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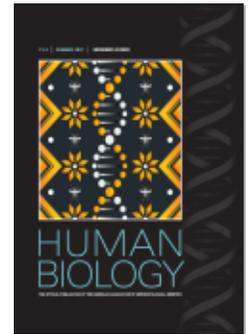
Methodology Matters: Designing a Pilot Study Guided by Indigenous Epistemologies

Sandra A. Juutilainen,[1]* Melanie Jeffrey,[2] and Suzanne Stewart[3]

ABSTRACT

Indigenous individuals and communities have experienced historic and ongoing negative interactions with Western health care and biomedical research. To rebuild trust and mitigate power structures between researchers and Indigenous peoples, researchers can adopt Indigenous epistemologies in methodologies, such as nonhierarchical approaches to relationship. This article shares models developed to bridge Indigenous epistemologies with Western qualitative and quantitative research methods and demonstrates how these epistemologies can be used to guide the authors' development of a pilot study on traumatic spinal cord injury.

In Canada, Indigenous peoples comprise three distinct cultural groups: First Nations, Métis, and Inuit. Canada generally has excellent health care data, but too often data depicting Indigenous health is deficit based. Disparities exist between Indigenous and non-Indigenous health, but without addressing cultural, social, and broad environmental contexts of these differences, underlying causes of these health disparities and policy initiatives affecting them cannot be understood. Currently in Canada, Indigenous governments and organizations are undergoing health transformations, reenvisioning what their health care systems could be like to best serve their diverse communities, both large urban communities and small rural/remote communities.

Unmet health care needs are common in First Nations populations both on and off reserves (Wilk et al. 2018), yet most statistics regarding Indigenous populations continue to perpetuate a narrative of dependency rather than areas of service provision improvement. Studies that are Indigenous focused usually note high injury rates among all Indigenous demographics. For example, Indigenous Canadians are particularly at risk for trauma-related injuries (Karmali et al. 2005) and are vulnerable to sustaining more severe injuries following a motor vehicle accident (Wearmouth and Wielandt 2009). Although these studies are important, the underlying causes of these differences were not explored. No studies to date have reported the strengths, resiliencies, and experiences of Indigenous persons, for example, those with traumatic spinal cord injury (TSCI), the focus of our pilot study. This commentary presents how our methodology decenters the prototypical "five Ds" of Indigenous data: disparity, depravation, disadvantage, dysfunction, and difference.

[1]School of Nutrition, Ryerson University, Toronto, Ontario, Canada.

[2]Centre for Indigenous Studies and Human Biology Program, Faculty of Arts and Science, University of Toronto, Toronto, Ontario, Canada.

[3]Waakebiness-Bryce Institute for Indigenous Health, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada.

*Correspondence to: Sandra A. Juutilainen, Assistant Professor, Indigenous Health and Nutrition, School of Nutrition, Ryerson University, 288 Church Street, Room DCC-601, Toronto, Ontario, Canada, M5B 2K9. E-mail: sandra.juutilainen@ryerson.ca.

Instead, our process includes an emphasis on positive aspects of individuals and communities to build a strengths-based, comprehensive, and culturally appropriate data set (Walter and Suina 2019). In addition, we share two epistemologies/methodologies that incorporate Western research into Indigenous knowledge and value systems.

Ethical Considerations

Many Indigenous scholars note that imbalanced power relationships between researchers and Indigenous persons results in erroneous interpretations of Indigenous experiences (Brant Castellano 2004; Corntassel and Gaudry 2014; Keskitalo 1976; Kuokkanen 2006; Kovach 2009; Schnarch 2004; Tuhiwai Smith 2012) and have discussed colonialism within research as an extractive process that benefits researchers but not communities. Extractive research processes are not only irrelevant but unethical. Such examples as the "discovery" of aspirin from willow bark and the Canadian government's ongoing sale of Indigenous health data to pharmaceutical companies demonstrate how Indigenous data has been used unethically and for purposes that were not consented to by Indigenous peoples (First Nations Information Governance Centre 2020). Too often academic careers are built, via publications and expert status, without Indigenous community benefit (Corntassel and Gaudry 2014; Jones et al. 2018).

