

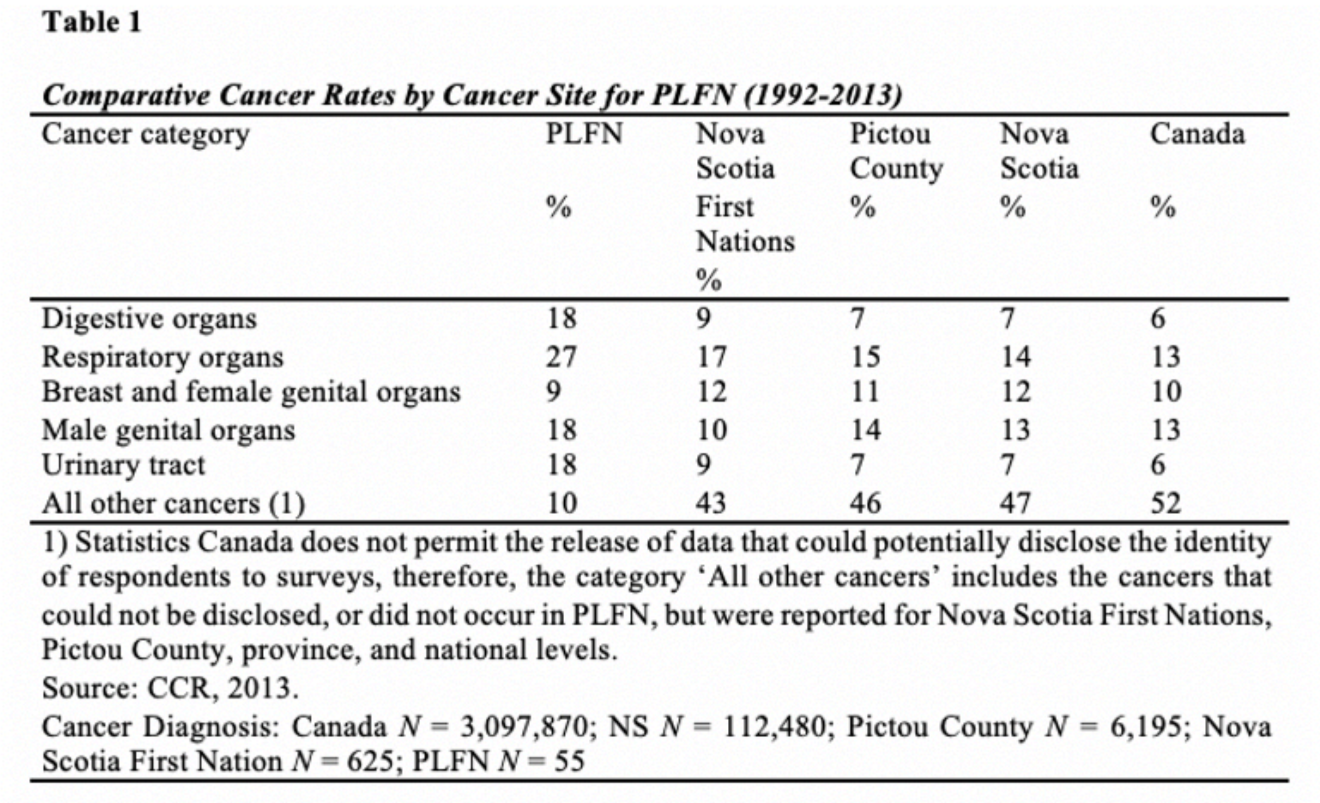

Table 1

Comparative Cancer Rates by Cancer Site for PLFN (1992-2013)

Cancer category	PLFN %	Nova Scotia First Nations %	Pictou County %	Nova Scotia %	Canada %
Digestive organs	18	9	7	7	6
Respiratory organs	27	17	15	14	13
Breast and female genital organs	9	12	11	12	10
Male genital organs	18	10	14	13	13
Urinary tract	18	9	7	7	6
All other cancers (1)	10	43	46	47	52

1) Statistics Canada does not permit the release of data that could potentially disclose the identity of respondents to surveys, therefore, the category 'All other cancers' includes the cancers that could not be disclosed, or did not occur in PLFN, but were reported for Nova Scotia First Nations, Pictou County, province, and national levels.

Source: CCR, 2013.

Cancer Diagnosis: Canada N = 3,097,870; NS N = 112,480; Pictou County N = 6,195; Nova Scotia First Nation N = 625; PLFN N = 55

Note. Adapted from https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207

Nova Scotia First Nations, with the exception of breast and female genital organ cancers, the incidence rate is eight to ten percent higher in PLFN. For digestive organ, respiratory organ, and urinary tract cancers the rates are twelve to fourteen percent higher in PLFN compared to Nova Scotia First Nations, Pictou County, provincial, and national rates. Tobias et al. (2013) note that where cancer rates in Indigenous populations were historically lower, they are now converging with the rates found in non-Indigenous populations in Canada today. This may be so for breast and female genital organ cancers and male genital organ cancers in the populations at the county, province, and national levels, where the rates tend to be converging with the rates seen in PLFN.

As we see in Table 1, digestive organ cancer rates occur at twice the rate in PLFN (18%) compared to the combined rate for all First Nations in Nova Scotia (9%), and almost triple, or triple, the rate for residents of Pictou County excluding PLFN (7%), Nova Scotia (7%), and Canada (6%). Respiratory organ cancers are 10% higher in PLFN (27%) than that for all First Nations in Nova Scotia (17%), and almost double, or double, that of Pictou County (15%), Nova Scotia (14%), and Canada (13%). Male genital organ cancer is highest in PLFN (18%), almost double that of all First Nations in Nova Scotia (10%) but is only four to five percent higher than the rates of Pictou County (14%), Nova Scotia (13%), and Canada (13%). Lastly, urinary tract cancers are at least double or more in PLFN (18%) than the rate for all First Nations in Nova Scotia (9%), Pictou County (7%), Nova Scotia (7%), and Canada (6%). Female breast and genital organ cancers, however, are 3% lower in PLFN than compared to the rate for all Nova Scotia First Nations (12%) and Nova Scotians (12%), 2% lower than the Pictou County (11%) rate, and 1% lower than the national (10%) rate. This is an unexpected finding since the NWG were certain that they were experiencing highest rates of cancer amongst their female community members (Pictou Landing Native Women's Group, 2011).

Limitations

There are several limitations to this study. Although this study analyzes data coming from PLFN for the first time, it is only capturing the data of those who were living on-reserve at the time of initial diagnosis. This does not capture those who may have lived on-reserve most of their lives but lived off-reserve for a period of time prior to diagnosis, or those who may have returned to PLFN since their diagnosis. This study is also limited by the availability of the CCR data in the ARDC at the time of data collection, which at the time was only available to 2013. Finally, unless a community has a relationship with a researcher who can be granted access to an RDC, the data is not accessible for their use.

Discussion and Conclusions

The significance of the study is that for the first time NWG were able to demonstrate that empirical evidence supported their anecdotal evidence of cancer prevalence in PLFN. The data confirmed that in every broad category where cancer diagnosis was present for PLFN, PLFN experiences the highest rates of cancer, with the unexpected finding of the lower prevalence of breast and female genital organ cancers compared to cancers specific to men. The authors (with the exception of the fifth author) presented the data to the members of the NWG first, who then instructed us to present the findings to the elected Chief and Council.

The Chief and Council instructed us to present our findings to the PLFN community as a whole. The community unanimously supported that data from 2013 to current needs to be collected. Since we have completed the research, the Canadian Research Data Centre Network (CRDCN) (n.d.) announced in May 2019 that the CCR data is now available up to 2016.

As noted earlier, and as a follow up to this initial study, data from the CCR must be linked to the Indian Registry List in order to give PLFN as thorough a record as possible of all registered members of the community, to determine cancer incidence of those who, at one time or another, may have lived in the community and have moved away. Using the SGCs gives only a partial picture. The JEHMC is mandated to establish and implement programs that would be "reasonably required to monitor the health of the band members" (Joint Environmental and Health Monitoring Committee, 1996, p. 1). The Indian Registry List already exists and sits within Indigenous Services Canada (formerly INAC). Access to this list would enable researchers to link the identity of registered PLFN band members to those in the CCR.

Statistics Canada data is available and accessible to government (Canadian Research Data Centre Network, n.d). Had the JEHMC adequately fulfilled its mandate, the research data that we were able to provide to the community, although not a complete picture of cancer incidence amongst registered community members, could have been achieved two decades ago, long before this study was conducted. Environmental health regulatory bodies like the JEHMC need to address health concerns voiced by First Nation and other Indigenous communities, especially serious concerns like cancer when data is readily available to make an assessment. The community believed there to be concern and our study validated them. These findings signal that more in-depth cancer studies are warranted. The PLFN can now decide what next steps it needs to take in their research efforts and health priorities.

This study demonstrates that if Indigenous Peoples believe that governmental regulatory agencies are not fulfilling their mandates, they can still acquire the data they need, even if the data tells only a portion of the story. It is empirical evidence that may change a narrative, by supporting Indigenous efforts for healthy equity and justice. As more and more Indigenous scholars are trained in the quantitative skills to work with data that is stored in government-controlled repositories, Indigenous Peoples can start to utilize the data in the ways that directly benefit community health and wellness. Sadly, this is the shocking reality of how Indigenous Peoples, the first peoples of Canada, are treated like 'second class citizens' (Allan & Smylie, 2015). If, as the United Nations Special Rapporteur on the Rights of Indigenous Peoples notes, Indigenous Peoples around the world lack access to reliable data to understand "how they are faring", this is directly related to the "weakness of governments" to implement decisions that would enable them to do so (Kukutai & Taylor, 2016, p. xxi).

We hope that government-controlled narratives like the one endured by PLFN are challenged. In doing so, environmental health justice for Indigenous communities can be achieved. We close by stating that Indigenous Peoples must advocate for easier access to data held by government, like that of the CCR, especially where regulatory bodies like the JEHMC are ostensibly unable to do so. The NWG have always been guided by the desire that what happened to their community should never happen to another Indigenous community again. While the results of our analysis show disturbing high rates of cancer, which would be scary for any community, if there is some benefit from the work that we have undertaken together to demonstrate how to access and use existing government data, then the NWG wants their story to be told.

References

Alberta First Nation Information Governance Centre. (2015). *Alberta baseline assessment report*. http://www.afnigc.ca/main/includes/media/pdf/digital%20reports/Alberta%20Baseline%20Assessment%20Report.pdf

Allan, B., & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous Peoples in Canada, Discussion Paper*. Wellesley Institute. https://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf/

Andreatta D. (2013, September). In Nova Scotia town, residents fight local mills pollution. *The Globe and Mail*. https://www.theglobeandmail.com/news/national/in-nova-scotia-town-residents-fight-local-mills-pollution/article14324606/

Canadian Research Data Centre Network. (n.d). *About the CRDCN*. https://crdcn.org/about-crdcn/

Castleden, H., Bennett, E., Pictou Landing Native Women's Group, Lewis, D., & Martin, D. (2017). "Put it near the Indians": Indigenous perspectives on pulp mill contaminants in their traditional territories (PLFN, Canada). *Progress in Community Health Partnerships: Research, Education, and Action*, *11*(1), 25-33. https://doi.org/10.1353/cpr.2017.0004

Chiefs of Ontario, Cancer Care Ontario. (2016). *Cancer in First Nations in Ontario: Risk factors and screening*. https://www.cancercareontario.ca/en/statistical-reports/cancer-first-nations-ontario-risk-factors-and-screening-report/

Decker, K. M., Demers, A. A., Kliewer, E. V., Biswanger, N., Musto, G., Elias, B., Griffith, J., & Turner, D. (2015). Pap test use and cervical cancer incidence in First Nations women living in Manitoba. *Cancer Prevention Research*, *8*(1), 49-55. https://doi.org/10.1158/1940-6207.CAPR-14-0277

Decker, K. M., Kliewer, E. V., Demers, A. A., Fradette, K., Biswanger, N., Musto, G., Elias, B., & Turner, D. (2016). Cancer incidence, mortality, and stage at diagnosis in First Nations living in Manitoba. *Current Oncology*, *23*(4), 225. https://doi.org/10.3747/co.23.2906

Erickson, B., Biron, V. L., Zhang, H., Seikaly, H., & Côté, D. W. (2015). Survival outcomes of First Nations patients with oral cavity squamous cell carcinoma (Poliquin 2014). *Journal of Otolaryngology-Head & Neck Surgery*, *44*(1), 4. https://doi.org/10.1186/s40463-015-0056-8

First Nations Information Governance Centre. (2020). *First Nations Regional Health Survey (RHS) 2008/10: National report on adults, youth and children living in First Nations communities*. https://fnigc.inlibro.net/cgi-bin/koha/opac-retrieve-file.pl?id=ccd66b67e9debb2c92f4a54703e1d050

Fritz, A., Percy, C., Jack, A., Shanmugaratnam, K., Sobin, L., Parkin, D. M., & Whelan, S. (Eds.). (2000). *International classification of diseases for oncology* (3rd ed.). World Health Organization. https://apps.who.int/iris/handle/10665/42344/

Government of Canada. (2020). *How to update the Indian Register?* https://www.aadnc-aandc.gc.ca/eng/1100100032475/1100100032476/

Hamilton, M. (2007). “Anyone not on the list might as well be dead”: Aboriginal Peoples and the censuses of Canada, 1851–1916. *Journal of the Canadian Historical Association/Revue de la Société historique du Canada*, *18*(1), 57-79. https://doi.org/10.7202/018254ar

Hoffman, E., Bernier, M., Blotnicky, B., Golden, P. G., Janes, J., Kader, A., Kovacs-Da Costa, R., Pettipas, S., Vermeulen, S., & Walker, T. R. (2015). Assessment of public perception and environmental compliance at a pulp and paper facility: a Canadian case study. *Environmental Monitoring and Assessment*, *187*(12), 766. https://doi.org/10.1007/s10661-015-4985-5

Indigenous and Northern Affairs Canada. (2020). *Welcome to First Nation profiles*. https://fnp-ppn.aadnc-aandc.gc.ca/fnp/Main/index.aspx?lang=eng

Institut National de Santé Publique Québec. (2009). *Cancer among Aboriginal people living on reserves and in northern villages in Québec 1984-2004: Incidence and mortality*. https://www.inspq.qc.ca/pdf/publications/981_CancerAutochtonesVAng.pdf

Joint Environmental and Health Monitoring Committee. (1996). *Canada and PLFN Micmac Joint Environmental and Health Monitoring Committee Report on Activities: July 1993 – March 1996*. Halifax, NS: Department of Indian and Northern Affairs Development.

Joint Environmental and Health Monitoring Committee. (1998). *Canada and PLFN Joint Environmental and Health Monitoring Committee Second Report on Activities April 1996 – March 1998*. Halifax, NS: Department of Indian and Northern Affairs Development.

Joint Environmental and Health Monitoring Committee. (2015). *Canada and PLFN Joint Environmental and Health Monitoring Committee Fourth Report on Activities April 2005 – March 2015*. Halifax, NS: Department of Indian and Northern Affairs Development.

Kukutai, T. & Taylor, J. (2016). Data sovereignty for Indigenous Peoples: current practice and future needs. In Kukutai, T. & Taylor, J. (Eds.). (2016). *Indigenous data sovereignty: Toward an agenda* (1-22). Canberra, NSW: Australian National University Press. https://doi.org/10.22459/CAEPR38.11.2016.01

Lewis, D., Castleden, H., Francis, S., Strickland, K., Denny, C. & Pictou Landing Native Women’s Group. (2016). Increasing response rates on face-to-face surveys with Indigenous communities in Canada: Lessons from PLFN. *Progress in Community Health Partnerships: Research, Education, and Action*, *10*(2), 197-205. https://doi.org/10.1353/cpr.2016.0021

Lewis, D., Francis, S., Francis-Strickland, K., Castleden, H., & Apostle, R. (2020). If only they had accessed the data: Governmental failure to monitor pulp mill impacts on human health in Pictou Landing First Nation. *Social Science and Medicine*. https://doi.org/10.1016/j.socscimed.2020.113184

Marrett, L. D., & Chaudhry, M. (2003). Cancer incidence and mortality in Ontario First Nations, 1968–1991 (Canada). *Cancer Causes & Control*, *14*(3), 259-268. https://doi.org/10.1023/A:1023632518568

Mazereeuw, M., V., Yurkiewich, A., Jamal, S., Cawley, C., Jones, C., & Marrett, L. (2017). Cancer risk factors and screening in First Nations in Ontario. *Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice*, *37*(6), 186-193. https://doi.org/10.24095/hpcdp.37.6.02

Mazereeuw, M. V., Withrow, D. R., Nishri, E. D., Tjepkema, M., & Marrett, L. D. (2018). Cancer incidence among First Nation adults in Canada: Follow-up of the 1991 census mortality cohort (1992–2009). *Canadian Journal of Public Health*, *109*(5-6), 700-709. https://doi.org/10.17269/s41997-018-0091-0

McGahan, C. E., Linn, K., Guno, P., Johnson, H., Coldman, A. J., Spinelli, J. J., & Caron, N. R. (2017). Cancer in First Nations people living in British Columbia, Canada: An analysis of incidence and survival from 1993 to 2010. *Cancer Causes & Control*, *28*(10), 1105-1116. https://doi.org/10.1007/s10552-017-0950-7

Nishri, E. D., Sheppard, A. J., Withrow, D. R., & Marrett, L. D. (2015). Cancer survival among First Nations people of Ontario, Canada (1968–2007). *International Journal of Cancer*, *136*(3), 639-645. https://doi.org10.1002/ijc.29024

Parliament of Canada. (1995, February 16). *Minutes of routine proceedings – House of Commons debates (no. 154). 35th Parliament.* https://www.ourcommons.ca/DocumentViewer/en/35-1/house/sitting-154/hansard

Picot, G., Berthelot, J. M., & Webber, M. (2006, January 25-27). *Possible future directions for longitudinal surveys at Statistics Canada*. [Conference Paper]. *Longitudinal Social and Health Surveys in an international perspective*. Montreal, PQ: McGill University. http://www.ciqss.umontreal.ca/Longit/session7_paper4.html

Pictou Landing Native Women's Group. (2010). *Meeting minutes of PLFN Native Women's Group, Oct. 4, 2010*. Pictou Landing First Nation, NS. Unpublished.

Pictou Landing Native Women's Group. (2011). *April 30, 2011 minutes of meeting of PLFN Native Women's Group meeting with academic experts*. Pictou Landing First Nation, NS. Unpublished.

Pictou Landing Native Women's Group, Castleden, H., Lewis, D., Jamieson, R., Gibson, M., Rainham, D., Russell, R., Martin, D., & Hart, C. (2016). *"Our ancestors are in our land, water, and air": A two-eyed seeing approach to researching environmental health concerns with PLFN – Final report*. http://heclab.com/wp-content/uploads/2019/06/PLFNReport2016.pdf

Stammers, D. M., Israels, S. J., Lambert, P. J., & Cuvelier, G. D. (2014). Cancer incidence, morbidity, and survival in Canadian First Nation children: A Manitoba population-based study from the cancer in young people in Canada (CYP-C) registry. *Pediatric Blood & Cancer*, *61*(12), 2164-2169. https://doi.org/10.1002/pbc.25005

Statistics Canada. (2009). *Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations, 2006 Census*. 53 p. Catalogue no. 97-558-XIE. http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/pdf/97-558-XIE2006001.pdf/

Statistics Canada. (2011). *Census Dictionary*. Catalogue n. 98-301-

X2011001. https://www12.statcan.gc.ca/census-recensement/2011/ref/dict/98-301-X2011001-eng.pdf

Statistics Canada. (2017a). *Canadian Cancer Registry*. http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207

Statistics Canada. (2017b). *Canadian Cancer Registry System Guide (2015/16 Edition)*. Accessed in Atlantic Regional Data Centre, Canadian Research Data Centre Network (CRDCN).

Statistics Canada. (2017c). *Standard Geographical Classification (SGC) 2011 – Volume 1, The Classification*. Catalogue n. 12-571-X. http://www.statcan.gc.ca/eng/subjects/standard/sgc/2011/index/

Statistics Canada. (2019). *Access to microdata*. https://www.statcan.gc.ca/eng/help/microdata

Statistics Canada. (2020). *Microdata access portal application process*. https://www.statcan.gc.ca/eng/microdata/data-centres/access

Tobias, J. K., Richmond, C. A., & Luginaah, I. (2013). Community-based participatory research (CBPR) with Indigenous communities: Producing respectful and reciprocal research. *Journal of Empirical Research on Human Research Ethics*, *8*(2), 129-140. https://doi.org/10.1525/jer.2013.8.2.129

Withrow, D. R., Pole, J. D., Nishri, E. D., Tjepkema, M., & Marrett, L. D. (2017). Cancer survival disparities between First Nation and non-Aboriginal adults in Canada: Follow-up of the 1991 census mortality cohort. *Cancer Epidemiology and Prevention Biomarkers*, *26*(1), 145-151. https://doi.org/10.1158/1055-9965.EPI-16-0706

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Cree Youth Engagement in Health Planning

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Indigenous communities experience a greater burden of ill health than all other communities in Canada. Across the Eeyou Istchee territory of northern Quebec, all nine James Bay Cree communities experience similar health challenges. In 2014, the Cree Health Board (CHB) supported an initiative to stimulate local community prioritization for health change. While many challenges identified were specific to youth (10-29 years of age), youth's perspectives in these reports to date have been limited. We sought to understand how Cree youth perceived youth health and their engagement in health and health planning across Eeyou Istchee. As part of a CHB-McGill partnership, this qualitative descriptive study adopted a community-based participatory research approach. Cree community partners recruited ten Cree youth to participate in two focus groups, and five Cree youth coordinators to participate in key informant interviews. Thematic analysis was conducted and inductive codes were grouped into themes. Cree participants characterized youth engagement into the following levels: participation in community and recreational activities; membership in youth councils at the local and regional levels; and, in decision-making as planners of health-related initiatives. Cree youth recommended greater use of social media, youth assemblies, and youth planners to strengthen their engagement and youth health in the region. Our findings revealed an interconnectedness between youth health and youth engagement; Cree youth described how they need to be engaged to be healthy and need to be healthy to be engaged. Cree participants contributed novel and practical insights to engage Indigenous youth in health planning across Canada.

Keywords: *Indigenous, youth, health engagement, community-based, participatory research, health planning*

Glossary

For the purposes of this manuscript, the following terms are defined as below.

Eeyou Istchee (in Cree, meaning the "Cree Peoples Land"): The territory corresponding to the regional authority of the Cree Nation Government. This region is composed of nine Cree Nation communities, including: Chisasibi, Eastmain, Mistissini, Nemaska, Oujé-Bougoumou, Waskaganish, Waswanipi, Wemindji, and Whapmagoostui.

Cree Nation Government: Represents the administrative arm of the Grand Council of the Crees (the highest political body representing the Cree). It is responsible towards environmental protection, the hunting, fishing and trapping regime, economic and community development, the Board of Compensation, and other matters. The Cree Health Board, an independent entity created through the James Bay and Northern Quebec Agreement, sits as observers when issues related to its mandate are discussed.

Cree Board of Health and Social Services of James Bay, hereafter referred to as Cree Health Board (CHB): Entity responsible for the administration of health and social services for all persons residing either permanently or temporarily in Region 18, the administrative region of the Ministry of Health and Social Services of Quebec corresponding to the Cree territory of James Bay. In partnership with the Government of Québec, the CHB provides health and social services to the nine communities of the Cree Nation in Eeyou Istchee (Cree Board of Health and Social Services of James Bay, 2012).

Miyupimaatisiiun: An all-encompassing Cree word for a global concept of health that can be loosely translated as "being alive well". Miyupimaatisiiun encompasses physical, mental, emotional and spiritual wellness: it implies a way of living that allows one to care for their family, enjoy life and participate in their community, and be sufficiently strong to be able to hunt in the frigid conditions of the North (Cree Board of Health and Social Services of James Bay, 2004).

Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) Team: In the Cree language, 'Iiyuu Ahtaawin' means 'Cree community' and Miyupimaatisiiun is defined as above. The IAMP initiative is a community-based and community-driven wellness planning process involving Eeyou Istchee's local and regional entities and groups. The IAMP Team as defined in this paper as the team of individuals responsible for the evaluation of the IAMP initiative, composed of seven CHB members (both Cree and non-Cree) and four McGill researchers (non-Cree).

Youth: A self-identified label, but also corresponding to the ages of 10 to 29 as defined by the CHB.

Youth coordinator: A Cree person who is actively involved in leading and planning youth activities and engagement opportunities, either locally in their community, or regionally across Eeyou Istchee. Youth coordinator may not be this individual's formal position or sole role in the community, but they serve as key informants regarding the structures that exist for youth to engage across Eeyou Istchee.

Youth council member: A Cree youth member who sits on either a local or regional youth council, and represents the youth and youth needs in their corresponding community or communities.

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Introduction

Indigenous communities experience a greater burden of ill health than all other communities in Canada (Adelson, 2005). Social determinants of Indigenous health including systemic racism have been associated with unfair differences in power, resources, capacities and opportunities, which lead to a considerable range of health disparities (Paradies, 2018). Peoples in Northern and remote areas face particular challenges with mental health, obesity, diabetes, substance abuse, and maternal or child health issues, with poorer health outcomes and barriers in healthcare resource access (Ford et al., 2012; National Collaborating Centre for Aboriginal Health, 2009, 2013; Young & Chatwood, 2017).

In the Eeyou Istchee territory of Northern Quebec, all nine Cree communities experience similar health challenges (Cree Board of Health and Social Services of James Bay, 2015b). While the Cree report longer life expectancies and lower infant mortality rates than other Indigenous populations, the Cree are currently overrepresented in diabetes, heart disease and sexually transmitted infections (Cree Board of Health and Social Services of James Bay, 2015b). Moreover, the Cree conceptualization of health is distinguished from a Western biomedical definition with the term Miyupimaatisiiun, best interpreted as “being alive well”. Miyupimaatisiiun encompasses physical, mental, emotional, and spiritual wellness: it implies a way of living that allows one to care for their family, enjoy life and participate in their community, and be sufficiently strong to be able to hunt in the frigid conditions up North (Cree Board of Health and Social Services of James Bay, 2004). For the Cree, health implies much more than merely the absence of disease.

In 2014, the Cree Health Board engaged in a major planning effort to align this more holistic notion of health and current service provision through a major community-based planning initiative – the Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) – for all nine Cree communities of the Cree Nation. Funded in part by Health Canada, the IAMP initiative aims to improve planning and outcomes across the region, encouraging communities to lead and create detailed plans for Miyupimaatisiiun. IAMP partnered with McGill researchers in an evaluation of this work using a community-based participatory research (CBPR) approach.

Notably, many health challenges that the James Bay Cree leadership have prioritized primarily affect youth (10 to 29 years of age, as defined by the CHB). For example, one in five Cree youth gets involved with Cree Youth Protection Services each year, and many of these visits are youth coming in for mental health crises, behaviours associated with alcohol and drugs, or suicide attempts (Cree Board of Health and Social Services of James Bay, 2016). In addition, increases in chronic diseases among youth, and the rate of diabetes and sedentary lifestyles of youth, are identified as healthcare and social issues important to the Cree Nation, and thus need to be addressed (Cree Board of Health and Social Services of James Bay, 2015b).

While many health priorities for change are specific to the youth sector, the IAMP evaluation thus far has not yet formally involved youth to ask them how they have been engaged or how they need to be engaged in health planning. This further corroborates current evidence stressing the absence of youth voice and participation in healthcare research on a global scale (United Nations, 2003). Particularly in the Eeyou Istchee context, half of the James Bay Cree population is under 25 years of age, and about 1 in 5 babies is born to a mother under the age of 20 (Cree Board of Health and

Social Services of James Bay, 2015a). In order to place the end-user's (youth's) priorities in research, young Cree people must be heard in all steps of the evaluation research and health planning efforts. This investigation aims to better understand how youth perceive health or Miyupimaatisiiun, as well as their past, present, and future engagement in health initiatives in the community. Accordingly, our three interconnected research questions are the following:

1. How are James Bay Cree youth engaged in health-related activities in their communities?
2. How would James Bay Cree youth like to be engaged in youth health planning in Eeyou Istchee?
3. How do James Bay Cree youth view their health in relation to their engagement in health and health planning?

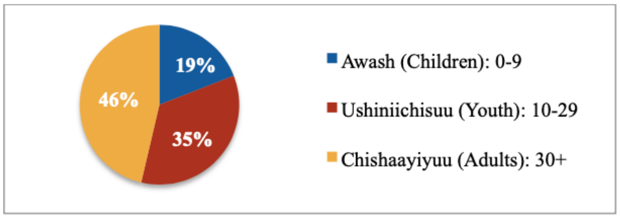
Methods

Context

Nemaska has a total population of approximately 851 in 2017 (Cree Board of Health and Social Services of James Bay, 2015-2016). Youth make up nearly half the total population in Nemaska (Figure 1).

Figure 1

Population Pie Chart of Nemaska



Research Approach

Community-based participatory research (CBPR) falls under the umbrella of participatory research as it involves all members of the project in key aspects of the research process, including the (1) identification of the research topic, (2) interpretation of the results, and (3) diffusion and dissemination of the findings (Israel et al., 2001).

Key characteristics of CBPR and how they align with the aims of this research are outlined in Appendix A.

Methodology

Research design

We used a qualitative descriptive study design as described by Sandelowski (2000) to gain an in-depth understanding of youths' and youth leaders' perspectives, and to access the emotional and motivational components of their lived experiences (Curry et al., 2009; Sandelowski, 2000). Qualitative descriptive designs stay close to the surface of the data and are ideal when full descriptions of phenomena are desired (Sandelowski, 2000).

Data collection

All data collection was guided by our Cree CHB and community school partners. Purposeful, snowball sampling was employed (Patton, 1990).

Two semi-structured youth focus groups were conducted with a total of 10 Cree youth participants, ranging from 15 to 17 years of age. The objectives of these focus groups were to identify key themes that represent youth health and health priorities, as well as how youth engage in their communities. Focus groups were led in collaboration with community leaders and were held at the local community school. As recommended by our Cree partners, groups were mixed gender and age since this was how youth were comfortable in their peer groups. Focus groups lasted approximately 50 minutes and were audio-recorded and transcribed. In accordance with our CBPR approach, focus groups were co-facilitated by a community youth leader and the primary author. Focus group guides were modified by our Cree partners.

Five key informant interviews were conducted with Cree community members who were involved with youth and youth health engagement and planning; these leaders worked in and represented either the regional- or community-level. The objective of these interviews was to better understand how youth health services are planned and the existing structures that exist for youth engagement in the community. Interviews lasted approximately 60 to 75 minutes and were audio-recorded and transcribed.

Data analysis and validation

Thematic Analysis was used to identify, analyze, and report themes within the focus group and interview transcripts (Glaser & Strauss, 1999), where emergent codes were in turn grouped into overarching themes (Lofland & Lofland, 1995). Themes were defined as important patterned responses or meanings from the text as they related to our research questions (Braun & Clarke, 2006). Analysis was recursive and conducted by the first author with virtual coding from the co-supervisors. Preliminary results were presented to and validated by two representatives of the CHB, one community representative, and one youth participant. In addition, regular meetings, phone calls, and text messages were used as debriefing strategies throughout the process, to ensure rigour with respect to the Cree context and to honour Cree ways of knowledge.

Relationship

This project built upon an existing partnership between McGill researchers and the CHB. Techniques used in accordance with Salsberg et al.'s strategies for a successful participatory research process (Salsberg et al., 2015) are delineated in Appendix B.

Results

Youth "Engagement" Revisited

Prior to discussing Cree youth engagement, it is important to characterize how youth viewed and defined youth engagement. While there was no one agreed upon framework, participants generally defined youth engagement as a spectrum.

The first level of youth engagement was defined as *participation*, where youth showed up and partook in an activity or attended an event. The second level of youth engagement was defined as *youth council membership*, where youth were nominated to represent the youth voice and were often solicited by decision-makers. The third and highest level of youth engagement spectrum described was youth engaged as *planners*, where youth were the decision-makers and led in planning towards action. These categories are illustrated in Figure 2.

Figure 2

Spectrum of Cree Youth Engagement

Perspectives on Current Levels of Youth Engagement

In general, participants described high levels of Level 1: Participation and

Level 2: Youth Council Membership engagement in their communities, with pride. Participants shared divergent feelings, however, regarding the extent to which youth are engaged as Level 3: Planners. They described how adult planners often ask for the 'youth voice' when making decisions (e.g., the Youth Grand Chief being included in the major Cree Nation Government meetings).

In these examples, adult planners are "asking" the youth for their opinions – in other words, it is still not the youth who are the health planners. This leaves room for potential disconnect between youth voice and youth action. Indeed, some youth expressed frustration with decision-makers who listened but did not act:

Participant: "They just listen. I don't know…

Facilitators: Are there things you've recommended that haven't been acted on?

Participant: Mhm.

Facilitator: So how can youth voices best turn into action?

Participant: Guess we have to wait till we're adults."

Youth participants highlighted how a lack of action can impact youth's trust: "You must be listening to the youth and what they're saying, and show you are taking action. So, when the youth see that, that's when they'll be more interested… to trust their leaders, or the councils, or the coordinators".

Future Youth Engagement Towards Health Action

For better youth engagement that leads to health action, youth and youth coordinators underscored the importance of the following themes:

Allowing Youth to be Health Planners

Participants highlighted the importance of opportunities for youth to plan and engage at the highest level in health initiatives. Participants discussed an array of benefits that arise when youth lead as listed below.

Utilizing role modelling for other youth to engage. Repeatedly, participants underscored the importance of role modelling in Cree youth culture, and how youth can inspire other youth towards more healthy behaviours. One youth coordinator observed how younger youth model off older youth in the gym:

> *"I've seen kind of younger kids coming in, ages 12 to 15, trying out the 5-pounders. I guess trying to do the same as the older teenagers, going to the fitness… they wanna try that too…"*

One youth put it simply: "If youth see other youth leading the activities or the programs, it will definitely get their attention".

Builds on pre-existing trust between youth. One youth council member felt that it was important for a youth to not only lead initiatives, but create a more trusting environment for other participating youth:

> *"I lead and participate in [activities]. Like I join them, so they can feel comfortable to join as well. It takes a while for a youth to get comfortable… I welcome them… I talk to [youth], and am a friend to them."*

That said, it is worthy to mention that deference and shyness was noted by participants to be an important part of this community's Cree culture. The use of social media and particularly Facebook was highlighted as helpful in this regard, making it easier to reach shy youth who are less likely to engage in person:

> "*Facebook is a big tool for our youth because, there are youth that don't speak and are very shy. So, they have Facebook and their own world, so they read through that… and maybe you can't reach them in person at school, but you'll be able to reach them alone in their room…*"

Longevity of youth engagement when youth lead. Youth coordinators are actively engaged in planning and decision-making for different youth programs in their communities. Notably, all youth coordinators who participated in this study were also former youth council members and had been working with and for youth for quite some time:

> *"What motivates me... there's so much... I guess I could say I have this channel, this desire to be a part of making change. From my experience when I was young, I guess I could say I was pretty observant - 'How come nobody's doing this'… It started to develop into: 'You know what, somebody needs to do something. I'm somebody. Alright - I'll do it.'"*

Furthermore, one youth participant described how having youth as planners and leaders can increase the relevance and longevity of the program to truly address youth health needs:

> *"Having the youth involved in the planning part, I think that would be helpful. Youth know what [youth] want and what they need, or what they're interested in. And it will definitely boost up the whole planning part."*

Finally, one youth coordinator highlighted the importance of youth sitting in on decision-making boards for their futures:

> *"When we have our big meetings… yes they're 18, but we can still welcome them. Cause they're gonna be sitting up there in a few years."*

Better promotion and uptake of health programs: One youth coordinator proposed the creation of a youth promoter to advertise and promote services, which could better program success and trust:

> *"A [youth] can explain to them, you know, healthy living ways and not being doubtful of the Cree Health Board and the services offered,… its services would be a little more utilized and understood, and trusted… there is a lot more outreach to be done"*

Finally, one youth coordinator described how testimonials from youth who have participated could inspire other youth to engage:

> *"I hope these individuals inspire the others. I mean yeah, [a previous participant] was telling me how much better she was feeling, but it doesn't necessarily mean that everybody knows it... reporting back or getting that feedback out there, I'd like to do that more."*

Appropriate evaluation of youth engagement and health programs

Youth spoke about the difficulties they encounter when coordinators and planners want greater youth engagement; specifically, how planners often use youth attendance rates and numbers as indicators of a program's success. One youth described how a program that was meaningful to them was terminated on the basis of low attendance, and how this could be problematic when program numbers overshadow positive experiences:

> *"There used to be an art program, I really enjoyed that program, but it stopped… because of the lack of numbers. I understand it has to do with the budget and all that, but what if those, let's say, 5 youth participants had a rough week, and going to that activity or program could change their mindset? Like they could have had motivation to do more, be more…"*

Indeed, certain youth coordinators illustrated the importance that they placed on numbers to indicate an event's success:

> *"I'm coming from a coordinator's perspective. You always wanna have, to be honest, double or triple the amount of participants that you have."*

Interconnectedness between youth health and youth engagement

Given that youth's conceptualizations of health or Miyupimaatisiiun (see **Glossary**) influences how they view their engagement in and planning of health activities, understanding their conceptions of health was essential.

Youth Need to be Healthy to be Engaged

Many community youth engagement opportunities and activities required an application process, where healthy behaviour (such as sobriety) was a prerequisite. When asked why these rules were in place, one youth explained how traditional hunting activities require mental and physical strength:

> "*You have to be quiet to hunt. You have to be patient to hunt. You have to be smart too. You have to be strong. You have to go places a lot, you have to walk, and sometimes there may be snow or grass, big trees, lakes..."*

Other youth spoke to the fact that health requirements could serve as stepping stones towards long-term change:

> *"They're trying to make the youth healthy you know… If you think you can go one week without drugs or alcohol, it makes you think you can continue."*

Youth also raised the notion that one person cannot fully engage and help others and the land before they help themselves:

> *"…If you want to engage and take care of our land and people, we need to take care of ourselves first… it sounds conceited, but still."*

Youth Need to be Engaged to be Healthy

Participation in community activities was fundamental to youth wellbeing, as expressed by one youth participant:

> *"Being back in the bush… without service or wifi… disconnected from some people, but connected with other people. You're being active everyday… it's probably a good thing."*

Moreover, participating in community gatherings was important for the social dimension of youth health:

> *"When people gather together, there's a lot of laughter and smiles. Everybody's having a great time. And doing that is also beneficial for the individual youth's health. Cause you never know when somebody's having a bad day or something, and they come to these [community] events and they feel better after."*

Beyond participation, opportunities to engage by planning activities were also described as essential to supporting youth health. Youth illustrated how leading cultural activities can connect them to their tradition and health:

> *"It's a way of life in the Cree region: walking, spending time in the bush, learning about medicine in the bush, leading more Cree-based cultural activities… that also can connect with healthy living"*

Being given opportunities to lead and plan can also help increase confidence and positive self-esteem for some, as one youth council member highlighted:

> *"When I got involved… it really boosted up my confidence in leading activities. I suggest that youth get involved with these activities. Like, let them do the work. Let them plan… so they can have the opportunity to lead and break their bubble."*

Limitations

As an external non-Cree person, there are limitations to what the primary author was able to understand and interpret; the validation process was essential to ensure our Cree partners identified with what is presented in this work. Partnership and extensive review of materials from three Cree partners (one of which is a youth), the primary author's eight-day immersion in the community, as well as co-leading the focus groups with a community youth leader, were all important to this end.

This study focused on a limited number of youth and youth coordinators from one community, hence intra- and inter-community differences may be masked. These results are still valuable and potentially transferable to other communities and youth in similar contexts.

Finally, the qualitative descriptive study design allowed for a deep, contextual understanding of the perspectives of a small number of relatively informed youth aged 15-17 years old, which also may not be generalizable to other ages or settings. We believe, however, that contextualized understanding is most valuable to local communities and policy makers.

Discussion

Much of the published literature on youth health lacks actual voices from youth themselves. In collaboration with the CHB and Cree community members, including youth, we explored ways in which youth and youth coordinators describe Cree youth engagement in the community, on councils, and in health decision-making, suggestions for the future, and how youth engagement and youth health are intertwined.

The levels of youth engagement according to the spectrum of *participation, youth council membership,* and *planners*, as outlined in Figure 2, were characterized. While positive towards youth engagement as health planners, a few Cree youth expressed dissatisfaction about decision-makers who listened but did not act. One youth stated that they simply needed to wait until they were older to be taken seriously in planning decisions. Participants also described how the disconnect between youth voices and action could improve if decision-makers understood the importance of building good relationships in this context – how being a friend could build trust and foster an understanding of youth needs, and how when one youth leads, their friends tend to follow. Program leaders' age was also considered a potential hierarchal factor in engagement. Issues of hierarchy in engaging youth have been previously characterized, especially with "high-risk" youth, and the associated dynamics of power (Iwasaki et al., 2016). The importance of informal role modelling for Cree youth was also described as an integral aspect of Cree teachings, as recognized in other Indigenous cultures (Klinck et al., 2005). The benefits of good role modelling and mentoring to promote positive health behaviours in youth can also fall under the connectedness factor of Indigenous Peoples' health and wellbeing (Reilly et al., 2008).