The legacy of colonial relationships between the academy and Indigenous communities continues to manifest in how knowledge is currently produced and perceived and what is considered valid for qualitative (Kuokkanen 2006) and quantitative (Kuhn 1970) studies. Qualitative data has been embraced almost to the exclusion of the quantitative in Indigenous research. This is not surprising, given very troubling relationships between Indigenous persons and the cultures of Western science and biomedicine, as well as purely quantitative health statistics that do not reflect Indigenous values (Smylie and Firestone 2015). A lack of meaningful quantitative data is particularly troubling since it forms the basis of policy change. To engage in more relevant and ethical research, researchers must question assumptions in disciplines and academia at large.

Working in a space between cultural and academic ethical principles involves redefining and rethinking research relationships (Bull 2010; Edwards et al. 2008; Vogel 2015). Indigenous worldviews are relational in nature (Hart 2010; Kovach 2009; Wilson 2008); a key aspect of Indigenous research involves ethical considerations of both individual- and community-level consent. Community consent is a process that occurs after meaningful community consultation; it does not preclude the need for individual consent (Dickert and Sugarman 2005).

The UN Declaration on the Rights of Indigenous Peoples specifies the rights of Indigenous peoples to self-determination and their collective right to exercise control over expressions of their cultural heritage and intellectual property (United Nations 2008). The main tenets of the framework for developing ethical guidelines and policy for Indigenous research worldwide are directly linked to self-determination. We provide three examples of research protocols that have been developed to improve research outcomes and rebuild trust between Indigenous communities and researchers.

Māori and Hawaiian Context of Self-Determination and Relationality

Research praxis provides a space for cross-cutting concepts of self-determination and relationality in a Māori context. The original 1840 Treaty of Waitangi between the British Crown and Māori Rangatira (Chiefs) establishes principles of partnership, participation, and protection. Researcher actions should align with rights, roles, and responsibilities implied in the Treaty of Waitangi, including potential risks, benefits, and outcomes of research. Research should take place in a framework of Maori values of *wahkapono* (faith), *tumanako* (aspirations), and *aroha* (awareness). The framework is oriented around four key questions, presented in Māori and English (Hudson et al. 2016: 162):

· *He aha te whakapapa o tēnei kaupapa?* / How did this project come about?
· *Kei a wai te mana mō tēnei kaupapa?* / Who is in charge of the project?
· *Me pehea e tika ai tēnei kaupapa?* / Will it produce the intended outcomes?

· *Mā wai e manaaki tēnei kaupapa?* / Who looks out for the people's interests?

These questions guide research practice to ensure that Maori values are upheld for the benefit of Maori communities.

Similarly, Native Hawaiian protocols in research praxis from project identification through to dissemination of results are firmly rooted in ongoing communication with community to ensure the project meets community needs (Keaulana et al. 2019). The Waimānalo Pono Research Hui is a community-academic partnership based on a decade-long relationship between a community leader from Waimānalo and a public health graduate student from the University of Hawaii Office of Public Health Studies. Waimānalo is a rural community located on the windward coast of the island of O'ahu and is home to a large number of Native Hawaiians. Prior to colonization, Waimānalo was a thriving community with an abundance of natural and cultural resources that sustained human and natural life. Waimānalo, which translates to "sweet water," was known for its lush waterways that fed and sustained the plants, animals, and people in the community. The mission of Waimānalo Pono Research Hui is "to collaborate and work toward a healthier Waimānalo through education, aloha 'āina (love and stewardship of land), and honoring and transferring 'ike (knowledge) and values of the kūpuna (elderly) to the keiki (children) through pono research principles" (Chung-Do et al. 2019: 111). In *'ōlelo Hawai'i* (Hawaiian language), *pono* loosely translates to righteous, goodness, uprightness, and moral qualities. *Pono* is a sense of being and a way to work, act, respect, and treat people and the land to create balance and harmony. The group agreed that *pono* research accurately captured the essence of Indigenous methodologies and community-based participatory research from a Hawaiian lens (Chung-Do et al. 2019). The Waimānalo Pono Research Hui Protocols and Rules of Engagement is a living document that continues to evolve. This was an important effort to promote transparency, equitable partnerships, and trust (Keaulana et al. 2019).

Ethical Guidelines for Sámi Research

The Nordic dialogue across Norway, Sweden, and Finland regarding Sámi research ethics includes Nordic Sámi researchers and leading Sámi politicians (Porsanger 2008). However, only in Norway has the dialogue come to the national level (NESH 2002). Collaborations regarding Sámi research ethics have taken place predominantly in Norway; although momentum among Sámi academic and self-government institutions in Finland and Sweden is occurring, collaborations have not been implemented (Juutilainen and Heikkilä 2016). The Norwegian *Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material* highlights principles that would ensure the integrity and recognition of Sámi peoples in research: principles of respect, responsibility, reciprocity, self-determination, and equal status (Sámediggi 2018). Adhering to these principles is a way forward for engaging in nonhierarchical relationships in health research with Sámi peoples.

Canadian Ethical Guidelines: OCAP (Ownership, Control, Access, Possession)

In Canada, ethical Indigenous research requires adhering to principles of OCAP, an acronym (and registered trademark of the First Nations Information Governance Centre) for research relationships in which the research agenda, data, and outcomes (in whatever form) will be owned, controlled, accessed, and possessed by the Indigenous community or their designated stewards (First Nations Information Governance Centre 2020). OCAP is self-determination applied to research. It is a political response to persistent colonial approaches to research and information management (Schnarch 2004). The principles of OCAP have guided researchers working with First Nations, Inuit, and Métis communities and have informed the development of national Indigenous research ethics policies within Canada (Canadian Institutes of Health Research et al. 2018). Communities, not researchers, decide the direction of the research study, who can access the data, and how it will be used. Communities are viewed as research collaborators, not as research subjects or participants. Community collaborators define the nature of the research questions, methods, benefits to the community, and how results are communicated. The four Rs, respect, responsibility, relevance, and reciprocity, provide a research framework for understanding and engaging with
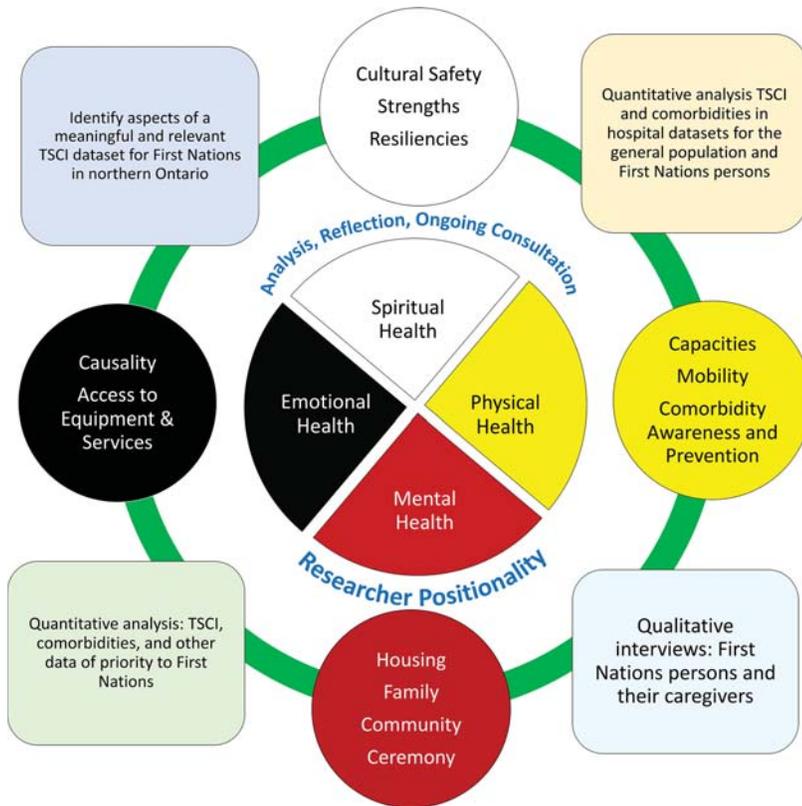
FIGURE 1. Research framework based on the Anishinaabe/Cree Medicine Wheel. Holistic health involves physical, mental, emotional, and spiritual dimensions (center). Research processes guided by these principles are indicated in boxes. Researchers must make iterative journeys around the wheel to remain ethically engaged with community (blue text). Initial concerns of collaborators are identified in circles.