Ultimately, a few participants spoke to a need for greater and more genuine youth engagement as health planners. This finding is congruent with the literature where most engagement is described in the youth council member capacity, and youth voices are solicited to bring to (presumably) adult health planners (Genuis et al., 2015). That said, our participants highlighted the sustainability and longevity of youth engagement when they were given the chance to lead. The intrinsic spark and motivations that youth felt they always had in order to create change was noted as continuing into adulthood. Participants described how youth leaders could help a program last longer by accurately identifying underlying issues and leading programs promoting for greater youth retention. This action agrees with previous studies on the importance of engaging Indigenous youth as planners in their own research, as they are best suited to identify, understand, and interpret their own health challenges (Clark et al., 2013; Genuis et al., 2015). Sustainability of projects under Indigenous youth leadership could also be explained by Jagosh et al.'s (2012) finding that a transfer of ownership often takes place when, through participatory research approaches, those who are directly involved in the program or its results lead the program itself (Jagosh et al., 2012). Finally, participants also expressed how youth engaged as health planners was good practice, since youth ultimately fill these positions in the future; similarly, the youth in Blanchet-Cohen's (2011) study advocated for communities to view youth engagement as a benefit to the whole community and future investment (Blanchet-Cohen et al., 2011).

In order to better engage youth in the future, social media strategies, particularly Facebook, were noted as important. The importance of these media in Indigenous youth engagement has not been highlighted by many previous youth engagement studies, which appear to focus more on arts-based and peer-to-peer mentorship methods. However, our participants highlighted Facebook as an important tool to solicit and advertise to youth, and particularly reach marginalized youth. Indeed, the fact that our youth focus groups were held in collaboration with the community school implies that youth who participated were already attending school; youth who are not in school, young parents, youth who are less involved, or youth who are dealing with addictions were likely not reached in this study – a challenge acknowledged in previous publications (Iwasaki, 2015). Hence, social media could be a valuable tool for service providers to consider, especially when reaching out to more marginalized youth.

One explicit finding of this study was the interconnectedness between Cree youth health and their engagement, and how one was needed for the other. Youth participants highlighted the importance of helping oneself before being able to engage and help others and the land, even though, as one participant described, prioritizing yourself could be interpreted as conceited. The importance of working on oneself was echoed throughout this study and may suggest a fundamental Cree value. Furthermore, this finding could be related to the influence of role modelling in Cree teachings as described.

In addition, youth described how they needed to be physically and mentally well, and abide by the required sobriety rules to partake in traditional activities. Youth participants also shared the potential long-term benefits of sobriety prerequisites. Taken together, these results underline Cree youth's strong desires to engage in cultural activities, perhaps enough to give up unhealthy behaviours. Considering the aforementioned interconnectedness, this health behavioural change could either be a cause or consequence of youth engagement.

Participants also described how engagement opportunities could lead to better health. The positive effects of Indigenous youth participating in sports and physical activities can be related to the well-characterized ability of physical activity to strengthen youth resilience and development (Bruner et al., 2016). Youth participants also shared how their engagement helped increase their self-confidence, and one youth shared how youth councils helped them break out of their shell. This finding agrees with previous Indigenous youth literature that links youth engagement with increased social skills and pride (Clark et al., 2013; Crooks et al., 2010) and permitting their true selves to come out (Stewart et al., 2008). In addition, engagement opportunities allowed youth to foster the social component of their wellbeing. Being engaged in traditional activities, away from technology, with their families and communities, and immersed in Cree ways of living, were the components of traditional activity participation that youth attributed to their feeling healthy and well. This is congruent with Blanchet-Cohen's (2011) finding that the impact of gatherings on Indigenous youth cannot be quantified, and it is the less tangible aspects of this social dimension that affect youth wellbeing (Blanchet-Cohen et al., 2011).

The quantification of youth health ties well into our participants' opinions on the quantification and evaluation of youth participation. This was a notable point of divergence between some youth and youth coordinator participants. One youth coordinator recommended the use of testimonials in their health programs to allow youth to share their sentiments and inspire other youth. Testimonials are a form of qualitative evaluation that could offer meaningful feedback for youth coordinators and financial decision-makers when planning for youth programs, so long as the feedback comes from participating youth themselves.

One of the primary goals of this research was to provide insights to the CHB to help inform current and future health plans for youth. Implications for policy, practice and future research as recommended by our Indigenous participants are delineated in Appendix C.

Finally, it should be noted that a marked desire for the community to succeed underscored this entire project, as indicated through cultural pride and strength-based optimism demonstrated by almost every participant. One Cree coordinator and partner shared a reflection worthy of including verbatim:

> *"[Working with the youth], it's my joy, it's my pleasure. Because I want this community to succeed and to be vibrant. Of course we have our challenges, but you know. There's a lot of people out there that want their community to run well… I know this next generation will make a big splash, like those remarkable achievers from the past."*

Conclusion

This study contributes Cree youth voices to the limited evidence currently available in Canadian research literature, offering practical strategies for greater youth engagement for the Cree Nation. This is a novel area of research that highlights the importance and potential for future research in partnership with Cree people of Eeyou Istchee and Indigenous Peoples of similar contexts. As described by the Cree youth in this study: youth need to be healthy to be engaged, and need to be engaged to be healthy.

References

Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health*, S45-S61. https://doi.org/10.1007/BF03403702

Blanchet-Cohen, N., McMillan, Z., & Greenwood, M. (2011). Indigenous youth engagement in Canada's health care. *Pimatisiwin, 9*(1), 87-111. https://www.suicideinfo.ca/wp-content/uploads/gravity_forms/6-191a85f36ce9e20de2e2fa3869197735/2018/03/Indigenous-Youth-Engagement-in-Canada%E2%80%99s-Health-Care_oa.pdf

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Bruner, M. W., Hillier, S., Baillie, C. P., Lavallee, L. F., Bruner, B. G., Hare, K., Lovelace, R., & Lévesque, L. (2016). Positive youth development in Aboriginal physical activity and sport: A systematic review. *Adolescent Research Review, 1*(3), 257-269. https://doi.org/10.1007/s40894-015-0021-9

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annual Review of Public Health, 29*, 325-350. https://doi.org/10.1146/annurev.publhealth.29.091307.083824

Clark, N., Walton, P., Drolet, J., Tribute, T., Jules, G., Main, T., & Arnouse, M. (2013, Jun). Melq'ilwiye: Coming together - intersections of identity, culture, and health for urban Aboriginal youth. *The Canadian Journal of Nursing Research, 45*(2), 36-57. https://doi.org/10.1177/084456211304500208

Cree Board of Health and Social Services of James Bay. (2004). *Strategic regional plan to improve health and social services*. CBHSSJB. Retrieved 2016.10.02 from http://www.creehealth.org/sites/default/files/CBHSSJB%20Strategic%20Regional%20Plan%202004-2014.pdf

Cree Board of Health and Social Services of James Bay. (2012). *About us*. http://www.creehealth.org/about-us

Cree Board of Health and Social Services of James Bay. (2015a). *The current and projected Eeyou population*. CBHSSJB Retrieved 2016.10.07 from http://www.creehealth.org/sites/default/files/Current%20and%20Projected%20Eeyou%20Population%20November%202015.pdf

Cree Board of Health and Social Services of James Bay. (2015b). *Overview of the health of the population of Region 18*. Cree Board of Health's Public Health Surveillance System. Retrieved 2016.10.07 from http://www.creehealth.org/surveillance-data/population-health

Cree Board of Health and Social Services of James Bay. (2015-2016). *Annual report of the Cree Board of Health and Social Services of James Bay, 2015-2016*. https://www.creehealth.org/sites/default/files/CBHSSJB%202015-2016%20AR%20FINAL%20low%20res.pdf

Cree Board of Health and Social Services of James Bay. (2016). *eHealth Solution: A youth mental health self-referral service*. http://www.creehealth.org/news/community-stories/ehealth-solution-youth-mental-health-self-referral-service

Crooks, C. V., Chiodo, D., Thomas, D., & Hughes, R. (2010). Strengths-based programming for First Nations youth in schools: Building engagement through healthy relationships and leadership skills. *International Journal of Mental Health and Addiction, 8*(2), 160-173. https://doi.org/10.1007/s11469-009-9242-0

Curry, L. A., Nembhard, I. M., & Bradley, E. H. (2009). Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation, 119*(10), 1442-1452. https://doi.org/10.1161/CIRCULATIONAHA.107.742775

Ford, T., Rasmus, S., & Allen, J. (2012). Being useful: Achieving Indigenous youth involvement in a community-based participatory research project in Alaska. *Int J Circumpolar Health, 71*(0), 1-7. https://doi.org/10.3402/ijch.v71i0.18413

Genuis, S. K., Willows, N., & Jardine, C. G. (2015). Partnering with Indigenous student co-researchers: Improving research processes and outcomes. *Int J Circumpolar Health, 74*, 27838. https://doi.org/10.3402/ijch.v74.27838

Glaser, B. G., & Strauss, A. L. (1999). *Discovery of Grounded Theory*. Routledge. https://doi.org/10.4324/9780203793206

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions, 26*(1), 13-24. https://doi.org/10.1002/chp.47

Holkup, P. A., Tripp-Reimer, T., Salois, E. M., & Weinert, C. (2004, Jul-Sep). Community-based participatory research: An approach to intervention research with a Native American community. *Advances in Nursing Science, 27*(3), 162-175. https://doi.org/10.1097/00012272-200407000-00002

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health, 14*(2), 182-197. https://doi.org/10.1080/13576280110051055

Iwasaki, Y. (2015). *Working with high risk, marginalized youth: Youth-led development of a framework of youth engagement*. https://youthrex.com/report/working-with-high-risk-marginalized-youth-youth-led-development-of-a-framework-of-youth-engagement

Iwasaki, Y., Dashora, P., McHugh, T.-L., McLaughlin, A.-M., & Springett, J. (2016). Reflections on the opportunities and challenges of youth engagement: Youth and professional perspectives. *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning, 1*(2). https://doi.org/10.15402/esj.v1i2.111

Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., Sirett, E., Wong, G., Cargo, M., & Herbert, C. P. (2012). Uncovering the benefits of participatory research: Implications of a realist review for health research and practice. *The Milbank Quarterly, 90*(2), 311-346. https://doi.org/10.1111/j.1468-0009.2012.00665.x

Kirmayer, L. J. (2012). Rethinking cultural competence. *Transcultural Psychiatry*. https://doi.org/10.1177/1363461512444673

Klinck, J., Cardinal, C., Edwards, K., Gibson, N., Bisanz, J., & Da Costa, J. (2005). Mentoring programs for Aboriginal youth. *Pimatisiwin, 3*(2). https://teipuwhakahauaa.teraumatatini.com/uploads/klinck/2005/1216_Klinck2005.pdf

LaVeaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin, 7*(1), 1. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2818123/pdf/nihms144307.pdf

Lofland, J., & Lofland, L. H. (1995). *Analyzing social settings: A guide to qualitative observation and analysis* (3rd Ed. ed.). Wadsworth Publishing Company Belmont, CA.

Macaulay, A. C., Commanda, L. E., Freeman, W. L., & Gibson, N. (1999). Participatory research maximises community and lay involvement. *The BMJ, 319*(7212), 774. https://doi.org/10.1136/bmj.319.7212.774

National Collaborating Centre for Aboriginal Health. (2009). *Health inequalities and social determinants of Aboriginal peoples' health*. NCCAH. Retrieved 2016.10.06 from http://www.nccah-ccnsa.ca/docs/social%20determinates/NCCAH-loppie-Wien_report.pdf

National Collaborating Centre for Aboriginal Health. (2013). *An overview of Aboriginal* *health in Canada*. NCCAH. Retrieved 2016.09.29 from http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/101/abororiginal_health_web.pdf

Paradies, Y. (2018). Racism and indigenous health. In *Oxford research encyclopedia of global public health*. Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.86

Patton, M. Q. (1990). *Qualitative evaluation and research methods: Fourth edition*. SAGE Publications, inc. https://doi.org/10.1002/nur.4770140111

Reilly, R. E., Doyle, J., Bretherton, D., Rowley, K. G., Harvey, J. L., Briggs, P., Charles, S., Calleja, J., Patten, R., & Atkinson, V. (2008). Identifying psychosocial mediators of health amongst Indigenous Australians for the Heart Health Project. *Ethnicity & Health, 13*(4), 351-373. https://doi.org/10.1080/13557850801903046

Salsberg, J., Parry, D., Pluye, P., Macridis, S., Herbert, C. P., & Macaulay, A. C. (2015). Successful strategies to engage research partners for translating evidence into action in community health: A critical review. *Journal of Environmental and Public Health, 2015*. https://doi.org/10.1155/2015/191856

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334-340. https://doi.org/10.1002/1098-240X(200008)23:4%3C334::AID-NUR9%3E3.0.CO;2-G

Stewart, S., Riecken, T., Scott, T., Tanaka, M., & Riecken, J. (2008, Mar). Expanding health literacy: Indigenous youth creating videos. *Journal of Health Psychology, 13*(2), 180-189. https://doi.org/10.1177/1359105307086709

United Nations. (2003). *World youth report*. http://www.un.org/esa/socdev/unyin/documents/ch04.pdf

Young, T. K., & Chatwood, S. (2017). Delivering more equitable primary health care in Northern Canada. *Canadian Medical Association Journal, 189*(45), E1377. https://doi.org/10.1503/cmaj.170498

Appendices

Appendix A

Characteristics of Community-Based Participatory Research in this Project

Study context	**Alignment with CBPR characteristics**
Indigenous context	• CBPR techniques have been shown to be particularly positive in historically disenfranchised communities (Holkup et al., 2004) • CBPR can address the negative impacts of prior research by ensuring community consultation, participation, and centrality of Indigenous ways of knowing (Macaulay et al., 1999) that are imperative to this project's epistemology • While CBPR does not guarantee cultural safety, it reminds us of the importance of ongoing reflection in order to minimize any assault on participants' cultural identity (Kirmayer, 2012)
Youth as end-users of this research	• Participatory research has roots in the self-determination and sovereignty movements of Canada's First Nations, united to "create scientific knowledge with those who are most affected by the issue being studied" (Cargo & Mercer, 2008) • Continued transparency of the research process with the youth participants facilitates enhanced trust between the researchers and communities (Ford et al., 2012)
Power relationships and imbalances	• CBPR as a framework takes into account the power imbalances that have resulted from a long history of colonialism and forced assimilation (LaVeaux & Christopher, 2009) for Indigenous peoples and populations • Further power relations exist for Indigenous youth; current and historical power relationships were continuously reflected upon, and were discussed with participants
Overarching purpose to inform CHB and IAMP teams' decision-making about healthier communities	• CBPR approaches aim to incorporate and honour community members' priorities, ensuring the equitable inclusion of youth voices in the development of policy and planning for healthier communities (Graham et al., 2006)

Appendix B

Strategies Used for a Successful Participatory Research Partnership

1) Memorandum of Understanding (MOU)	The pre-existing memorandum with the CHB was followed and respected. It is worthy to highlight that the respect for Cree culture, historical trauma, Cree ownership of data and confidentiality was followed strictly according to the MOU and Institutional Review Board Ethical guidelines.
2) Use formal and informal group facilitation techniques	The focus group sessions were co-facilitated by the primary author and a community partner who works at the local community school, providing valuable contextual knowledge of local conditions for the Nemaska youth. Informal techniques, such as opening the discussion based on hobby sharing, and the primary author's frequent community activity participation prior to the discussions, were used as advised by our community partners.
3) Frequent communication	Communication was maintained via frequent email, social media, and text message exchange, as well as physical trips between Montreal and Nemaska.

Appendix C

Implications for Policy, Practice and Future Research

To reach a more optimal level and capacity of youth engagement in health planning for the Eeyou Istchee, Cree participants in this study have suggested and recommended the following points of action:

- Create positions for youth to be health planners, to better the engagement, relevance, trust in, sustainability and promotion of the initiative.
- Create positions for youth to be health delegates, and to share knowledge of and promote existing CHB and other healthcare services in schools and in the community amongst youth groups.
- Highlight youth role models and include youth testimonials to capitalize on youth inspiring other youth.
- Incorporate a social media plan for youth communication, and continue to try and reach marginalized youth and solicit their particular needs.
- Continue to support and invest in all forms of engagement opportunities for youth, including participation, youth council membership, and health planning, in recognition of the interconnectedness between health and engagement for Cree youth.
- Implement regular and holistic evaluations of youth positions or programs, incorporating the use of qualitative research and testimonial evaluation methods in addition to other measures, such as attendance rates and outcomes, to better understand effective mechanisms for engagement and other implications in Eeyou Istchee.

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"The land is a healer": Perspectives on land-based healing from Indigenous practitioners in northern Canada

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Cultural knowledge is currently being revitalized by Indigenous practitioners where land is understood as a relational component of healing and wellbeing. Land-based activities such as harvesting, education, ceremony, recreation, and cultural-based counselling are all components of this integrative practice. Land-based practices are centered in Indigenous pedagogy and recognize that identity is interwoven with and deeply connected to land. Formally cultivating this fundamental relationship increases positive mental health and wellness outcomes in Indigenous populations as assessed through a culturally relevant lens. This research paper articulates a cultural concept described here as "land-based" healing or wellness which has been understood and taught for millennia by Indigenous knowledge holders and has largely remained undefined within mainstream mental health promotion and intervention. In this study, qualitative narrative methods were used to document the experiences of eleven land-based program practitioners from three northern territories in Canada. As experts in this field, practitioners' narratives emphasized the need for a greater understanding and recognition of the value of land-based practices and programs within contemporary health and education systems. The development of working definitions, terminology, and framing of land-based healing and wellness practices as a common field is delineated from relevant literature and practitioner narratives in order to enable cross-cultural communication and understanding in psychology. Land-based healing is presented as a critical and culturally appropriate method for mental health intervention and community resilience in northern Canada.

Keywords: *Mental health, intervention, land-based healing, health promotion, Indigenous knowledge, Northern Canada, land-based pedagogy, resilience*

Glossary

Land-based: Relationship with the land as a central feature or concept rooted in Indigenous epistemology and pedagogy. Land-based implies a deep connection with and non-separation between human beings and the natural world. A reference to land includes all aspects of the natural world: plants, animals, ancestors, spirits, natural features, and environment (air, water, earth, minerals). The term can also be used in reference to a physical location or geographical concept.

Land-based healing: A culturally defined practice, program, or service that takes place in an urban nature-based, rural, or remote location, on a land base that has been intentionally spiritually cultivated, honoured, and respected (Hanson, 2012). The land is situated as firmly relational within an Indigenous pedagogy, and is understood to be an active "partner to the person or people engaged in the healing process" (Hanson, 2012, p. 2). Steps are taken to identify how an individual or community's relationship with the land, self, and others has been disrupted and how best to help renew this relationship (Laurie, 2013). This has also been referred to as "land-based intervention" in the literature (Walsh et al., 2018).

Land-based program: A culturally defined program or service that takes place in an urban nature-based, rural, or remote location, which involves cultural teachings and intergenerational knowledge transfer, combined with any number of other activities or goals. Programs are informed by an Indigenous pedagogy wherein the land is the main source of knowledge and teaching.

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Introduction

Indigenous knowledges and ways of life are embedded in the land (Tobias & Richmond, 2014; Wildcat et al., 2014; Zoe, 2012). Environmental health is a determinant of human health (Cunsolo et al., 2015; Durkalec et al., 2015) and connection to the land is recognized as a central feature in Indigenous health and well-being (Kant et al., 2013; Richmond & Ross, 2009). Rebuilding a sense of connection with the land is important for Indigenous mental health promotion and intervention (Kirmayer et al., 2003; Walsh et al., 2018).

Indigenous peoples in Canada are revitalizing land-based initiatives to strengthen community resiliency and address challenges arising from a continuing legacy of colonization and land-dispossession (Ballantyne, 2014; Ilisaqsivik, 2014; Mikraszewicz & Richmond, 2019; Takano, 2005; Thompson et al., 2018; Tidlumaluk, 2007). These initiatives are "rooted in the land, traditional knowledge, spiritual values and ceremonial practice" (Walsh, 201, p. 209).