A key starting point for this process is for researchers to respect Indigenous knowledge systems and accept input from community partners and individual participants. This process can make researchers uncomfortable, because ways of knowing in Western knowledge systems may not necessarily be the best way of knowing when working with Indigenous peoples. Contrary to academic disciplinary training, researchers must put aside notions of medical and Western academic expertise when engaging in ethical research with Indigenous peoples. Furthermore, to impose research strategies or health policy recommendations without involving Indigenous leadership and communities is a form of colonization (Allan and Smylie 2015; Walter and Suina 2019). Researchers must listen to and respect what Indigenous peoples choose to share and why they chose to share it.

To listen well, researchers must engage communities to direct research questions and agendas. It is imperative that researchers, Indigenous and non-Indigenous, reflect critically on their own motivations and engage in ongoing consent with collaborators throughout the research process (Figure 1, blue text). At many institutions, in order to mitigate harm, separate ethical review protocols exist for working with Indigenous communities and individuals. Researchers can access health care data sets linked to the general population relatively easily, by showing academic and health merit for their research question. Yet the ethics are complicated when working with Indigenous populations. For First Nations peoples in Ontario who are Status Indians (official identity imposed by the Canadian federal government's Indian Act of 1876), access to their health care data is governed by the Chiefs of Ontario (COO). Researchers must show an awareness of the principles of Indigenous research and significant community consultation for COO to allow access to these data for applied health research questions.

In Ontario, the health data of First Nations persons who are recognized as Status Indians are administratively separable from the general population. For First Nations persons not considered Status Indians, their data are not administratively separable from the general population and are not governed by COO, and self-identification on treatment intake forms is the only way they are recognized as an Indigenous person within existing

First Nations in a culturally appropriate and safe manner (Kirkness and Barnhardt 1991).

Listening Well

Indigenous research in Canada has been largely qualitative, to the exclusion of the quantitative, which can limit the evidence base used to make policy decisions (Walter and Suina 2019). It is well established that Indigenous persons in Canada experience poorer health outcomes than the general population (Allan and Smylie 2015; National Collaborating Centre for Aboriginal Health 2013; Aboriginal Health Access Centres and Aboriginal Community Health Centres 2016). Insights on how to improve these health outcomes can be known only by speaking with Indigenous individuals and communities (Bull 2010). Indigenous research is by nature interdisciplinary in the context of Western academics. Health care registries and data sets informed by both qualitative and quantitative data are needed to understand health outcomes and, subsequently, to enact meaningful policy change.

registries. This is a complexity in Indigenous research involving registries and linked data sets. Existing health care data sets and registries identify only Indigenous persons who are Status Indians, leaving many Indigenous persons uncounted. Furthermore, Indigenous persons may choose not to self-identify on treatment intake forms due to actual and perceived systemic racism in Canadian health care. Since Canada does not track race-based statistics in health care data sets and Indigenous identities are far broader than Status Indians as defined by the Indian Act, the ability to plan effective health care delivery and policies is limited.

Another key element of ethical Indigenous research is that methodological choices must center on Indigenous communities and reflect the communities' priorities and interests. For us, that meant reframing our research query from "How can we build an Indigenous TSCI registry?" to "What are the characteristics of a TSCI registry that is meaningful and relevant for Indigenous persons?" To engage in relational ways of knowing and being, researchers must be cognizant of their positionality. Research practices have targeted Indigenous peoples worldwide to further interests of colonial control; this continues in well-intentioned research that is culturally insensitive and does not meet needs and protocols of communities. Researchers in academia have power and privilege, including when they are working in community-based models. To understand what constitutes knowledge and how it is gathered and shared, we must constantly reexamine values in the community and academic setting (Cochran et al. 2018). Researchers also need to be aware that many communities are overengaged or exhausted by continuing requests to participate in health studies, and that cultural sensitivity and research questions emerging from community-identified needs can mitigate these stressors (Maar et al. 2011).

Our Pilot Study

In the past human biology focused on the physical aspects of health; today it is clear that the interactions between and within environmental, spiritual, emotional, and mental health significantly impact physical health, and vice versa (Burke et al.

2016; Berger et al. 2017; Braaf et al. 2017). Trusting and navigating Western biomedical care generally is problematic for many Indigenous persons. Facilitators and barriers to healing journeys for First Nations individuals with TSCIs, as well as their families, caregivers, and communities, are unknown, as are the relationships between TSCIs and culturally safe supports for physical, social, spiritual, and emotional health. With the guidance of collaborators, our study will investigate these relationships.