Land-Based Programs as Mental Health Promotion and Intervention

In order to promote wellness in Indigenous communities, it is vital to reconnect with cultural identity and practices within an Indigenous pedagogy (Simpson, 2014; Stewart, 2008). According to Stewart (2008), Indigenous conceptions of mental health and healing must be incorporated into counselling, therapy, and other efforts in promoting Indigenous mental health. This includes framing mental health holistically, within physical, emotional, and spiritual aspects (Lavallee & Poole, 2009; McCormick, 2000). The study of resilience is a strength-based way of framing mental health intervention in communities (Goodkind et al., 2012; Kirmayer et al., 2011; Wexler et al., 2009) by focusing on building socio-ecological networks and protective factors that strengthen cultural ties and identity (Allen et al., 2013; Andersson & Ledogar, 2008; Tousignant & Sioui, 2009). Indigenous conceptions of psychological resilience recognize the importance of a "person's relations with others and the environment" (Kirmayer et al., 2009, p. 63). The importance of culture and community-led interventions are widely recognized throughout the field of psychology, including responding to youth suicide (Chandler et al., 2003; Kirmayer et al., 2003; Menzies, 2008; Wexler & Gone, 2012).

Land as a central dimension of wellness is embedded in Indigenous knowledge, and is a necessary foundation for culturally responsive mental health care in Indigenous communities (Dobson & Brazzoni, 2016; Redvers et al., 2019). Northern Canada faces many barriers to health care delivery, including limited access to culturally relevant health services and the challenge of service provision in remote locations (Oosterveer & Young, 2015; Redvers et al., 2019; Young et al., 2019). As such, many communities are turning to land-based healing and wellness programs (Dobson & Brazzoni, 2016; Hirsch et al., 2017; Hond et al., 2019; Laiti & Sorbye, 2013; Luig et al., 2011; Radu et al., 2014; Smethurst, 2012; Thunderbird Partnership Foundation, 2018). Evaluations have demonstrated that land-based programs increase resilience and wellness in youth by improving self-esteem, interpersonal relationships, and cultural pride (Healey et al., 2016; Janelle et al., 2009; Ritchie et al., 2014). There is still a need for more cross-cultural research around the conceptualization, design, delivery, and evaluation of these initiatives (Ritchie et al., 2014) with a call to invite more of those involved to share their stories in the literature (Walsh, 2018).

The objectives of this study were to: (1) articulate the epistemological foundations of land-based healing and wellness in northern Canada; and (2) explore practice-based definitions of land-based programs in the context of Indigenous mental health promotion and intervention.

Methods

Conceptual Framework

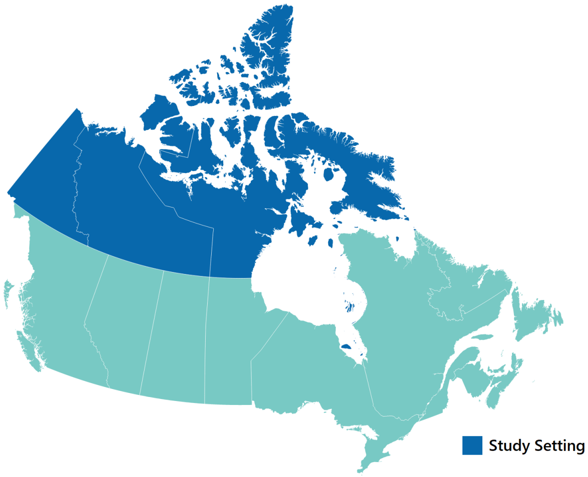
An Indigenous research methodology was employed in this study, drawing on qualitative research tools which were most convergent (Kovach, 2010; Lowan-Trudeau, 2012) with my own Dene ontology. Despite rich cultural diversity, common aspects and beliefs are found within the research paradigms of Indigenous peoples (Wilson, 2008). Central to this paradigm is the importance of storytelling as a way to represent lived experience, and the importance of building respectful research relationships (Mehl-Madrona, 2005; Wilson, 2008). Smith (2012) explains that an Indigenous research approach takes a political stance on research, recognizing the historical context of oppression and exclusion of Indigenous values found in dominant research paradigms. I recognize the historical exclusion of Indigenous and multicultural voices within mainstream psychology and a need for the articulation of Indigenous voices and knowledges within proposed research and interventions (Gergen & Gulerce, 1996).

Study Setting

The Northwest Territories, Yukon, and Nunavut are the three territories of Canada (Please see Figure 1). Collectively, they represent 39% of the total land mass of Canada, with 0.3% of the national population, and the three highest per capita Indigenous populations (Statistics Canada, 2016). There are 18 official Indigenous languages spoken and over 24 community and regional First Nations, Métis, and Inuit governments (Government of Canada, 2017).

Figure 1

Yukon, Northwest Territories, and Nunavut



Participant Selection

I interviewed 11 Indigenous experts in land-based programming from 10 different nations across the study area. The participants represented diverse genders, ages, First Nations, Métis, and Inuit backgrounds. Participants were chosen through purposive sampling, an intentional selection of community-vetted experts and a subsequent ‘snowball strategy’ (Polkinghorne, 2005, p. 140).

Relationship Building

Positionality is important in Indigenous methodologies (Lowan-Trudeau, 2012). I identify as Denesųłıné from the Northwest Territories (NWT), and my own connection to this field and worldview informed the research conceptualization. I had prior professional relationships with six of the participants and approached my work with known participants as an “insider” (Innes, 2009). This was countered by my “outsider” status as a researcher (Smith, 2012) and, at times, differences among our own cultural backgrounds. Time was spent building relationships with all participants, including travelling out on the land when invited.

Ethics approval for this study was obtained through the University Conjoint Faculties Research Ethics Board, and detailed community feedback sought through two research licence applications with the Aurora Research Institute and the Nunavut Research Institute. Elder mentors were consulted throughout the study.

Data Collection and Analysis

In-Depth Interviews

Audio-recorded, in-depth semi-structured interviews (Please see Table 1) took place in five different communities. The interview questions were translated into Inuktitut for Inuk participants.

Table 1

Interview Guide

1. Why has creating opportunities for Indigenous youth, adults, and/or Elders to spend time out on the land been important to you?
2. What do you think is an appropriate way of referring to these land-based initiatives?
3. Can you share with me some positive experiences or stories from your work in this field?
4. Has your experience been that there are health benefits from all the programs or bush trips you have been involved with, or do some activities or programs provide more benefits than others?
5. What are some of the personal barriers you have experienced in organizing programs or land practices in your community?
6. What would you like to see happen in the future with land-based health initiatives?
7. Is there anything else you feel is important or that I missed?

Preliminary Analysis

A process of narrative analysis was used for working with transcripts (Clandinin, 2013). The initial transcripts were sent back to the participants in draft format for clarification and feedback before becoming final copies (Clandinin, 2013). Important narratives from the informants were kept intact as much as possible in the research texts (Kovach (2010, p. 52). I utilized thematic analysis to generate themes from the final transcribed texts (Braun & Clarke, 2006; Kovach, 2010). My theoretical framing was within Indigenous ways of knowing with aspects of a social constructivist paradigm, which "values context in cultural construction of knowledge, language and communication" (Stewart, 2008, p. 50).

Final Analysis and Dissemination

To organize participant stories into a coherent format, broader themes and subthemes were identified (Braun & Clarke, 2006). During the analysis, I looked for connections between the experiences of participants in order to find commonalities across different geographic and cultural regions. Final results were presented back to the participants for feedback. Plain language summaries were completed for knowledge sharing in each geographic territory.

Results

Practitioners shared their extensive knowledge about land-based practices and assisted in framing the work they do into a common field of practice, which I will refer to as "land-based" healing and wellness. They were deeply grounded in their cultures and saw their own resilience and languages as rooted in a relationship with the land. The nuances of bringing land-based practices into the contemporary systems of education, health, and justice were described in detail. Participants shared stories and materials, including unpublished program reports on at least forty different land-based programs, including pilot programs and multi-year initiatives. They described land-based programming as an intricate, cross-disciplinary, and highly developed field of professional practice. As one program manager stated:

> *There is so much groundwork that needs to be done. You can't just go out and set up a tent and start a fire, I mean it's so much more than that. I don't think people realize how much more to it there is.*

Epistemology

The term "land-based" was described as a reminder of humanity's fundamental and inherent connection with the natural world and was agreed upon as a common English term across all regions for cross-cultural dialogue. This was after an acknowledgement of the diverse terminology describing land in each traditional language. This culturally-infused term differentiated the concept from western-based conceptions of nature which were seen to approach humans and the land as separate entities. For example, one practitioner explained, "it's a weird thing because we will say, we will *go out in nature*, but what the heck are we? We *are nature*, we can't get out in nature." See Table 2 describing this concept in detail.

Table 2

Land-Based Epistemology

Practitioner Quotes
Land-based is one of those words, it's a beautiful, wonderful term. It is bringing people back to the land and helping them become alive and remembering their humanity and their connection to all living things. We are the land. So, if we remember who we are, then the same miracle that we see all around us, will be us.
At some point, my grandmother…she told lots of stories about the land, the life of the land. She spoke to me one time, I might have been about 13, and she'd talk about how… we were the land, not from it, but we are the land. That I was the earth and I was the fire, and I was the water and I was the air, and all of them were things that contributed to give me life. And so, without any one of them I would not be able to exist.

The knowledge holders explained that the land is a healer, and described its central role in physical, mental, emotional, and spiritual health. They talked about its inherent connection with their way of being and seeing the world through their own land-based (traditional) languages. Further to this, they emphasized the "experiential language" of the land and described "land-based" as a lived connection built over generations, shared through the oral tradition, and understood only through direct practices or experiences.

Terminology

It was noted that the term "land-based" provided a foundational term that could be followed by any number of words including "program", "practice", "camp", "activity", "education", "pedagogy", "resilience", "health", "wellness", "healing", or "skills", describing different concepts united in an Indigenous epistemology. These designations were made for organizational and practical considerations within different program areas. All practitioners indicated that a "land-based program" ultimately promoted healing and wellness regardless of its disciplinary origins, and identified a need for more conceptual clarity around this. One program manager stated:

> *I'm always thinking of how to explain things in certain ways to funders…and I think it [having a common term] would be useful in terms of articulating what we do and why it's important. To have some kind of term, or a way that can concisely convey what it is, the model, that includes the health components and the education components together as one.*

Land-Based Programs

Within land-based practices, there was a distinction made between activities and programs. Many activities continue to be lived as a way of life including berry picking, ceremonial gatherings, and hide tanning. When it came to operating programs or services more formally through various organizations, the importance of programming was recognized. It is important to note that this recognition was not always comfortable, with practitioners noting an unfortunate irony within the contemporary context, specifically, that they now have to tailor their way of life into the Western concept of a "program" in order for this way of life to continue (please see Table 3).

Table 3

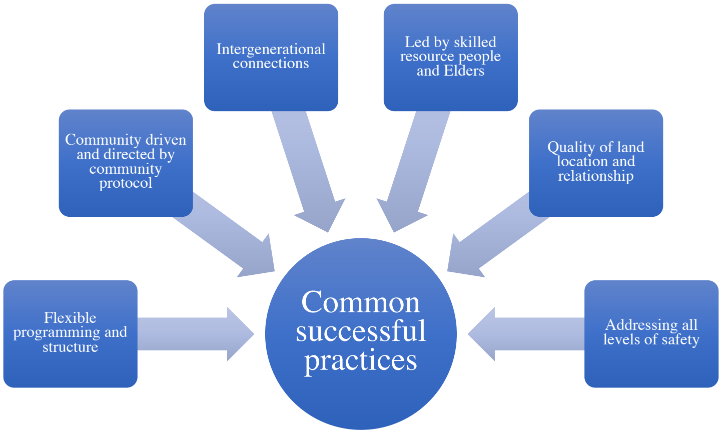
Importance of Land-Based Programs

Practitioner Quotes
I've been in this position where I try to find…third party funding to come in and pull people together. So that I provide the resources, what's needed for the exchange to happen for youth and Elders to be able to connect, just to facilitate what naturally happened for thousands of years, now you need to do it in a very formal kind of way...and then we have to go out and fight to create these opportunities. It's really kind of sad that you have to do things this way, but it's become necessary I guess.
Because there are some people who aren't fortunate to be able to go out on the land with their families, and so often, those organized trips are the only opportunities for them. Do we need to do this to help them [our people] to understand? If it takes 'program,' then let's do it. And later on, we'll just call it life...a program called *life*.

Throughout the interviews, six common elements of successful land-based programs were mentioned by the practitioners. These elements are presented in Figure 2.

Figure 2

Common Elements of Successful Land-based Programs



Land-Based Healing

"Land-based healing" was the term used that most closely aligned for application within the field of mental health. One practitioner explained this concept:

> *For me, I think that land-based healing is remembering who you are. I think it's returning to that place, becoming who you really are, and getting out of the illusion, or the stuff that the world taught us. I think land-based healing is remembering. It is when you can become...when you start to remember who you are by your connection.*

Land-based healing programs were organized within various organizations as supportive interventions for a range of mental health outcomes including addictions treatment and complex trauma recovery. All programs highlighted the importance of the land as beneficial to health at the individual and community level. The practitioners observed that people who participated showed improved health and social outcomes related to self-esteem, physical fitness, interpersonal relationships, educational goals, feelings of positive health and wellbeing, positive behavioural changes, connection to cultural identity, traditional language skills, and interest in environmental stewardship. Practitioners shared a vision for land-based activities continuing and expanding as a core way of addressing intergenerational healing and overall wellbeing. The main themes common across the conceptualization and operation of land-based healing programs are presented in Table 4.

Table 4

Land-Based Healing Program Subthemes

Subthemes	Practitioner Quotes
The innate healing ability of the land itself	The land will heal people. What I know, is that when I bring a group of people out on the land, the land knows exactly who they are, they know exactly what they are struggling with. May not know it intellectually, but it knows it on a way deeper level than the intellectual.
The importance of traditional healing and spirituality	Why we believe in it so much, because going back there [to traditional land location] brought, what we hear people saying, it brought a sense of belonging and it helped a lot of people in their memories of residential school. It helped them to remember and connect with who they were prior to being taken away to the residential schools.
Combining western therapeutic supports	We had people saying, "There's no way I am talking to a shrink, no way!", and I said, "No problem", I said "just come out to [the camp]". And then next thing you know, they are walking down the lake talking with the psychiatrist or the therapist and they are doing therapy and they don't realize it.

Professional Expertise

Finally, five areas were identified by practitioners as professional challenges which require expertise to navigate in land-based program operation (please see Table 5).

Table 5

Land-Based Program Professional Challenges

Subthemes	Practitioner Quotes
Cross-cultural barriers defining outcomes and importance	One of the biggest differences I see is that most of the time government programs are designed to be this age group, or this type of clientele. It is really compartmentalized. In terms of what we do, we see benefits straight across the board, from even the most challenging child or teenager…or an adult who has been struggling for a long time…And all we'd have to do is we'd tell them some stories…and that's *our* proof.
Accessing funding and resources	I think making sure the resources are there, and the money is definitely a stressor…a camp can cost up to $30,000-$40,000. It's almost like government will fund other things or will fund people who have Masters, PhDs, or some-called professional, and will offer a workshop here and will pay for that, but they don't want to give money to our Elders. And they are our greatest teachers, and we have to cherish this knowledge, but we don't get the recognition in terms of support for funding.
Logistics and safety	Logistically there's a lot of safety concerns with bringing a bunch of people out on the land who don't have much land-based experience…so there's a lot of that to manage, well and safely. What's been a challenge is the reporting process… the administration aspects of holding out on the land programs.
Intensity and unique challenges of the work	When I first started doing them [running land-programs], I didn't [really enjoy it], it was a lot of work, so much work….at the beginning when you are in the planning process, and dealing with all the logistics and stuff, you are super stressed out. And the more people want it [land-based healing] …that's where it's scary if it's person dependent. Because our spiritual counselor, he's just one guy…and he can't work 365 days a year and give give give…It could have the tendency that it could be really hard on them.
Colonial disruption of knowledge transmission	Getting people into the program and out on the land a lot of times it's really challenging in a bunch of different ways, like physically challenging… but for a lot of young Indigenous people it's challenging because they get out there and realize "Hey, no one ever taught me how to fillet a fish, like why can't I do that?" "No one ever taught me how to set a fish net, why? Why do I not know how to do this, I'm a native person, and I can't. I've never fired a gun, I don't know how to hunt, and I don't know how to fish and I can't even start a fire right now!", and I think it triggers a lot of feelings of shame which is pretty difficult to deal with.

Future Directions

All practitioners were committed to the work they do and motivated to overcome the many issues of cultural inequity in the current health and education systems. Ultimately, the hope is for these initiatives to become more commonplace and for all community members, Indigenous and non-Indigenous, to benefit from the inherent wisdom being used to restore collective health.

> You know... one time my brother got up to talk at a meeting. He said, "You know why I do this work?" He said, "I do this work for the less fortunate." And then he waited for a small while and he said, "Don't get me wrong, I am not talking about street people, I'm not talking about people who don't have a home or people that are having a hard time", he says, "I am talking about the less fortunate; I am talking about doctors and lawyers and judges, that's who I do this work for," he said, "because they don't know." (Practitioner quote)

Discussion

Many northern Indigenous communities have been vocal in their understanding that reconnecting people with land practices is a preferred mode of healing (Porter, 2012; "*Yukon to invest*", 2014). Both informal activities and contemporary programs are united under an integrated and culturally-determined epistemology, referred to in this study and corresponding literature as "land-based" (Dylan & Smallboy, 2016; Thompson et al., 2018; Walsh et al., 2018; Wildcat et al., 2014). For Indigenous practitioners, this cultural understanding differentiates it from other terms in the literature such as "outdoor", "adventure", "wilderness" or "nature-based" (Russell, 2001) which stem from Western conceptualizations and values of land ethic, often including a laden separateness or "stewardship over" (DeLancey, 2012) rather than *interdependence with* the natural world (Lowan, 2009). Lowan (2009) provides a detailed discussion of some of the key differences attributed to place from an Indigenous Canadian context, including describing the deep historical and spiritual relationship with the land which lives on through place names, languages, and storytelling.

Land-based programming, as described in this study, is a highly-developed field of practice, informed by Indigenous epistemologies within Indigenous communities. Fundamental to this are Indigenous ways of teaching and learning. Wildcat et al. states "Land-based education, in resurging and sustaining Indigenous life and knowledge, acts in direct contestation to settler colonialism and its drive to eliminate Indigenous life and Indigenous claims to land" (Wildcat et al., 2014, p. lll). Further, land-based pedagogy acts through engagement in direct conversations with and "on the land in a physical, social and spiritual sense" (p. 11).Through this direct engagement, participants helped articulate the concepts and healing benefits behind land-based healing, which are similar to those provided in other studies across Canada (Dobson & Brazzoni, 2016; Gesink et al., 2019; Hansen, 2018; Radu et al., 2014; Tobias & Richmond, 2014; Walsh et al., 2018). The *land as healer* wisdom held by knowledge keepers is now recognized in the literature demonstrating a myriad of scientifically validated health and wellness outcomes stemming from spending time connecting with natural areas (Barton et al., 2016; Barton & Pretty, 2010; Berman et al., 2008; Bratman et al., 2012; Bratman et al., 2015; James et al., 2015; Li, 2010; Maller et al., 2006). This key finding demonstrates the connection between culturally-validated knowledge around human-land relationships and the scientific evidence base.

The dispossession of land and culture through colonization and residential schools has fundamentally affected Indigenous mental health in Canada (Kant et al., 2013; Kirmayer et al., 2003) and participants in this study described many aspects of this disruption. The forcible alteration of the connection between land and identity, which sustains a sense of well-being, is within living memory in northern Canada with the last residential school closing in the late 1990's (Iglolliorte, 2011; Wilk et al., 2017). With this in mind, participants' knowledge provides support for the value of land-based healing as vital to the reconciliation process in Canada (Walsh et al., 2018). This includes not just the recognition of different vocabulary around "land-based" but the validation of a rich history and interconnectedness between land, languages, knowledges, health, and people, all of which are experienced through a living connection with traditional lands. The available literature and narratives presented provide evidence that land-based programs are a socially acceptable and culturally safe form of therapeutic care in Indigenous communities. In this case, recognition of 'practice-based' evidence becomes a relevant way of validating this field combined with the increasing evaluative data (Healey et al., 2016; Janelle et al., 2009; Ritchie et al., 2014). This means using "real-life practice as a basis for building evidence" (Sahota & Kastelic, 2012, p.108). This finding has direct applications for mental health policy.

Barriers to Accessing Land-Based Healing

Practitioners articulated that land-based activities continue to be a part of everyday life for people who have the time, knowledge, and resources. However, there are diverse contemporary conceptual and physical barriers to accessing the land and taking part in activities. Walsh et al. (2018) describes many challenges of practice, including costs; liability insurance; transportation; specialized labour; payments for Elders; strict rules and regulations of funding bodies; issues around the use of firearms; and programs not being considered mental health interventions (Walsh et al., p. 215). These concerns are echoed by northern practitioners.

The narratives presented highlight the concern that mental health service provision still operates in a western-dominated discourse, compartmentalizing services and creating a narrow view of mental health, and more specifically what practices are considered counselling and therapy (Hadjipavlou et al., 2018). This discourse is largely defined by western understandings of mental health and the language of evidence-based practice (EBP), which is still so often interpreted as empirically supported treatments (Carter & Goodheart, 2012; Laska et al., 2014). The result is mental health interventions that rely on systematic reviews, large effect sizes, statistical, and clinical significance (Sahota and Kastelic, 2012, p. 107). These facets of empirical evidence are often unrealistic to obtain in remote northern communities and culturally inappropriate (Janelle et al., 2009; Smith, 2012). Stewart (2008) points out that due to the disconnect between Indigenous and western approaches, and despite high needs in many communities, mental health services are underutilized in comparison to non-Indigenous populations in Canada. Further, the counselling of Indigenous people from non-Indigenous worldviews and frameworks has been presented as a form of continued colonial oppression, while discrediting traditional understandings of health and healing (Stewart, 2008).

Land-Based Healing and Wellness

Land-based healing and wellness programs are conceptually highly-developed and offer an alternative and complement to current mental health services and approaches to therapy (Dobson & Brazzoni, 2016; Walsh et al., 2018). Many of the cultural counsellors and Elders involved in these programs are in high demand in their respective communities, but not recognized as professionals by mainstream counselling organizations or licensing authorities. This study supports a call for the equitable inclusion of cultural counsellors in the strategy to improve care of Indigenous clients in the Canadian health care system (Hadjipavlou et al., 2018). Land-based interventions have the potential to draw on local strengths and keep people who need help close to home, instead of being sent to larger communities for mental health services (GNWT, 2014). Success is noted in the flexible program design, cultural competence, and the expertise of the people involved.

The rich narratives in this field illustrate many forms of integrative practice and opportunities for coexisting interventions that are feasible or currently operating in a range of communities (Walsh et al., 2018). A single program is able to address a range of related mental, physical, social, educational, and environmental concerns. For example, programs can offer culturally relevant addictions support, family counselling, rehabilitation of offenders, physical fitness, environmental stewardship, and life skills training. They also include benefits for cross-cultural professional training and awareness (Mashford-Pringle & Stewart, 2019). Indigenous youth are notably a key demographic for land-based interventions who benefit at all levels of land-based health promotion, prevention, and service delivery (Allen et al., 2013; Chandler & Lalonde, 1998; Corntassel & Hardbarger, 2019; Healey et al., 2016; MacDonald et al., 2013). I have proposed some working definitions as a way of framing this dialogue in the glossary.

I propose that discussions around culturally relevant intervention at the policy level should continue to acknowledge the reality and significance of Indigenous land connection within all levels of mental health service, from promotion to treatment, counselling and aftercare. This would continue to build on the ground-breaking work in recognizing the potential of Indigenous-led mental health solutions by many organizations, including the Aboriginal Healing Foundation, Thunderbird Partnership Foundation, and initiatives such as the Northwest Territories on the Land Collaborative. Creating opportunities and spaces for "land-making" within urban centres (Hatala et al., 2019) and land-based connection within counselling sessions or treatment programs are recommended as culturally relevant sources of therapy and resilience (Hadjipavlou et al., 2018; Stewart, 2008). Further research is recommended in order to increase our collective understanding and re-negotiate the terminology and working definitions proposed for cross-cultural dialogue across Turtle Island[3], keeping in mind the rich diversity within Indigenous communities.

Limitations

The three northern territories in this study are large, and although efforts were made to represent diverse knowledge groups, logistics limited the dataset of practitioners who could be interviewed to specific regions, therefore desired terminology may differ across communities.

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[3] Turtle Island refers to the continent of North America.

There is also a wealth of land-based terminology in the 18 traditional languages spoken throughout the study region which wasn't captured in this research. I feel it is important to note here, that in many areas of Canada, traditional land-access and land rights are severely restricted, with direct implications for this field of research, and knowledge is highly contextualized to place. This research examined narratives specifically from a northern Indigenous perspective and, although commonalities do exist in cultural teachings across Turtle Island, there is much diversity in these knowledges and land contexts, which will further inform this study's ability to be generalized to other locations. Finally, an Elder advisor reminded me of a limitation to this topic of research, stating that it is a concept that is ultimately "beyond words."

Conclusion

This study outlined the experiences of northern Indigenous practitioners in the field of land-based healing and wellness. In order to rediscover and re-establish a fundamental relationship with the land, one must first experience it directly through practical, culturally-rooted activities, languages, and interactions that return us to the land physically, emotionally, mentally, and spiritually. By bringing land connection to the forefront in the dialogue within Indigenous mental health in Canada, we can draw on the resilience of the land itself to more effectively overcome ongoing impacts of colonization and land-degradation. A healthy land relationship not only ensures the land's health, it also facilitates healthy relationships within ourselves, between one another, and within the larger world, leading to greater balance and mental wellbeing for future generations.

References

Allen, J., Hopper, K., Wexler, L., Kral, M., Rasmus, S., & Nystad, K. (2013). Mapping resilience pathways of Indigenous youth in five circumpolar communities. *Transcultural Psychiatry*, 1-31. https://doi.org/10.1177/1363461513497232

Andersson, N., & Ledogar, R. J. (2008). The CIET Aboriginal youth resilience studies: 14 years of capacity building and methods development in Canada. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health, 6*(2), 65-88. http://www.pimatisiwin.com/online/?page_id=228

Ballantyne, E. F. (2014). Dechinta Bush University: Mobilizing a knowledge economy of reciprocity, resurgence and decolonization. *Decolonization: Indigeneity, Education & Society, 3*(3), 67-85. https://jps.library.utoronto.ca/index.php/des/article/view/22238

Barton, J., Bragg, R., Pretty, J., Roberts, J., & Wood, C. (2016). The Wilderness Expedition. *Journal of Experiential Education, 39*(1), 59-72. https://doi.org/10.1177/1053825915626933

Barton, J., & Pretty, J. (2010). What is the best dose of nature and green exercise for improving mental health? A multi-study analysis. *Environment, Science and Technology, 44*, 3947-3955. https://doi.org/10.1021/es903183r

Berman, M., Jonides, J., & Kaplan, S. (2008). The cognitive benefits of interacting with nature. *Psychological Science, 19*(12). https://doi.org/10.1111/j.1467-9280.2008.02225.x

Bratman, G. N., Hamilton, J. P., & Daily, G. C. (2012, Feb). The impacts of nature experience on human cognitive function and mental health. *Ann N Y Acad Sci, 1249*, 118-136. https://doi.org/10.1111/j.1749-6632.2011.06400.x

Bratman, G. N., Hamilton, J. P., Hahn, K. S., Daily, G. C., & Gross, J. J. (2015, Jul 14). Nature experience reduces rumination and subgenual prefrontal cortex activation. *Proc*

Natl Acad Sci U S A, 112(28), 8567-8572. https://doi.org/10.1073/pnas.1510459112

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. https://doi.org/10.1191/1478088706qp063oa

Carter, J. A., & Goodheart, C. D. (2012). Interventions and evidence in counseling psychology: A view on evidence-based practice. In *APA handbook of counseling psychology, Vol. 1: Theories, research, and methods*. (pp. 155-166). https://doi.org/10.1037/13754-006

Chandler, M. J., & Lalonde, C. (1998). Cultural continuity as a hedge against suicide in Canada's First Nations. *Transcultural Psychiatry, 35*(2), 191-219. https://doi.org/10.1177/136346159803500202

Chandler, M. J., Lalonde, C. E., Sokol, B. W., & Hallett, D. (2003). Personal persistence, identity development, and suicide: A study of Native and Non-native North American adolescents. *Monogr Soc Res Child Dev, 68*(2), vii-viii, 1-130; discussion 131-138. https://doi.org/10.1111/1540-5834.00246

Clandinin, D. J. (2013). *Engaging in narrative inquiry* (1st ed.). Routledge. https://doi.org/10.4324/9781315429618

Corntassel, J., & Hardbarger, T. (2019). Educate to perpetuate: Land-based pedagogies and community resurgence. *International Review of Education, 65*(1), 87-116. https://doi.org/10.1007/s11159-018-9759-1

Cunsolo, W., A., Stephenson, E., Allen, J., Bourque, F., Drossos, A., Elgarøy, S., Kral, M., Mauro, I., Moses, J., Pearce, T., MacDonald, J., & Wexler, L. (2015). Examining relationships between climate change and mental health in the Circumpolar North [Original Paper]. *Regional Environmental Change, 15*(1), 169. https://doi.org/10.1007/s10113-014-0630-z

DeLancey, C. (2012). An Ecological Concept of Wilderness [Article]. *Ethics & the Environment, 17*(1), 25-44. https://doi.org/10.2979/ethicsenviro.17.1.25

Dobson, C., & Brazzoni, R. (2016). Land based healing: Carrier First Nations' addiction recovery program. *Journal of Indigenous Wellbeing, 1*(2), 9-17. https://journalindigenouswellbeing.com/journal_articles/land-based-healing-carrier-first-nations-addiction-recovery-program/

Durkalec, A., Furgal, C., Skinner, M. W., & Sheldon, T. (2015). Climate change influences on environment as a determinant of Indigenous health: Relationships to place, sea ice, and health in an Inuit community. *Soc Sci Med, 136-137*, 17-26. https://doi.org/10.1016/j.socscimed.2015.04.026

Dylan, A., & Smallboy, B. (2016). Land-based spirituality among the Cree of the Mushkegowuk territory. *Journal of Religion & Spirituality in Social Work: Social Thought, 35*(1-2), 108-119. https://doi.org/10.1080/15426432.2015.1067589

Gergen, K. J., & Gulerce, A. (1996). Psychological science in cultural context [Article]. *American Psychologist, 51*(5), 496. https://doi.org/10.1037/0003-066X.51.5.496

Gesink, D., Whiskeyjack, L., & Guimond, T. (2019). Perspectives on restoring health shared by Cree women, Alberta, Canada. *Health Promot Int, 34*(3), 454-461. https://doi.org/10.1093/heapro/dax099

GNWT. (2014). *Healing voices: The Minister's forum on addictions and community wellness*. D. o. H. a. S. S. Government of the Northwest Territories. https://www.hss.gov.nt.ca/sites/hss/files/ministers-forum-addictions-report.pdf

Goodkind, J. R., Hess, J. M., Gorman, B., & Parker, D. P. (2012). "We're still in a struggle": Dine resilience, survival, historical trauma, and healing. *Qual Health Res, 22*(8), 1019-1036. https://doi.org/10.1177/1049732312450324

Government of Canada. (2017). *Indigenous peoples and communities* https://www.rcaanc-cirnac.gc.ca/eng/1100100013785/1529102490303

Hadjipavlou, G., Varcoe, C., Tu, D., Dehoney, J., Price, R., & Browne, A. J. (2018). "All my relations": experiences and perceptions of Indigenous patients connecting with

Indigenous Elders in an inner city primary care partnership for mental health and well-being. *Canadian Medical Association Journal, 190*(20), E608. https://doi.org/10.1503/cmaj.171390

Hansen, J. (2018). Cree Elders' perspectives on land-based education: A case study. *Brock Education Journal, 28*, 74-91. https://doi.org/10.26522/brocked.v28i1.783

Hanson, G. (2012). *Strong woman's voices: Final report Jackson lake land based healing women's program August-September 2012 (Building a path to wellness)*. Kwanlin Dun First Nation. http://www.kwanlindun.com/images/uploads/KDFN%20Building%20a%20Path%20to%20Wellness%20-%20Evaluation%20Final%20Report%202012.pdf

Hatala, A. R., Morton, D., Njeze, C., Bird-Naytowhow, K., & Pearl, T. (2019). Re-imagining miyo-wicehtowin: Human-nature relations, land-making, and wellness among Indigenous youth in a Canadian urban context. *Soc Sci Med, 230*, 122-130. https://doi.org/10.1016/j.socscimed.2019.04.012

Healey, G. K., Noah, J., & Mearns, C. (2016). The Eight Ujarait (Rocks) Model: Supporting Inuit Adolescent Mental Health With an Intervention Model Based on Inuit Ways of Knowing. *International Journal of Indigenous Health, 11*(1). https://doi.org/10.18357/ijih111201614394

Hirsch, R., Furgal, C., Hackett, C., Sheldon, T., Bell, T., Angnatok, D., Winters, K., & Pamak, C. (2017). Going Off, Growing Strong: A program to enhance individual youth and community resilience in the face of change in Nain, Nunatsiavut. *Études/Inuit/Studies, 40*(1), 63-84. https://doi.org/10.7202/1040145ar

Hond, R., Ratima, M., & Edwards, W. (2019). The role of Maori community gardens in health promotion: a land-based community development response by Tangata Whenua, people of their land. *Glob Health Promot, 26*(3_suppl), 44-53. https://doi.org/10.1177/1757975919831603

Igloliorte, H. (2011). “We were so far away”: Exhibiting Inuit Oral Histories of Residential Schools. In E. Lehrer, C. E. Milton, & M. E. Patterson (Eds.), *Curating Difficult Knowledge*. Palgrave Macmillan Memory Studies,. https://doi.org/10.1057/9780230319554_2

Ilisaqsivik. (2014). "*Land based programming*". Retrieved April 21 from http://ilisaqsivik.ca/programs-and-services/land-based-programming

Innes, R. A. (2009). "Wait a second. Who are you anyways?" The insider/outsider debate and American Indian studies. *American Indian Quarterly, 33*(4), 440-461. www.jstor.org/stable/40388481

James, P., Banay, R. F., Hart, J. E., & Laden, F. (2015). A Review of the Health Benefits of Greenness. *Curr Epidemiol Rep, 2*(2), 131-142. https://doi.org/10.1007/s40471-015-0043-7

Janelle, A., Laliberte, A., & Ottawa, U. (2009). Promoting traditions: An evaluation of a wilderness activity among First Nations of Canada. *Australas Psychiatry, 17 Suppl 1*, S108-S111. https://doi.org/10.1080/10398560902948605

Kant, S., Vertinsky, I., Zheng, B., & Smith, P. M. (2013). Social, cultural, and land use determinants of the health and well-being of Aboriginal peoples of Canada: A path analysis [Article]. *Journal of Public Health Policy, 34*(3), 462-476. https://doi.org/10.1057/jphp.2013.27

Kirmayer, L., Dandeneau, S. F., Marshall, E., Phillips, M. K., & Williamson, K. J. (2011). Rethinking resilience from Indigenous perspectives. *Canadian Journal of Psychiatry, 56*(2), 84-91. https://doi.org/10.1177/070674371105600203

Kirmayer, L., Sehdev, M., Whitley, R., Dandeneau, S. F., & Isaac, C. (2009). Community resilience: Models, metaphors and measures. *International Journal of Indigenous Health, 5*(1), 62-117. https://doi.org/10.1046/j.1038-5282.2003.02010.x

Kirmayer, L., Simpson, C., & Cargo, M. (2003). Healing traditions: culture, community and mental health promotion with Canadian Aboriginal peoples. *Australasian*

Psychiatry, 11(s1), S15-S23. https://doi.org/10.1046/j.1038-5282.2003.02010.x

Kovach, M. (2010). *Indigenous methodologies: Characteristics, conversations, and contexts*. University of Toronto Press.

Laiti, T., & Sorbye, T. S. (2013). "Meahcceterapiija" adapting the family treatment to an Indigenous Sami population: Camping out with the family. *Proceedings of the 15th International Congress on Circumpolar Health, International Journal of Circumpolar Health, 72*(1), 605. https://doi.org/10.3402/ijch.v72i0.22447

Laska, K. M., Gurman, A. S., & Wampold, B. E. (2014). Expanding the lens of evidence-based practice in psychotherapy: A common factors perspective. *Psychotherapy, 51*(4), 467-481. https://doi.org/10.1037/a0034332

Laurie, V. (2013). *Land based treatment programs: Promising practices, key considerations, and ideas for action*. Council of Yukon First Nations Health and Social Development Department. http://www.kwanlindun.com/images/uploads/CYFN%20Report%20-%20Land%20Based%20Treatment%20Programs%20-%20Practices,%20Considerations%20&%20Ideas%20(2013).pdf

Li, Q. (2010). Effect of forest bathing trips on human immune function. *Environ Health Prev Med, 15*(1), 9-17. https://doi.org/10.1007/s12199-008-0068-3

Lowan, G. (2009). Exploring place from an Aboriginal perspective: Considerations for outdoor and environmental education. *Canadian Journal of Environmental Education, 14*, 42-58. https://cjee.lakeheadu.ca/article/view/885

Lowan-Trudeau, G. (2012). Methodological metissage: An interpretive Indigenous approach to environmental education research. *Canadian Journal of Environmental Education, 17*, 113-130. https://cjee.lakeheadu.ca/article/view/1082

Luig, T., Ballantyne, E. F., & Scott, K. K. (2011). Promoting well-being through land-based pedagogy. *International Journal of Health, Wellness & Society, 1*(3), 13-26. https://doi.org/10.18848/2156-8960/CGP/v01i03/41181

MacDonald, J. P., Ford, J. D., Willox, A. C., & Ross, N. A. (2013). A review of protective factors and causal mechanisms that enhance the mental health of Indigenous Circumpolar youth. *Int J Circumpolar Health, 72*, 21775. https://doi.org/10.3402/ijch.v72i0.21775

Maller, C., Townsend, M., Pryor, A., Brown, P., & St Leger, L. (2006). Healthy nature healthy people: 'contact with nature' as an upstream health promotion intervention for populations. *Health Promot Int, 21*(1), 45-54. https://doi.org/10.1093/heapro/dai032

Mashford-Pringle, A., & Stewart, S. L. (2019). Akiikaa (it is the land): exploring land-based experiences with university students in Ontario. *Global Health Promotion, 26*(3_suppl), 64-72. https://doi.org/10.1177/1757975919828722

Mehl-Madrona, L. (2005). *Coyote wisdom: The power of story in healing*. Bear & Company.

Menzies, P. (2008). Developing an Aboriginal healing model for intergenerational trauma. *International Journal of Health Promotion and Education, 46*(2), 41-48. https://doi.org/10.1080/14635240.2008.10708128

Mikraszewicz, K., & Richmond, C. (2019). Paddling the Biigtig: Mino biimadisiwin practiced through canoeing. *Soc Sci Med, 240*, 112548. https://doi.org/10.1016/j.socscimed.2019.112548

Oosterveer, T. M., & Young, T. K. (2015). Primary health care accessibility challenges in remote indigenous communities in Canada's North. *International Journal of Circumpolar Health, 74*(1). https://doi.org/10.3402/ijch.v74.29576

Porter, J. (2012). First Nations seek healing by reconnecting to the land. http://www.cbc.ca/news/canada/thunder-bay/first-nations-seek-healing-by-reconnecting-to-the-land-1.1149180

Radu, I., House, L. M., & Pashagumskum, E. (2014). Land, life, and knowledge in Chisasibi: Intergenerational healing in the bush. *Decolonization: Indigeneity, Education & Society, 3*(3), 86-105. https://jps.library.utoronto.ca/index.php/des/article/view/21219

Redvers, N., Marianayagam, J., & Blondin, B. (2019). Improving access to Indigenous medicine for patients in hospital-based settings: a challenge for health systems in northern Canada. *Int J Circumpolar Health, 78*(1), 1577093. https://doi.org/10.1080/22423982.2019.1577093

Richmond, C. A. M., & Ross, N. A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health & Place, 15*(2), 403-411. https://doi.org/http://dx.doi.org/10.1016/j.healthplace.2008.07.004

Ritchie, S. D., Wabano, M.-J., Russell, K., Enosse, L., & Young, N. L. (2014). Promoting resilience and wellbeing through an outdoor intervention designed for Aboriginal adolescents. *Rural and Remote Health, 14*(1), 1-19. www.rrh.org.au/journal/article/2523

Russell, K. C. (2001). What is wilderness therapy? *The Journal of Experiential Education, 24*(2), 70-79. https://doi.org/10.1177/105382590102400203

Simpson, L. B. (2014). Land as pedagogy: Nishnaabeg intelligence and rebellious transformation. *Decolonization: Indigeneity, Education & Society, 3*(3), 1-25. https://jps.library.utoronto.ca/index.php/des/article/view/22170

Smethurst, T. (2012). Well-being and ethnic identity promotion for Aboriginal youth: A community based mixed methods study of tribal journeys. *Thesis Department of Psychology University of Victoria*, 1-118. http://voyager.library.uvic.ca/vwebv/holdingsInfo?bibId=2959572

Smith, L. T. (2012). *Decolonizing methodologies: Research and Indigenous peoples*. Zed Books Ltd.