Therefore, the objectives of the study include understanding the current picture of TSCIs among First Nations populations in Ontario with regards to their health care experiences, services, and supports via stakeholder interviews; using qualitative data to determine priorities and direction for quantitative analysis of existing registries and data sets; identifying aspects of a cohesive and meaningful spinal registry for First Nations persons living with TSCIs and their caregivers in Ontario in a holistic, culturally appropriate manner; and addressing barriers and emphasizing strengths in local contexts.

Currently, there are no national Canadian registries of incidence and prevalence of TSCIs for the general population, only estimates of TSCI rates in the provinces (Noonan et al. 2012), which may include Indigenous self-identification on treatment intake forms at spinal centers in major urban hospitals. Despite high costs associated with traumatic and nontraumatic spinal cord injuries, there is a paucity of incidence and prevalence data in Canada (Noonan et al. 2012), particularly among Indigenous peoples. McCammon and Ethans (2011) acknowledge that the trend of higher incidence rates of spinal cord injuries among the First Nations population in Manitoba is of concern. In Saskatchewan, motor vehicle accidents are a primary cause of TSCIs for both the general population and Indigenous persons. In the general population, the second most common cause of TSCIs is falls, but for Indigenous persons the second most common cause of TSCIs is assault (Ahmad et al. in press).

Using the quantitative health care data measurements in Ahmad et al. (in press), our study will inform spinal cord registries and a proposed database of neurological conditions for First Nations persons across Canada (NWAC 2013). However, these medical diagnostic and data registry codes do not capture the nuances of TSCIs and how it

is experienced by Indigenous persons in Canada. Hence, we are listening to First Nations persons in northern Ontario living with TSCIs (n = 10), their caregivers (n = 10), and care providers (n = 10) throughout the treatment journey from initial injury through rehabilitation to community, to identify key measures of and barriers to holistic well-being. Qualitative interviews will inform research priorities in quantitative, linked data sets (Figure 1). This process includes iterative consultations with First Nations persons and communities.

Despite significant gaps in the continuum of care, we are using strategies to piece together a person's physical treatment journey using available quantitative data (Figure 1, top right). In both general population and Indigenous-specific data analysis, proxy measures and pathways identified by collaborators and qualitative research are used to identify characteristics of physical, mental, emotional, and spiritual well-being in First Nations persons living with TSCIs to the extent possible with existing quantitative data (Figure 1, bottom right). These findings will be shared with stakeholders, and further proxy measures and data of priority for wellness will be identified and analyzed (Figure 1, bottom left) to the extent possible. The measures most meaningful and relevant to First Nations persons living with TSCIs will be the basis of a TSCI registry for First Nations persons (Figure 1, top left).

Indigenous Perspectives on Neurological Conditions: Implications for Our Study

The Native Women's Association of Canada (NWAC 2013) offers one of the few resources regarding First Nations and neurological conditions across Canada and informs our study. In this report, they identify spirituality as a coping mechanism for emotional, physical, and mental impacts. Unmet spiritual needs made recovery more challenging, whereas being able to interact with traditional healers and elders familiar with their culture and traditions helped persons adjust to and cope with their neurological conditions. Participants expressed that they would like Indigenous spiritual needs, such as smudging, sweats, and other ceremonies, to be accepted and encouraged within health care systems. Family could contribute significantly to positive or negative recovery processes. In northern Ontario, participants described the financial and social burdens of the long journey from home to attend medical appointments, in which they were sometimes alone for long periods of time . The costs of transportation and accommodation were a barrier to accessing health care and other services. A lack of service providers, including physicians and home care providers, was cited as another barrier to recovery and wellness (NWAC 2013).

The report also identified systemic barriers, such as policies that required medical forms completed by physicians to access social services. Poor-quality and expensive foods from stores in environmentally degraded areas compromised positive and protective factors associated with traditional foods and lifestyles. Environmental contamination was further associated with psychological stressors, such as fear, lack of control, and helplessness (NWAC 2013). Recommendations made in the NWAC report are listed in Table 1. In addition to that report, consultation with our collaborators revealed that hospital stays can be unnecessarily prolonged while First Nations patients try to obtain necessary health care equipment. Often, waiting for minor equipment items can prevent hospital discharge for weeks, causing a substantial increase in net cost for the system. In addition, much of the equipment and care covered by the Non-insured Health Benefits program for Indigenous persons recognized by government as Status Indians is inadequate.