Statistics Canada. (2016). *Statistics on Indigenous Peoples* Statistics Canada, Government of Canada. https://www.statcan.gc.ca/eng/subjects-start/indigenous_peoples

Stewart, S. L. (2008). Promoting Indigenous mental health: Cultural perspectives on healing from Native counsellors in Canada. *International Journal of Health Promotion and Education, 46*(2), 49-56. https://doi.org/10.1080/14635240.2008.10708129

Takano, T. (2005). Connections with the land: Land-skills courses in Igloolik, Nunavut. *Ethnography, 6*(4), 463-486. https://doi.org/10.1177/1466138105062472

Thompson, H. A., Mason, C. W., & Robidoux, M. A. (2018). Hoop House Gardening in the Wapekeka First Nation as an Extension of Land-Based Food Practices. *Arctic, 71*(4), 407-421. https://doi.org/10.14430/arctic4746

Thunderbird Partnership Foundation. (2018). *Land for healing: Developing a First Nations land-based service delivery model*. https://thunderbirdpf.org/wp-content/uploads/2018/07/Thunderbirdpf-LandforHealing-Document-SQ.pdf

Tidlumaluk, I. M. (2007). Kayak adventureres deliver message to Inuit youth: Live life! . *Inuktitut Magazine, 102*, 38-45. https://www.itk.ca/inuktitut-issue-102/

Tobias, J. K., & Richmond, C. A. (2014). "That land means everything to us as Anishinaabe....": Environmental dispossession and resilience on the North Shore of Lake Superior. *Health Place, 29*, 26-33. https://doi.org/10.1016/j.healthplace.2014.05.008

Tousignant, M., & Sioui, N. (2009). Resilience and Aboriginal communities in crisis: Theory and interventions. *International Journal of Indigenous Health, 5*(1), 43-61. https://doi.org/10.3138/ijih.v5i1.28977

Walsh, R., Danto, D., & Sommerfeld, J. (2018). Land-Based Intervention: a Qualitative Study of the Knowledge and Practices Associated with One Approach to Mental Health in a Cree Community. *International Journal of Mental Health and Addiction, 18*(1), 207-221. https://doi.org/10.1007/s11469-018-9996-3

Wexler, L. M., DiFluvio, G., & Burke, T. K. (2009). Resilience and marginalized youth: Making a case for personal and collective meaning-making as part of resilience research in public health. *Social Science & Medicine, 69*(4), 565-570. https://doi.org/10.1016/j.socscimed.2009.06.022

Wexler, L. M., & Gone, J. P. (2012). Culturally responsive suicide prevention in Indigenous communities: unexamined assumptions and new possibilities. *Am J Public Health, 102*(5), 800-806. https://doi.org/10.2105/ajph.2011.300432

Wildcat, M., McDonald, M., Irlabacher-Fox, S., & Coulthard, G. (2014). Learning from the land: Indigenous land based pedagogy and decolonization. *Decolonization: Indigeneity, Education & Society, 3*(3), I-XV. https://jps.library.utoronto.ca/index.php/des/article/view/22248

Wilk, P., Maltby, A., & Cooke, M. (2017). Residential schools and the effects on Indigenous health and well-being in Canada-a scoping review. *Public Health Rev, 38*, 8. https://doi.org/10.1186/s40985-017-0055-6

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Fernwood Publishers.

Young, T. K., Chatwood, S., Ng, C., Young, R. W., & Marchildon, G. P. (2019). The north is not all the same: comparing health system performance in 18 northern regions of Canada. *Int J Circumpolar Health, 78*(1), 1697474. https://doi.org/10.1080/22423982.2019.1697474

Yukon to invest $1 million in Kwanlin Dun healing camp. (2014, May 28, 2014). Canadian Broadcasting Cooporation. Retrieved May 30 from http://www.cbc.ca/news/canada/north/yukon-to-invest-1-million-in-kwanlin-dun-healing-camp-1.2657187

Zoe, J. B. (2012). Ekwo and Tlicho Naowa/ Caribou and Tlicho language, culture and way of life: An evolving relationship and shared history. *Rangifer Special Issue, 32*(20), 69-74. https://doi.org/10.7557/2.32.2.2253

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A Culturally Safe and Trauma-Informed Sexually Transmitted Blood Borne Infection (STBBI) Intervention Designed by and for Incarcerated Indigenous Women and Gender-Diverse People

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Indigenous women are grossly overrepresented both within the federal correctional system and among Sexually Transmitted Blood Borne Infection (STBBI) diagnoses in Canada. Mainstream approaches continue to fall short in addressing Human Immunodeficiency Virus, Hepatitis C and other STBBIs within this population. In this paper, we argue that, in order to be successful, STBBI programs and services must hinge on meaningful community participation, community ownership, and incorporate Indigenous knowledge, perspectives and decolonizing methodologies. Further, they must take a strengths-based approach and focus on healing and resiliency rather than challenges and deficits.

Keywords: *STBBI, Indigenous, incarceration, women, gender-diverse, cultural safety, trauma-informed, First Nations, Inuit, Métis, Canada*

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Introduction

When it comes to Human Immunodeficiency Virus (HIV) and other STBBI prevention efforts, there is an increasing awareness around the importance of having Indigenous women leading the prevention efforts for their peers and communities (Peltier et al., 2013; Unger, Soto, & Thomas, 2008). This strengths-based notion acknowledges that people are the experts of their own lives and uplifts the belief that a person has the strength and ability to overcome adverse experiences. The benefits to strengths-based perspective is further demonstrated in a recent report from the Office of the Auditor General of Canada (2017), which recognized that Indigenous women benefit from greater access to gender-based, culturally appropriate programming in prisons. A strengths-based perspective is important to keep in mind when approaching the overrepresentation of incarcerated Indigenous women in the occurrence of HIV and other STBBI diagnoses. Indigenous women living in Canada (inclusive of First Nations, Inuit, and Métis) are grossly overrepresented both within the federal correctional system and among STBBI diagnoses. In fact, Indigenous women now represent the fastest growing prison segment in Canada (OCI, 2019). Indigenous women and girls are also acquiring HIV at a significantly higher rate than other Canadian women and girls (PHAC, 2015). Furthermore, the prevalence rates of Hepatitis C (HCV) and HIV are higher among federally incarcerated Indigenous women compared to any other population group in Canada (OCI, 2018).

While the overrepresentation of Indigenous women in corrections has been recognized for decades, it continues to grow. The most recent Annual Report from the Office of the Correctional Investigator of Canada (2019) found that since 2009-2010, there has been an increase of 73.8% within the population of federally sentenced Indigenous women. Complicating the matter further is the lack of access to culturally safe and trauma-informed healthcare both within and outside of federal correctional institutions. This demonstrates that mainstream approaches within the Canadian justice system and the healthcare system are not responding to the unique needs and circumstances of Indigenous women and therefore, they will continue to fall short in addressing HIV health-care related needs within this population (Ryan et al., 2019). These failings are why strengths-based programs, which acknowledge the enduring strength and resiliency of Indigenous women, are more important than ever.

Despite these challenges, many strengths and opportunities exist within the population to respond to both the over-incarceration and overrepresentation of Indigenous women among STBBI diagnoses. Furthermore, there is growing recognition of the need for approaches to successfully reintegrate Indigenous offenders and for STBBI prevention measures to be Indigenous-led and culturally grounded. Building off this momentum and in response to the unique needs of incarcerated Indigenous women, the Native Women's Association of Canada has developed the Walking the RED Path (**R**e-forging connections, **E**mpowering Indigenous women to heal, and **D**riving change for a healthy future)– HIV/HCV Initiative. Throughout this article, we outline the process and methods and share preliminary results from the project as well as our insights into the importance of this emerging best practice.

Background

Prior to colonization, Indigenous women were honoured for their unique role and for the power they held in their abilities to give and nurture life (Stinson, 2016-a) and while roles between men and women were different, both were valued and respected. These roles were disrupted by the arrival of settler colonists from Europe and the Western values of patriarchy and capitalism they brought with them (Stinson, 2016-b). Through acts of colonialist violence like the implementation of *The Indian Act*, theft of Indigenous lands, the Residential School System and the Sixties Scoop, Indigenous women saw their rights and ways of life severely disrupted and, in some cases, stripped away entirely. Perhaps the most devastating result of centuries of human rights violations perpetrated and condoned by the Canadian state, which has amounted to cultural genocide, is the epidemic of missing and murdered Indigenous women and girls across Turtle Island and Inuit Nunangat (MMIWG, 2019).

The traumatic impacts of these historical and ongoing attempts at colonization and assimilation can be directly linked to multiple health and social inequities that can lead to higher rates of substance use, sex work, mental health difficulties, abuse, and violence (Marsh et al., 2015) all of which may contribute to greater risk of STBBIs and incarceration. These increased prevalence rates combined with the entrenched racist values within the criminal justice and health care systems can explain why Indigenous women are overrepresented in federal correctional facilities and among STBBI diagnoses. Despite representing just 4% of the Canadian female population (Arriagada, 2016), Indigenous women accounted for 41.4% of all federally incarcerated women in the 2018-2019 fiscal year (OCI, 2019).

The connection between childhood abuse and incarceration is well known. People abused during childhood may be at an increased risk of intergenerational transmission of abuse and substance use, both of which can increase interactions with the criminal justice system and imprisonment (Bodkin et al., 2019). The 2018-2019 Correctional Investigator of Canada's report painted a stark reality of incarcerated Indigenous women's experiences and challenges in CSC's federal institutions. In fact, 92% of federally sentenced Indigenous women were assessed to have moderate to high substance abuse needs and 72% reported experiencing abuse in their childhood (OCI, 2019). Given that the main mode of transmission of HIV and HCV is injection drug use for Indigenous women (PHAC, 2014), this is a cause for concern.

Canada's Federal Prison Landscape for Women

The total number of federally sentenced women in custody in 2018-19 was 705, with 292 (41.4%) being Indigenous (OCI, 2019). While Indigenous women are overrepresented across all federal correctional institutions, the issue of overrepresentation is even greater in the Prairie regions where the percentage of federally incarcerated Indigenous women is nearly 60% (OCI, 2019).

Federally sentenced women can be housed in one of five Correctional Service of Canada (CSC) run federal institutions or one Healing Lodge. Additionally, there are two Section 81-run Healing Lodges for women. Section 81 refers to a section of the Corrections and Conditional Release Act (1992) which is the legislative framework for CSC and includes several additional regulations and directives for prisons. Section 81 was created in response to the over-representation of Indigenous Peoples in federal prisons. CSC and Section 81 Healing Lodges have similar intents and purposes; however, they are operationalized, governed, and administered in very different ways (CSC, 2015). As Section 81 Healing Lodges are run by an Indigenous community, they provide greater opportunities for community control and the provision of culturally safe and trauma-informed services and supports. Consequently, “offenders who participated in Healing Lodge programs had very low rates of reoffending upon release” (Office of the Auditor General, 2017, p. 8). However, Healing Lodges are only able to house a minimum number of medium security individuals on an infrequent basis. Given that Indigenous women are disproportionately designated higher risk offenders, making up 56% of all women in maximum-security (OCI, 2019), many incarcerated Indigenous women are not able to access Healing Lodges. This presents a great barrier to accessing culturally safe and trauma-informed care.

RED Path Project

The rising incarceration rates amongst Indigenous women and the high rates of HIV and HCV, prompted the development of the RED Path project. This is a five-year Public Health Agency of Canada (PHAC) funded project, currently in its fourth year, that aims to develop sustainable, evidence-based, and culturally safe STBBI interventions for Indigenous women in four correctional institutions including: Fraser Valley Institution for Women, Edmonton Institute for Women, Okimaw Ohci Healing Lodge for Aboriginal Women, and Buffalo Sage Wellness House. The project provided NWAC staff the opportunity to build relationships and engage with incarcerated Indigenous women on their knowledge of STBBIs, their perceptions on effective interventions, and gaps in access to services to inform the development of project activities. Upon the completion of the project, policy recommendations and learnings from the development and implementation of the RED Path project will be shared with CSC in hopes of facilitating institutional buy-in and continued uptake.

Process/Methods

Community Engagement

Community-led and community owned projects have repeatedly been shown to be more effective and have more support and engagement from participants (Goodman, 1998; Minkler et al., 2008). They are also more likely to successfully change behaviour and improve health outcomes (Elder et al., 1993). This approach is necessary and integral to Indigenous research, program, and policy development and is underscored in a number of documents including the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2008), the Truth and Reconciliation Commission of Canada’s Calls to Action (TRC, 2015) and the Tri-Council Policy Statement 2 (CIHR et al., 2018). Programs that center community engagement in Indigenous communities are viewed as relevant, beneficial, and have improved uptake (Ball & Janyst, 2008; Smylie et al., 2016). Furthermore, research and programs with Indigenous populations can be enhanced through the inclusion of Indigenous knowledges and decolonizing methodologies (Ryan et al., 2019). Additionally, over the past two decades, evidence has repeatedly indicated that connection to Indigenous culture can not only serve as a protective factor in terms of mental health and substance use but can also foster mental wellness at the individual, family, and community level (AFN & GoC, 2015; Brady, 1995; Dijk et al., 2017).

According to the World Health Organization (2007), HIV health promotion programming in prisons are more likely to be effective if developed and delivered by peers. Further, principles of Greater/Meaningful Involvement of People

Living with HIV/AIDS (GIPA/MIPA) have been shown to be a powerful tool to identify priorities, needs, and common grounds within a diverse group. Therefore, to ensure that the project is seen as valid, beneficial, and relevant, and to generate community support and program uptake, the RED Path project brought individuals living with or affected by HIV (including project staff), HCV, and other STBBIs into the planning and development of project activities.

Program Development

Following ethics approval through Health Canada and PHAC's Research Ethics Board, the RED Path team held seven sharing circles in four institutions with 62 women (34 First Nations, 16 Métis, one Inuk, and 11 identified as other or preferred not to say). The sharing circles were opened and closed by an Elder with a prayer and smudge. Sharing circles are accessible, recognize community knowledge, practice, and experiences and allow equal opportunities for participants to share, and express knowledge through a process of open dialogue and reflection (Lavallée, 2009; Rothe et al., 2009). Sharing circles create a safe environment for women to talk about their experiences surrounding STBBIs and effective interventions and supports. This fostered a sense of community that worked to decrease feelings of isolation and stigmatization while providing a link to culture within the institutional setting.

Program Delivery

The knowledge and perspectives gathered through the sharing circles were synthesized by project staff to inform the development of an interactive, culturally safe, gender based, and trauma-informed STBBI knowledge exchange activity. This activity was then piloted in all four institutions. Feedback and questions from participants were then used to revise, refine, and optimize the knowledge exchange activity. This ensured that it was continually meeting the needs of the participants and target audience. Ultimately, it was incarcerated Indigenous women and gender-diverse peoples who determined what content would be included in the activity and how it was delivered. The activity aimed to increase knowledge, reduce stigma, dispel misconceptions, and increase awareness of STBBIs. This in turn would inform participants' future choices surrounding prevention and treatment of STBBIs and increase awareness about services available to them, both within and outside of the institutions. It also aimed to increase uptake of prevention and harm reduction measures, to improve health outcomes, and prevent further transmission of STBBIs. Finally, the resource aimed to increase participants' capacity in their ability to navigate and ultimately access health, social, and support services available to them within the correctional facility and upon release.

The knowledge exchange activity was developed into three learning modules delivered over three days. The first module focused on Healthy Relationships and Sexual Health 101, the second on STBBI Prevention and Harm Reduction and the third on STBBI Treatment and Support. First Nations, Inuit, and Métis cultures, traditions, and ways of knowing were emphasized and weaved throughout the modules. Each day of the knowledge exchange activity was designed in a way that it could stand alone in its own right, or if taken consecutively, could provide participants with a well-rounded understanding of STBBIs including healthy sexuality, harm reduction, treatments, and supports. To ensure Indigenous knowledge and methodologies were embedded in our approach, each module was opened and closed with a land acknowledgement, prayer, and smudge led by an Elder and always started with drumming and singing the "Strong Women Song". According to oral history, the Strong Women's song was created by Anishinaabe women, who were in solitary confinement in a Prison for Women in Kingston, Ontario in the 1970's (Davis & Rice, n.d.; *Strong Women's Song*, n.d.). RED Path facilitators shared the history and importance of the song and used it as an opportunity to ground the activity in culture.

Evaluation

After attending each module, participants were administered an evaluation survey to retrospectively assess changes to their knowledge, behaviours, and self-efficacy related to HIV STBBIs. Retrospective analysis provided participants with the opportunity to reflect on whether the knowledge exchange activity positively impacted their knowledge, capacity, and behavior. Qualitative data was also collected from the sharing circles and thematically analyzed by project staff.

Key Informant Interviews

Finally, key informant interviews were conducted with health and social service staff within the four institutions. This allowed project staff to gain an in-depth understanding of interviewees' views, perceptions, and opinions of the RED Path project and to gather insights on the observed outcomes. In total, five health and social program staff across three of the institutions were interviewed. Interviews were semi-structured and approximately 45 minutes long.

Results

In total, 21 knowledge exchange activities were delivered to 232 incarcerated women and gender-diverse peoples during seven visits to the four institutions between July 2019 and February 2020. Surveys were anonymous and administered for all three learning modules. Therefore, it was impossible to cross-reference which participants had participated in the evaluation survey more than once (by attending more than one module). To ensure that all responses were considered, surveys were analysed separately, each being treated as an isolated participant and each module was considered independently. Further, evaluation surveys were entirely optional and not always completed by all participants. Four hundred and fifty-eight evaluation surveys were received from all three modules. Of these respondents, 226 identified as First Nations, 88 identified as Métis, none identified as Inuit, and 144 preferred not to say or identified as "other". According to aggregated data from the evaluation surveys, after participating in the knowledge exchange activity, 83% of respondents indicated an increased willingness to ask about what health, social, and support services are available to them within the correctional institution. Similarly, 85% of respondents reported an increased willingness to use health, social, and support services within and outside the correctional institution. Further, 86% reported that their ability to change personal behaviours to reduce their risk of getting STBBIs had increased and 67% of respondents rated their level of knowledge of STBBIs topics as "excellent". This marks a 50% increase in the reported strong knowledge of STBBIs (see appendix A for more details).

Qualitative data gathered during key informant interviews with health and social service staff within the correctional facilities similarly indicated that staff observed an increased level of knowledge surrounding STBBIs amongst participants. One interviewee noted participants remembered from modules that were held six to eight months prior. Another interviewee noticed an increase in informed questions and knowledgeable discussions while others reported that information provided during the knowledge exchange activity was valuable and relevant.

> *"They seemed to have learned things they were not aware of and many indicated that their knowledge had increased."*-Interviewee A
> *"Women were very engaged and involved, women who are very shy were opening up. The facilitators were great at delivering info. Was very impressed at the healthy impact on the women and gave them a lot to take control of their health"* – Interviewee C

Key informants also noted an increased involvement and an improved ability to navigate and use services available to participants following the knowledge exchange activity. Some interviewees commented on the positive repercussion of having open discussions and starting a dialogue on stigmatizing subject matter.

> *"Bringing these programs into the institution and making them accessible, making it fun really helped. There was a lot of laughter and facilitators were able to bring light to things. It seemed like the more fun it was the more women became relaxed and were able open up and ask more questions. And the person who talked about their experience with HIV really helped the women open up and engage."* – Interviewee C

> *"RED Path program has to be given a lot of credit, there was a lot of eye opening and good info, took the stigma off of things – took the stigma off of HIV in particular, that's a big one!"* – Interviewee D

Discussion

Due to the intersectionality of Indigenous status and incarceration status, incarcerated Indigenous women represent a hard to reach, marginalized community within a marginalized population. Their needs are complex as they face compounding, multifaceted challenges and barriers. To succeed, efforts that address these needs must be community-driven, community-led and integrate Indigenous knowledge and methodologies. Provided that individuals cannot be considered separately from their environments, interventions must extend beyond the individual level (Elder et al., 1993). Further, interventions that do not meaningfully engage the target population will not be valid, useful, beneficial or relevant, and this will likely translate to decreased uptake and lack of success.

While we do consider this project to be Indigenous-led, it is important to point out that the majority of participants identified as First Nations, with a smaller proportion identifying as Métis and only one as Inuk. However, these percentages do mirror findings from the most recent annual report of the Correctional Investigator which found that, First Nations women account for nearly 80% of the federally incarcerated Indigenous population, with Métis women accounting for just under 20% and Inuit women representing less than one percent (OCI, 2019). These findings are important for informing distinctions-based programs which consider the unique realities and needs of the populations they are intended for. Furthermore, our findings add to an important gap in the need for distinctions-based programming within CSC as Indigenous offenders are typically treated as one homogenous group, conceptually and methodologically. This is evidenced by the lack of Métis and Inuit programming in prisons, with programming heavily focused on First Nations cultural knowledge such as the seven grandfather teachings and the medicine wheel. Conversely, in recognition of the heterogeneity of the population and the importance of taking a distinctions-based approach, the RED Path knowledge exchange activity includes First Nations, Inuit, and Métis cultural teachings and language throughout including videos by Elders.

Data from the RED Path project indicates that overall, participants found the project was a positive and empowering experience that was relevant, effective and met their needs. This, in large part, can be attributed to the fact that the RED Path project hinged on meaningful community participation and community ownership. Planning, development, and implementation of the project was led and directed by incarcerated Indigenous women. The RED Path project incorporates traditional Indigenous knowledge, perspectives, and decolonizing methodologies by utilizing sharing circles, ceremonies, an Elder's guidance, and cultural teachings as they pertain to sexual health, harm reduction, and STBBIs.

The RED Path project provides evidence for the efficacy of taking a strengths-based approach to STBBI prevention that focuses on healing and resiliency instead of the challenges and deficits within the population. Peltier et al. (2013) have pointed out that researchers have been so focused on the determinants of Indigenous ill health that few have attempted to look at wellness for Indigenous women living with or affected by HIV. Furthermore, they have argued that HIV-related programs and services must build on Indigenous Peoples strengths, including cultural knowledge and assets. In fact, Ryan et al. (2019) argue that mainstream HIV programs and services that do not resonate culturally will continue to be unsuccessful. Therefore, this project fills a gap in the lack of access to historically and culturally grounded HIV prevention programs that are required to effectively confront the HIV epidemic among Indigenous women living with and at risk of HIV (Peltier et al., 2013).

Conclusion

In recognition of the ongoing colonial violence against Indigenous women as demonstrated by the over-incarceration of Indigenous women and their increased vulnerabilities to the social drivers that lead to STBBIs and incarceration, now more than ever, programs and services must be designed to meet the distinct and unique needs of Indigenous women, girls and gender-diverse peoples. Therefore, initiatives like The RED Path project that are Indigenous-led and involve the full participation of incarcerated Indigenous women from conception to completion should be used as a best practice when working with this population. This strengths-based, trauma-informed, and culturally safe project offers a pathway to healing through a decolonized approach to health promotion and STBBI prevention.

References

Arriagada, P. (2016). *First Nations, Métis and Inuit Women*. Statistics Canada. https://www150.statcan.gc.ca/n1/pub/89-503-x/2015001/article/14313-eng.htm

Assembly of First NAtions, & Government of Canada. (2015). *First Nations Mental Wellness Continuum Framework*. Government of Canada. https://thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf

Ball, J., & Janyst, P. (2008). Enacting Research Ethics in Partnerships with Indigenous Communities in Canada: "Do it in a Good Way." *Journal of*

Empirical Research on Human Research Ethics, *3*(2), 33–51. https://doi.org/10.1525/jer.2008.3.2.33

Bodkin, C., Pivnick, L., Bondy, S. J., Ziegler, C., Martin, R. E., Jernigan, C., & Kouyoumdjian, F. (2019). History of Childhood Abuse in Populations Incarcerated in Canada: A Systematic Review and Meta-Analysis. *American Journal of Public Health*, *109*(3), e1–e11. https://doi.org/10.2105/AJPH.2018.304855

Brady, M. (1995). Culture in treatment, culture as treatment. A critical appraisal of developments in addictions programs for indigenous North Americans and Australians. *Social Science & Medicine*, *41*(11), 1487–1498. https://doi.org/10.1016/0277-9536(95)00055-C

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council. (2018). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2*. Government of Canada. https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf

Correctional Service Canada. (2015). *Aboriginal community development in corrections: Enhancing the Role of Aboriginal Communities Booklet*. Government of Canada. https://www.csc-scc.gc.ca/aboriginal/11-eng.shtml

Corrections and Conditional Release Act, S. C. C 20 (1992). https://www.canlii.org/en/ca/laws/stat/sc-1992-c-20/latest/sc-1992-c-20.html#document

Davis, M., & Rice, B. (n.d.). *Daughters, Sisters, Mothers and Wives: An Anishnaabe Reader*. Ontario Native Literacy Coalition. https://onlc.ca/wp-content/uploads/2017/05/Anishinaabe-Language-Wookbook.pdf

Dijk, C. F.-V., Rowan, M., Dell, C., Mushquash, C., Hopkins, C., Fornssler, B., Hall, L., Mykota, D., Farag, M., & Shea, B. (2017). Honoring Indigenous culture-as-intervention: Development and validity of the Native Wellness AssessmentTM. *Journal of Ethnicity in Substance Abuse*, *16*(2), 181–218. https://doi.org/10.1080/15332640.2015.1119774

Elder, J. P., Schmid, T. L., Dower, P., & Hedlund, S. (1993). Community heart health programs: Components, rationale, and strategies for effective interventions. *Journal of Public Health Policy*, *14*(4), 463–479. https://doi.org/10.2307/3342878

Goodman, R. M. (1998). Principals and tools for evaluating community-based prevention and health promotion programs. *Journal of Public Health Management and Practice: JPHMP*, *4*(2), 37–47. https://doi.org/10.1097/00124784-199803000-00006

Lavallée, L. F. (2009). Practical Application of an Indigenous Research Framework and Two Qualitative Indigenous Research Methods: Sharing Circles and Anishnaabe Symbol-Based Reflection. *International Journal of Qualitative Methods*, *8*(1), 21–40. https://doi.org/10.1177/160940690900800103

Marsh, T. N., Coholic, D., Cote-Meek, S., & Najavits, L. M. (2015). Blending Aboriginal and Western healing methods to treat intergenerational trauma with substance use disorder in Aboriginal peoples who live in Northeastern Ontario, Canada. *Harm Reduction Journal*, *12*.

https://doi.org/10.1186/s12954-015-0046-1

Minkler, M., Wallerstein, N., & Wilson, N. (2008). Improving health through community organization and community building. In *Health behavior and health education: Theory, research, and practice* (4th Edition, pp. 287–312). Jossey-Bass.

MMIWG. (2019). *Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls*. //www.mmiwg-ffada.ca/final-report/

Office of the Auditor General. (2017). *Preparing Indigenous Offenders for Release*. Correctional Service Canada. https://www.oag-bvg.gc.ca/internet/English/osh_20170215_e_41987.html

Office of the Correctional Investigator. (2018). *Office of the Correctional Investigator Annual Report 2017-2018*. Government of Canada. https://www.oci-bec.gc.ca/cnt/rpt/annrpt/annrpt20172018-eng.aspx

Office of the Correctional Investigator. (2019). *Office of the Correctional Investigator Annual Report 2018-2019*. Government of Canada. https://www.oci-bec.gc.ca/cnt/rpt/annrpt/annrpt20182019-eng.aspx

Public Health Agency of Canada. (2014). *HIV/AIDS Epi Updates: HIV/AIDS Among Aboriginal People in Canada*. https://pacificaidsnetwork.org/files/2015/02/Chapter-8-Epi-Update_ENG_Web.pdf

Rothe, J. P., Ozegovic, D., & Carroll, L. J. (2009). Innovation in qualitative interviews: “Sharing Circles” in a First Nations community. *Injury Prevention*, *15*(5), 334–340. https://doi.org/10.1136/ip.2008.021261

Ryan, C., Jackson, R., Gabel, C., King, A. M., Masching, R., & Thomas, E. C. (2020). *Successful Aging: Indigenous Men Aging in a Good Way with HIV/AIDS*. https://doi.org/10.1017/s0714980819000497

Smylie, J., Kirst, M., McShane, K., Firestone, M., Wolfe, S., & O’Campo, P. (2016). Understanding the role of Indigenous community participation in Indigenous prenatal and infant-toddler health promotion programs in Canada: A realist review. *Social Science & Medicine*, *150*, 128–143. https://doi.org/10.1016/j.socscimed.2015.12.019

Stinson, J. (2016)-a. Colonialism and its impacts. *FemNorthNet*: *Resource Development in Northern Communities: Local Women Matter #3*. Ottawa: Canadian Research Institute for the Advancement of Women. http://fnn.criaw-icref.ca/images/userfiles/files/LWM3_ColonialismImpacts.pdf

Stinson, J. (2016)-b. How colonialism affects women. *FemNorthNet*: *Resource Development in Northern Communities: Local Women Matter #4*. Ottawa: Canadian Research Institute for the Advancement of Women. http://fnn.criaw-icref.ca/images/userfiles/files/LWM4_ColonialismWomen.pdf

Strong Women’s Song. (n.d.). Ojibwe.Net. https://ojibwe.net/songs/womens-traditional/strong-womens-song/

TRC. (2015). *Truth and Reconciliation Commission of Canada: Calls to Action*. https://doi.org/10.5663/aps.v5i1.25647

United Nations. (2008). *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)*. United Nations. https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf

World Health Organization, United Nations Office on Drugs and Crime, & UNAIDS. (2007). *Effectiveness of Interventions to Address HIV in Prisons*. World Health Organization. https://www.who.int/hiv/idu/OMS_E4Acomprehensive_WEB.pdf

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"We all know each other": A Strengths-based Approach to Understanding Social Capital in Pictou Landing First Nation

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With over three decades of attention drawn to the health of Indigenous peoples in Canada and around the world, an outpouring of health research has been undertaken. Much of this research, however, has emphasized the experience of disparity at the expense of recognizing strengths. In this case study, we challenge the damage-centred rhetoric of mainstream health research by reporting the findings of 20 qualitative interviews on community strength and health with members of Pictou Landing First Nation, a Mi'kmaw nation located in Nova Scotia, Canada. We then relate and compare these findings with the emerging conceptualization of Indigenous social capital, which is a concept that has been associated with positive health outcomes in a variety of contexts. Our findings indicate that Pictou Landing First Nation is strengthened by **qualities of familiarity, reciprocity, safety, and solidarity**, which are rooted in the value of family and embedded within a broader Mi'kmaw worldview. These strengths align, in part, with the concept of Indigenous social capital, which we suggest may be better harnessed to be a means for conducting strengths-based health research. To this end, our findings support the need for reworking social capital conceptualizations to more strongly centralize cultural identities and worldviews in order to authentically and comprehensively affirm Indigenous and decolonizing health research practices.

Keywords: *Social capital, community well-being, Mik'maq, Indigenous health, strengths-based research, Canada*

Glossary

LCAB: Local Community Advisory Board

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Introduction

For over three decades, dominant non-Indigenous narratives about Indigenous peoples, as found in media, government reports, and research papers, have rarely acknowledged the strengths and abilities of Indigenous peoples. In the realm of health research, this rhetoric is manifest in the disproportionate study of Indigenous peoples' health problems (Reading & Nowgesic, 2002). Such research is problematic, as it typically neglects the distal determinants of health underlying those disparities, namely the negative determinants of colonialism and racism (Reading & Wien, 2009). Consequently, this research perpetuates a dominant narrative of Indigenous peoples as despondent and dependent (Reading & Nowgesic, 2002; Tuck, 2009) and in doing so, ultimately reinforces the colonial agenda.

To oppose this narrative, strengths-based research has been pursued by Indigenous and ally scholars to reclaim Indigenous ownership over health and well-being (Craven et al., 2016; Smith, 1999; Tuck, 2009). Approaches to strengths-based research are varied, having been applied to social work (Harris, 2006), pedagogy (Crooks et al., 2010) and health promotion (Brough et al., 2004). It should be noted that though the recognition of Indigenous strengths has only recently begun to surface in the academic literature, this knowledge has in fact been vested within and celebrated by Indigenous communities for generations. This is a knowledge that has been silenced, denied, and refuted by the colonial orientation of western academia, and it is entirely a demonstration of colonialism that strengths-based research is now emerging as a "novel" research paradigm. In this article, we explore the potential for the concept of Indigenous social capital to be used as an alternate avenue through which to conduct strengths-based health research. This proposition exists in light of multiple studies that have associated improved health outcomes with higher levels of social capital (Ehsan et al., 2019; Kawachi & Berkman, 2001; Kim et al., 2008), as well as the intimately connected and highly social nature of many Indigenous communities (Hart, 2010). To date, the published literature on Indigenous social capital has not explicitly applied a strengths-based lens, although the concept has been discussed in association with strengths-based concepts such as resilience (Ledogar & Fleming, 2008).

Broadly defined, social capital is a resource arising from social networks and associations that generates positive benefits for members of a group through shared trust, norms and values. More simply, it has also been described as the 'glue that holds a community together' (Durlauf & Fafchamps, 2004; Freuchte, 2011). Despite the recognition that social capital may differ depending on community context, research describing the nature of Indigenous social capital as an independent construct is relatively limited. In Canada, the most extensive study of Indigenous social capital as a unique concept was undertaken in 2003 by Javier Mignone, who constructed an Indigenous social capital framework (Mignone, 2003). In this framework, Mignone compartmentalized the social capital of a community into three components: (1) the degree to which its resources are socially invested; (2) the culture of trust, reciprocity, collective action, and participation within the community; and (3) whether social networks are inclusive, flexible, and diverse (Mignone, 2009). While the formation of this framework was informed by the input of three First Nations communities in Manitoba, the degree to which this model resonates across different First Nations across the country is unclear, as is the extent to which this model critically engages with and adopts Indigenous epistemologies into its definition of social capital.

In view of this previous work, we conducted a qualitative study with the Mi'kmaw community of Pictou Landing First Nation to explore the strengths of the community's social environment. In this article, we discuss the findings of this case study in the context of Indigenous social capital to identify ways this concept might better encompass community strengths and be utilized for more affirming health research practices.

Study Context

Pictou Landing First Nation is a small Mi'kmaw community located on the northern shore of mainland Nova Scotia, Canada that is accessible year-round by road. Mi'kmaw presence has been traced to this region for over 10,000 years (Paul, 2006). In 1967, the community became subject to an act of environmental racism and injustice when a local pulp and paper mill began using an estuary bordering the community to operate the 'Boat Harbour Effluent Treatment Facility' (Castleden et al., 2017). This estuary was a culturally significant resource to which the community had strong relationship (Castleden et al., 2017). As the pollution by the mill began harming the quality of the water, land, and air, Pictou Landing First Nation began its rights-based legal efforts concerning 'Boat Harbour'. In recent years, community-led studies have also emerged to show how 'Boat Harbour' destroyed the lagoon and by extension, negatively impacted the physical, mental, emotional, and spiritual health of the entire community (Castleden et al., 2017; Lewis, 2018). In 2015, the Government of Nova Scotia passed the Boat Harbour Act, ordering that the treatment of effluent in Boat Harbour be ceased by January 31, 2020 (Withers, 2019). Pictou Landing First Nation continued its political pressure upon provincial authorities during those five years, and the Province ultimately maintained its legislated promise. Earlier this year (2020), the treatment facility stopped receiving effluent, and the pulp mill closed shortly thereafter. Currently, extensive cleanup efforts are required, and it remains to be seen whether the harm can be undone and the Mi'kmaw relationship to the land re-established. Data collection for this study took place in 2018, before the closure of the mill, during a time when the advocacy of Pictou Landing First Nation was beginning to be recognized widely. Given that the interviews conducted for this study took place at this critical point in time, the emotions and lived experiences relayed through these interviews largely centred upon the community fight against Boat Harbour.

Methods

Data Collection

Semi-structured interviews were conducted with 20 key informants from Pictou Landing First Nation. Participants were members of the Local Community Advisory Board (LCAB) in addition to others purposively recruited through a hired community-based Health Research Coordinator. All participants met inclusion criteria of being older than eighteen, having self-identified Indigenous ancestry, and having lived in Pictou Landing First Nation. Interviews were conducted by the first author. Of the 20 participants, 15 (75%) were women and 19 were currently living in Pictou Landing First Nation. The remaining one participant had grown up in and around Pictou Landing First Nation but was, at the time, living in a nearby municipality. All interviews were audio recorded (with permission), transcribed verbatim into electronic format, and emailed back to each participant to review for accuracy, clarifications, or removal. One participant requested a minor change in their interview transcript, which was made. No other changes were requested. Interviews focused on three key areas: 1) perceptions of the strengths of the community, with focus on the social environment; 2) the effect of these community strengths on physical, mental, and emotional health; and 3) personal definitions of health and well-being. In this manuscript, we emphasize reporting our findings from key areas 1 and 3, as these organically emerged as the more prominent areas of discussion within our interviews.

Data Analysis

Transcripts were analyzed using an inductive thematic analysis approach to identify common themes across the interviews (Joffe, 2012). The analysis focused on understanding the strengths of the social environment in Pictou Landing First Nation, the significance of these strengths in the context of Pictou Landing First Nation's culture and history, and the impact of these strengths on health and well-being. The process adhered to the steps articulated by Braun and Clarke (2006) and involved data familiarisation, followed by coding using frameworks developed recursively to systematically identify features of the data (Braun & Clarke, 2006). A qualitative software package (NVivo 12) facilitated this process. Codes were collated into themes and checked in relation to coded data using thematic maps and charts. Finally, these themes were defined and labeled. The preliminary analysis was member-checked by LCAB members for credibility and resonance (Tracy, 2010).

Relationship

Pictou Landing First Nation has collaborated with the principal investigator of this study on environmental health research for nearly a decade. The study described in this manuscript took place in Pictou Landing First Nation with the permission of a Local Community Advisory Board (LCAB), which included the Chief, the Community Health Representative, and three members of the community. The community's interest in understanding the broader, contextual determinants of health has always driven their environmental health research agendas and community goals and helped create the conditions necessary for proceeding with this research in a good way (Ball & Janyst, 2008). The research was cleared by the academic authors' university research ethics board and fell under the principal investigator's larger research program approved by the Mi'kmaw Ethics Watch.

Results

The four themes that emerged from the data on community strengths in Pictou Landing First Nation were **familiarity, reciprocity, safety, and solidarity**. While these themes are individually detailed below, they manifested fluidly and in an interwoven nature within the interview data, and were expressed strongly in relation to values of family and Indigenous culture. The effects of these identified community strengths on health were reported to be largely positive. Pseudonyms are used in this article to maintain participant confidentiality.

Familiarity

The social environment of Pictou Landing First Nation was described by participants as friendly and sociable, qualities that enable community members to be comfortable with one another. Participants reported that familiarity was grounded in the small size of the community and the interconnected nature of family networks.

> *It makes me feel good to be part of people; it makes me feel good to be able to go to the store and say, you know, "Hi [John], hi [Robert]." It makes me feel good and these people say hi back because we all know each other - like we know about each other… I think it affects me in a positive way most of the time*
>
> - *Nicole*

> *I like how… you know everybody around here. Again, I'm not too sure with [neighbouring community], but with it being so big and huge, like I think it takes like 10-15 minutes to drive through or something, so you don't really know everybody; you don't have the casual head nod or smile or something nice.*
>
> - *Jordan*

Furthermore, the distinction between 'the professional' and 'the personal' was often identified as inseparable and participants indicated that this benefits community members by enabling them access to resources in an informal way.

> *Our community health rep[representative], she'll like…if she sees you at a crib tournament or whatever, she'll be like how's your [blood] sugars … she's checking on you on her own time. So, she reminds you to keep on your health and stuff, so yeah like a lot of people take their work home with them.*
>
> - *Kelly*

Overall, familiarity was identified as a quality of the community that makes it strong, though some participants articulated that it could also lead to a lack of personal privacy. Familiarity was also described as a quality that enabled norms of reciprocity to exist among members, as described below.

Reciprocity

Many participants expressed that the familiarity they felt with one another creates a culture of reciprocity that enables them to find help in the face of major life events. Many participants, like Christine (below) gave the example of a death in her family as an example of this community-minded act of reciprocity.

> *In my family one of the major events that happened with us was when [relative] died and we didn't – actually, we weren't even thinking right or whatever… but you know she's gonna need the headstone, there's gonna be other bills that come up or whatever right. Everybody around us went above and beyond and they just raised so much money we had more than enough for her headstone and paid for everything else and we even had money left over and with the money left over we got some benches made and donated them to the church at Maligomish and bought a bunch of food and cooked it up and gave it away during the [annual gathering at St. Anne's] Mission.*
>
> - *Christine*

While reciprocity is evidently displayed in times of need, many participants also gave examples of reciprocity that manifests on a regular, daily basis that exemplifies the extent to which this value is ingrained within the quotidian functioning of the community.

> *When I cook at my house, I cook so much, and my husband, being from outside of the community, he's like 'why do you cook so much?' And I'm like' well, you never know who's going to*

> *stop in'. And even when I go to town, I leave my door unlocked and people will go in and eat - when I get home it's either there or it's gone. But nobody's hungry, in so many ways. That's not just with food, that's with love, that's with care, that's with consideration.*
>
> - *Sandra*

Beyond enjoying the benefits of these norms, participants also identified that upholding reciprocity by volunteering and giving back to the community are sources of joy and pride for them. As Judy described (above), there is a strong moral philosophy in the community and embedded within the Mi'kmaw ethic of sharing and contributing to collective well-being. Some participants also noted that they hope to pass this value on to their children, so that the community may continue to thrive.