The effects of TSCIs differ across geographies (urban, rural, remote) as well as within and between First Nations' cultures in Ontario. Surgical and rehabilitation spinal centers exist in the southern, more populous regions of Ontario, where TSCI-specific databases collect information from willing participants who may choose to self-identify as Indigenous on treatment intake forms. Our study's focus is on the vast regions of northern Ontario from Thunder Bay to Hudson's Bay, which have a higher proportion of First Nations persons and lack spinal centers and spinal registry data. In northern Ontario the less dense population may preclude TSCI statistics in existing provincial health care data sets; in regions where there is a prevalence of fewer than five injuries, none would be reflected in linked data sets. TSCI cases may be missed entirely in rural or remote settings, a large omission given the substantial personal and health

care costs associated with them (Krueger et al. 2013), including medical evacuation to appropriate facilities. These costs will be compounded by inadequate access to culturally safe health care (Bourassa et al. 2015).

After initial injury and rehab, subsequent readmissions for common (and largely preventable) comorbidities are also of concern. These are important data for optimal health care service delivery. For example, knowing the rates of urinary tract infection would allow for cost-benefit analysis. Our collaborators have identified not having enough catheters as a problem; some people were forced to wash and reuse them, even in areas without potable water. One simple solution to prevent bladder infections from becoming life-threatening would be to give all persons living with TSCIs "touch-free" catheters and urinary tract infection dipsticks through the Non-insured Health Benefits and the provincial health care system. This would allow persons with TSCIs to monitor and maintain their urinary health more independently and seek treatment for infections in early stages before they become health emergencies.

Guiding Indigenous Epistemologies

The significance of Indigenous epistemologies and worldviews is their nonhierarchical structures that embody a broader notion of health compared with traditional biomedicine. Conducting research using an Indigenous lens promotes the use of cultural protocols and recenters marginalized knowledge in respectful ways, as well as relating to one another according to Indigenous ethical codes (Getty 2010). This starting point has strong cultural agency and reconfigures approaches to research that privilege the agency of all things relational (Martin 2017). It also attempts to unseat the power dynamics between Indigenous and Western ways of knowing.

Our approach was guided by epistemologies of Anishinaabe/Cree and Haudenosaunee First Nations in Ontario: The Medicine Wheel (Figure 1) and Two Row Wampum Belt (Figure 2), respectively. Utilizing Indigenous cultural frameworks ensures contextual reflection, whereby researchers situate themselves and the Indigenous peoples with whom they are collaborating in the research process. Emphasizing the respectful inclusion

Table 1. Recommendations to Support and Promote First Nations Neurological Well-Being in Canada (compiled from NWAC 2013)

Theme	Recommendation
Improved relationships	Provide Indigenous patient advocates
	Promote the use of plain language
	Show respect for traditional ways
	Implement a national cultural competency program for all health care providers
	Provide dedicated space for spiritual ceremonies and cultural practices
Indigenous-driven health services	Bring more services to the community
	Provide Indigenous health programming for Indigenous peoples by Indigenous peoples
	Promote Indigenous engagement in Indigenous health policy
	Encourage Indigenous-specific data collections
Research needs	Study Indigenous men's health
	Examine interactions of comorbidities with neurological conditions
	Align impacts with available supports
	Examine how Indigenous-specific risk factors differ from mainstream
	Study relationships between risk factors and prevalence (social determinants of health perspective to ensure holistic health and well-being is considered)
	Examine conditions that cause higher morbidity rates
	Ensure the study meets community needs
	Investigate why some subpopulations are more affected than others
	Study role of violence in neurological disorders

FIGURE 2. Two Row Wampum (photo courtesy of Chandra Maracle).

of Indigenous peoples in the research process preserves self-determination and prioritizes Indigenous ways of knowing (Drawson et al. 2017).