> *I always helped out wherever I could, right, you volunteer, you lend a hand, you do what you can um, so that would never change and that's what always made me grounded in this community.*
>
> - *Alison*

> *You can pass on your knowledge to your kids so they can help out the community too in some way when it's time.*
>
> - *Nicholas*

Overall, participants described a strong sense of reciprocity in the community as a treasured quality of living in Pictou Landing First Nation that enables members to feel comfortable, connected, and ultimately, always able to seek the help they require.

Safety

Participants described the ways in which the nature of familiarity and reciprocity within Pictou Landing First Nation gives rise to a sense of safety. Safety was discussed often in relation to family, with many participants, like Laura (below) expressing comfort in knowing their family will always be there for them in times of need. Some, like Julia (below) also attributed this to community leadership.

> *If anything was to ever, ever happen here to me or to my daughter or to my family or anybody, somebody's gonna be right there…it's not like twelve hour wait to have to see that person or do this…they're like right there. So, I think it's pretty cool that my family lives right up the street from me.*
>
> - *Laura*

> *It'll always give me [peace of mind] that I have a place to go no matter how bad things get in the world…I always felt like, you know, if all else failed I have a home here…Here the band would help me, you know if I really needed it, I know it's there so it's like a bit of a safety net… instead of having that 'oh my god' that sense of doom, like I could be homeless on the street… like, no my Band would not allow anybody to be homeless on the street.*
>
> - *Julia*

For many, safety was also experienced in terms of physical protection and freedom from dangers that participants associated with living off-reserve. Examples given largely related to experiences of racism outside their community. Participants expressed feeling better able to trust the intentions of those in the community and feeling safe in knowing that everyone will look out for each other if potential threats appear in the community.

> *In town you might get followed, I get followed around in a store, it always*

> *friggin' surprises me… following me around shopping in Walmart; it happens to a lot of folks from the rez[reserve].*
>
> - *Judy*

> *[On living off-reserve] Living in the apartments, you always had… you know, I always found, you know, little kids running around saying things like, "There's those Indians that make the loud noise, mommy…" and, you know, shit like that, yeah so you know I encountered stuff like that a lot.*
>
> - *George*

> *I almost got kidnapped… when I was a kid…that wouldn't happen here because everybody knows each other; if I see a strange car that I'm not used to, seeing it come across to some kids, I'd probably run out to the road and lose my shit [on the driver].*
>
> - *Nicole*

Participants likewise expressed feeling emotional safety and mental wellbeing within their community that they derived from their shared personal and collective histories. Participants related this quality to the familiarity within the community and their knowledge of one another's lives.

> *A lot of people down here have the same background as me, like I have friends or family that lost their parents at a young age like I did, that had an uncle as a parent or had their own individual home problems, so we connect on that because we grew up together, we all knew it. And then when you go off-reserve, my friends are usually shocked that I have over 20 aunts and uncles and over 50 first cousins… And then when they hear about my back story of what's what, they're like, "Oh what? Really? We never would have pictured that as you," so like yeah home is a lot easier because like I said, we all know each other's stories.*
>
> - *Joanne*

> *I'm Native, so I feel more at home where my people are…you know, I could go down [to any community member], I could go down there and tell them, you know, what my day was about, and stuff like that, and he'd probably, he'd listen, right? You know what I mean? Opposed to someone elsewhere that's not, that can't relate.*
>
> - *Nicholas*

Overall, the social environment of the community was reported by participants to possess a safety that transcends domains of physical, emotional, and mental well-being and ultimately makes their community 'home' to them in ways other places are not.

Solidarity

The community's ability to come together in solidarity with one another to campaign for their rights was identified as a core strength and source of pride for members. The most salient example of this strength was with regards to Pictou Landing First Nation's sustained fight for environmental justice involving Boat Harbour.

> *I think we're good fighters, because we've always, since the 60s, we've fought against Boat Harbour, so I think everybody here's a fighter. They all grew up here with a fighter mentality. I didn't grow up here, so I recognized it when I moved here: I can see everybody, yeah, they're fighters for injustice. And they're just used to it and*

> *I think it's second nature… if someone [came] here and [tried to] do something else…the band would rally, and not just the band council, like everybody here would rally and stop [the] injustice if they saw it.*
>
> - *Judy*

Some participants described specific events that displayed this community solidarity, including a "No Pipe" Land and Sea rally, which was held in 2018 to protest a plan from the pulp mill to create a new effluent facility in the nearby Northumberland Strait to replace Boat Harbour.

> *We went out to the mouth of the harbour and there was already so many people out there, as far as the eye can see… like you can keep looking and still see a boat… and then when we were in the causeway, you can still see the boats coming into the mouth of the harbour… just to see everybody stand so strong, that was probably the best moment out of all my 35 years other than my birth of my little girl, but like seeing the community pull together and just have so much strength like that, that was amazing.*
>
> - *Jordan*

Pictou Landing First Nation's solidarity has a strong intergenerational nature and a gravity of attachment to place that can only be found in Indigenous communities; participants expressed that their fight was to honour their ancestors who first observed the devastation of the effluent treatment facility, as well as for their children and future generations, who they hope will again experience the beauty of the estuary as their ancestors did.

> *I'm really proud of [how the community has] fought for so many years and there's been so many leaders that have dealt with that [effluent treatment facility] and so I'm carrying that legacy with me…I'm really proud of that fact that they never ever stopped fighting and I find because of them, it has brought a community to that same…expectation for me… so um I can't stop fighting because the expectation is so high that you need to make sure that you never stop talking about it and you continue to represent and um bring the issues to the forefront*
>
> - *Alison*

> *Especially with the fight with Boat Harbour… that's been a continuous fight and everybody's still fighting, and everybody's still together with it, so that's really…that's probably another thing that makes me proud of how strong [we are]. Of course, there's other things I'd like to see, but this is a big start because it's been going on for a long time.*
>
> - *Joanne*

The solidarity of the community is being further realized by their channeling of efforts towards restoring Boat Harbour. Many participants described the strength of Pictou Landing First Nation in its ability to imagine the future with a sense of hope, optimism, and devotion to its restoration.

> *I'm involved with Boat Harbour…what we want to do after it's shut down…what we're gonna do with this…we're just throwing ideas out right now…maybe a park here, maybe a walking trail here you know, maybe a plate there, where we put names on it where people passed that were helping with Boat Harbour…*

- *Ryan*

> *The other piece I'm really proud of is where we're headed with the [Boat Harbour] cleanup project….that's becoming more and more a reality every day right, and so that [Boat Harbour closure] date is coming so quickly and then you know, to see that transformation, and so I got to make sure that I stay healthy so I see all of that… the important thing is that I want to still be here when that's all being transformed, because geez you know, the generation coming up, they will be definitely blessed to have, what well I never had it, but I'll get to see it… but they'll have what their great grandparents or great great grandparents had…*

- *Alison*

Of all the themes, solidarity in the First Nations' collective fight against environmental racism was the most prominent. For participants, this solidarity brought about a deep sense of pride, as it testified not only to the importance of their relationship to the land, but more broadly, to the community's power to self-determine and forge a future for the generations to come.

Limitations

To our knowledge, this study is the first to critically explore Mignone's concept of Indigenous social capital for its ability to capture community strengths in a specific context. Limitations of this study include potential self-selection bias, as the study was explicit about its interest in community strengths. Furthermore, as the community strengths discussed by (predominantly female) participants related mostly to intra-community social, other domains (i.e., relationships with other communities or with formal authorities) were not explored.

Discussion

The purpose of this study was to explore the strengths of the social environment for one First Nations community in Canada and to identify ways for the study of Indigenous social capital to be adapted to better capture these strengths. Our findings identified four main community strengths within the social environment of Pictou Landing First Nation which reflect, first and foremost, an intrinsic congruence between community strength and the concept of social capital. The essence of social capital is that it is a resource within the social fabric of a community that benefits its members. In our study, participants described the strengths of their social environment within a similar vein, expressing the ways they draw upon the strengths of their community as resources for individual and community well-being.

The only existing framework for Indigenous social capital in Canada (Mignone, 2003) describes one of the key components of social capital to be community 'culture', which includes characteristics of trust, norms of reciprocity, collective action, and participation (Kawachi & Berkman, 2014; Mignone, 2003; Putnam, 1995). The community strengths of safety, reciprocity, solidarity, and familiarity identified by our study support, in some ways, the qualities of Mignone's framework, but demonstrate that the scope of community strengths is more nuanced than what has been conceptualized to date within the construct of social capital, and that adaptations to the concept must be made to adopt a stronger strengths-based orientation. For instance, the emotional and mental components of 'safety' identified in our findings are in part accounted for by the concept of 'trust' present in Mignone's framework. However, within this concept, we found that the language of "safety" was a more strengths-oriented means of capturing the same underlying concepts, as many participants expressed that they found it difficult to 'trust' others in light of their shared experiences with environmental racism and dispossession, and intergenerational colonial trauma (Thibodeau & Peigan, 2007). Participants also described safety in comprehensive terms of physical, mental, and emotional security, in contrast to the emphasis on physical safety (e.g., whether it is safe to walk outside) that other social capital literature has traditionally emphasized (Bullen & Onyx, 2005; De Jesus et al., 2011; Ziersch et al., 2005).

The concept of reciprocity was another clear parallel with Mignone's framework, emerging from our findings as well. However, in Mignone's framework, reciprocity was described as 'a future obligation to return "the favour"' (Mignone, 2003), while reciprocity, in our findings, was not necessarily described in these obligatory terms. Rather, reciprocity was rooted in a language of kinship, of connection to and respect for one another. The essence of this sentiment similarly underlay the tenor of solidarity in our findings; the fight to restore the estuary exemplified a reciprocity and accountability to the natural world and to past and future generations. It was this philosophy that ultimately drove the community's advocacy efforts. This was, perhaps, the differentiating factor between our findings and the theme of collective action in Mignone's framework. While both concepts centre upon the community 'coming together' to pursue a course of action for collective well-being, solidarity encompasses not only the actionables of the collective, but a psychological unity and shared interest that drives the collective action itself.

The concept of familiarity was one that uniquely arose in our findings as a strength of the community; in Mignone's framework, this characteristic was not directly articulated, although it is alluded to within (or exists as a prerequisite for) reciprocity. Our findings, however, argue that while these concepts are related, familiarity may benefit community members distinctly in its ability to cultivate a sense of shared identity and emotional and mental security from belonging to the community. This finding is in contrast to the ways reciprocity is typically illustrated as direct provision of material help (recognizing that this too may contribute positively to emotional or mental security). Finally, Mignone's framework included the concept of participation to describe individual's participation in common activities for personal interest. While participants in our study did not articulate this as a community strength, some noted that they enjoyed the abundance of activities available to engage in.

The inadequacies of conventional models of social capital in capturing the full extent of Pictou Landing First Nation's strengths emerge from the reality that these strengths are fundamentally grounded in a broader Mi'kmaw worldview. The importance of this worldview in Pictou Landing First Nation has been intimately studied by Mi'kmaw scholar Diana Lewis in her research on the importance of the land to Pictou Landing First Nation health and well-being. In this work, she describes the concepts of *ko'kmanaq* (our relations) and *n'mit no'komaq* (all my relations) to explain the ways in which Mi'kmaq peoples, as Lewis describes, 'extend a relationship to both animate and inanimate objects, thereby creating a relationship of respect and kinship, a reciprocity that includes values and obligations'(King, 1990; Lewis, 2018; Sable & Francis, 2012). These values are important ways of maintaining *tlilnuo'lti'k*, translated as "how we (Mi'kmaq) will maintain our worldview" (Lewis, 2018). These values, embedded within the social fabric of Pictou Landing First Nation, shape the existence of familiarity, reciprocity, solidarity, and safety in the community. While this research is but one case study, we argue that for the study of Indigenous social capital to comprehensively reflect the strengths of any Indigenous community, it must centre the definition of social capital upon the philosophies of the underlying cultural worldview and apply a community-centred approach to the research. To do otherwise would be to place the study of Indigenous social capital at risk of applying generic measures that ignore the unique strengths of individual communities, or worse, of exclusively capturing areas of social 'deficiency', thereby perpetuating damage-centered rhetoric.

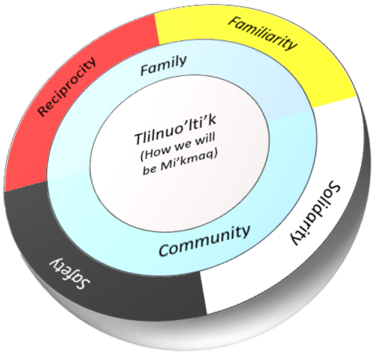
Figure 1 illustrates our findings of community strength in Pictou Landing First Nation, aiming to reflect their grounding in *tlilnuo'lti'k*.

Conclusion

The discourse of defect, flaw, maladjustment, and dysfunction has disproportionately surrounded Indigenous communities, particularly in the realm of health research, which continues to emphasize the study of health deficits. This discourse exists at the expense of appreciating the unique strengths vested within Indigenous communities that are foundational to their health and well-being. In this case study of Pictou Landing First Nation, we illuminate that the concept of Indigenous social capital, overlapped in multiple ways with the strengths of the community and suggest that the social capital framework is compatible with a strengths-based approach to health research. At the same time, our findings call for greater consideration of Indigenous worldviews within the social capital framework, and for diversity to be better recognized across different Indigenous communities and nations. Social capital exists uniquely within different worldviews, and it is only with this appreciation that the study of Indigenous social capital may be tailored to capture the true depth and texture of the social fabric of a community.

Figure 1

Thematic Findings of Key Community Strengths in Pictou Landing First Nation



Note. In this model, *tlilnuo'lti'k* is centrally located to represent the fundamental importance of Mi'kmaw identity in shaping the social environment in Pictou Landing First Nation. The second layer represents family and community, inseparable entities for the community. Finally, the outermost layer represents the themes we used to describe the observable social characteristics of the community, all of which are rooted in the underlying 'layers'. This model is positioned in three-dimensional space to reflect the dimensions of time and the connection of the past, present, and future.

References

Ball, J., & Janyst, P. (2008). Enacting research ethics in partnerships with Indigenous communities in Canada:

"Do it in a Good Way." *Journal of Empirical Research on Human Research Ethics, 3*(2), 33–51. https://doi.org/10.1525/jer.2008.3.2.33

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brough, M. K., Bond, C., & Hunt, J. (2004). Strong in the city: Toward a strength-based approach in Indigenous health promotion. *Health Promotion Journal of Australia, 15*(3), 215-220. https://doi.org/10.1071/HE04215

Bullen, P., & Onyx, J. (2005). Measuring social capital in five communities in NSW: A practitioner's guide. Retrieved from http://www.mapl.com.au/pdf/SocialCapitalPracGuideBullen&Onyx.pdf

Castleden, H., Bennett, E., Pictou Landing Women's Group, Lewis, D., & Martin, D. (2017). "Put It Near the Indians": Indigenous perspectives on pulp mill contaminants in their traditional territories. *Progress in Community Health Partnerships: Research, Education, and Action, 11*(1), 25-33. https://doi.org/10.1353/cpr.2017.0004

Craven, R. G., Ryan, R. M., Mooney, J., Vallerand, R. J., Dillon, A., Blacklock, F., & Magson, N. (2016). Toward a positive psychology of indigenous thriving and reciprocal research partnership model. *Contemporary Educational Psychology, 47*, 32-43. https://doi.org/10.1016/j.cedpsych.2016.04.003

Crooks, C. V., Chiodo, D., Thomas, D., & Hughes, R. (2010). Strengths-based programming for First Nations youth in schools: Building engagement through healthy relationships and leadership skills. *International Journal of Mental Health and Addiction, 8*(2), 160-173. https://doi.org/10.1007/s11469-009-9242-0

De Jesus, M., Puleo, E., Shelton, R., & Emmons, K. (2011). Associations between perceived social environment and neighborhood safety: Health implications. *Health & Place, 16*(5), 1007-1013. https://doi.org/10.1016/j.healthplace.2010.06.005

Durlauf, S. N., & Fafchamps, M. (2004). *Social Capital*. NBER Working Paper Series No. 10485). https://doi.org/10.3386/w10485

Ehsan, A., Klaas, H., Bastianen, A., & Spini, D. (2019). Social capital and health: A systematic review of systematic reviews. *8. SSM - Population Health*. https://doi.org/10.1016/j.ssmph.2019.100425

Freuchte, K. (2011). Social capital: The glue that holds a community together. SDSU Extension Extra Archives. 514. Retrieved from https://openprairie.sdstate.edu/extension_extra/514

Harris, B. (2006). A First Nations' Perspective on Social Justice: Are we there yet? *The Canadian Journal of Native Studies XXVI, 2*, 229-263. http://www3.brandonu.ca/cjns/26.2/02harris.pdf.

Hart, M. A. (2010). Indigenous worldviews, knowledge, and research: The development of an Indigenous research paradigm. *Journal of Indigenous Voices in Social Work, 1*(1). Retrieved from http://hdl.handle.net/10125/15117.

Joffe, H. (2012). Thematic Analysis. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 209-223). Chichester: Wiley-Blackwell.

https://doi.org/10.1002/9781119973249.ch15

Kawachi, I, & Berkman, L. (2014). Social capital, social cohesion, and health. In L. Berkman, I. Kawachi, & M. Glymour (Eds.), *Social Epidemiology (pp. 290-319)*. New York: Oxford University Press. https://doi.org/10.1093/med/9780195377903.001.0001

Kawachi, Ichiro, & Berkman, L. F. (2001). Social Ties and Mental Health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 78*(3). https://doi.org /10.1093/jurban/78.3.458.

Kim, D., Subramanian, S. V. V, & Kawachi, I. (2008). Social capital and physical health: A systematic review of the literature. In I Kawachi, S. V. Subramanian, & D. Kim (Eds.), *Social Capital and Health (pp. 139-190)*. New York: Springer. https://doi.org/10.1007/978-0-387-71311-3_8

King, T. (1990). All my relations: An anthology of contemporary Canadian Native prose. McClelland & Stewart.

Ledogar, R. J., & Fleming, J. (2008). Social capital and resilience: A review of concepts and selected literature relevant to Aboriginal youth resilience research. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, *6*(62). Retrieved from http://www.pimatisiwin.com/uploads/492281261.pdf.

Lewis, D. (2018). Tlilnuo'lti'k - weji-sqalia'timk - How we will be Mi'kmaq on our Land. Dalhousie University.

Lopez, S. J., & Louis, M. C. (2009). The principles of strengths-based education. https://doi.org/10.2202/1940-1639.1041

Mignone, J. (2003). Social capital in First Nations communities: Conceptual development and instrument validation. University of Manitoba.

Mignone, J. (2009). Social capital and Aboriginal communities: A critical assessment. *Journal of Aboriginal Health*, 101-147. Retrieved from https://jps.library.utoronto.ca/index.php/ijih/article/view/28989.

Paul, D. N. (2006). We were not the savages: collision between European and Native American civilizations. Halifax, N.S.: Fernwood Publishing.

Putnam, R. D. (1995). Bowling alone: America's declining social capital. *Journal of Democracy*, *6*(1), 65-78. https://doi.org/10.1353/jod.1995.0002

Reading, C., & Nowgesic, E. (2002). Improving the health of future generations: the Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health. *American Journal of Public Health, 2*(9). https://doi.org/10.2105/AJPH.92.9.1396

Sable, T., & Francis, B. (2012). The Language of This Land, Mi'kma'ki. Sydney, N.S.: Cape Breton University Press.

Smith, L. (1999). Decolonizing Methodologies: Research and Indigenous Peoples. New York, N.Y.: Zed Books; University of Otago Press.

Thibodeau, S., & Peigan, F. (2007). Loss of trust among First Nation people: Implications when implementing child protection treatment initiatives. *First Peoples Child & Family Review, 3*(4). https://doi.org/10.7202/1069374ar

Tracy, S. (2010). Qualitative quality: Eight "Big-Tent" criteria for excellent qualitative research. *Qualitative Inquiry*. https://doi.org/10.1177/1077800410383121

Tuck, E. (2009). Suspending damage: A letter to communities. *Harvard Educational Review, 79*(3), 409-427.

https://doi.org/10.17763/haer.79.3.n0016675661t3n15

Withers, P. (2019). Premier unmoved by Northern Pulp's ask for more time to close wastewater facility. Retrieved September 19, 2019, from https://www.cbc.ca/news/canada/nova-scotia/northern-pulp-requests-extension-boat-harbour-waste-treatment-facility-1.5000139

Ziersch, A., Baum, F., MacDougall, C., & Putland, C. (2005). Neighbourhood life and social capital - The implications for health. *Social Science & Medicine, 60*(1), 71-86. https://doi.org/10.1016/j.socscimed.2004.04.027