The Medicine Wheel has many teachings, but for our pilot study it represents TSCIs in an Indigenous perspective of holistic health: an equal balance of physical, mental, emotional, and spiritual health (Figure 1). Data measures

identified in qualitative research will be recommended for inclusion in future databases and will shape the analyses of existing data. In Figure 1, research processes guided by the Indigenous perspectives of holistic health are indicated in boxes. Researchers must make iterative journeys around the wheel to remain ethically engaged with the community (blue text). Using this model is a way to coconstruct meaningful and relevant measures with our collaborators and as a guide for our iterative reflections.

The Two Row Wampum Belt (Kaswentha; Figure 2) is one of the first treaties between the Haudenosaunee and the early settlers to North America (the Dutch, later the French and English). The Haudenosaunee have shared the story of this wampum belt for many generations, explaining the treaty through the metaphor of two water vessels sailing parallel to each other in the river of life (Freeman and Van Katwyk 2019). The purple rows of beads represent the Haudenosaunee and the settlers' lives/cultures as separate but equal and the rows of white beads on either side and in between represent the river of life (Freeman and Van Katwyk 2019). Longboat (2010: 277) describes the metaphor of two vessels traveling down the river of life: the big ships represent the structures of the colonizing society with the captain at the helm, organizing large groups of people in a hierarchical fashion; in contrast, the Aboriginal canoe is maneuvered by the cooperative efforts of its occupants. Despite the different ways of being between the two cultures, the underlying concept of the Two Row Wampum emphasizes the distinct identity of the two peoples and a mutual engagement to coexist in peace without interference in the affairs of the other (Parmenter 2013). Thus, the Two Row Wampum provides instruction on how to engage with one another on matters of importance to both nations and peoples. The same principles of peace, friendship, and respect can be applied to any relationship, in particular among researchers (Indigenous and non-Indigenous) who are working together to find solutions to issues identified by the community (Freeman 2015; Hill and Coleman 2018). Academics have an opportunity to learn from community collaborators by centering Indigenous knowledges and ways of being from within Indigenous philosophical contexts rather than assimilating the knowledge systems into their own Eurocentric worldviews (Freeman and Van Katwyk 2019; Hill and Coleman 2018).

Consultation with Indigenous elders, faculty, and persons is also central to the study's research framework. Considerations around nonhierarchical thinking include discussions of the equal value of Indigenous healing traditions and Western medicine along the care journey, and ensuring no person felt shame for preferring access to either or both healing modalities. Elders reiterated the importance of taking the time to listen to the knowledge shared from an Indigenous perspective and to be clear with participants about project outcomes. Participants are considered collaborators in this study, and their responses will help to: characterize barriers to wellness; identify facilitators to care for Indigenous persons living with TSCIs, making a "soft moccasin path" for others to have an easier journey; and, on a broader scale, inform community health transformation. A key aspect of this is understanding how participants are supported (or not) in their social environments. Lastly, Indigenous informants reinforced that researchers need to go back to communities and show reciprocity in a tangible way by sharing research results via a social event to bring people together.

We also consulted with nongovernment organizations addressing spinal cord injury and with acute and chronic spinal cord injury researchers, surgeons, and rehabilitation specialists affiliated with the University of Toronto and Thunder Bay Hospitals and Rehabilitation Centres. Working with collaborators who have preexisting, respectful relationships with First Nations communities and individuals has facilitated our outreach to potential study participants across northern Ontario. Speaking with First Nations persons living with TSCIs, and their caregivers, as well as spinal cord injury health care service providers throughout the care journey (acute, rehabilitation, and postdischarge) is necessary to identify barriers and facilitators to health care and wellness. Once established, these relationships need to be maintained beyond the scope of a single study. The results of the study will include suggestions for future data principles in spinal registries when working with First Nations persons that also align with larger community goals for health transformation. This relational approach will inform the creation of more comprehensive, culturally relevant spinal cord injury registries for

First Nations peoples in northern Ontario, with implications for Indigenous data sovereignty across Canada.

Conclusion

Indigenous communities worldwide are gathering strength. Their rights to self-determination are important predictors of health. This includes the right to determine what research questions are of interest to communities and how they should be investigated. To engage in relationality, researchers need to understand that Indigenous knowledge systems must be valued and respected, not subsumed into a Eurocentric academic construct. Using Indigenous epistemologies can build trust, mitigate problematic hierarchical perspectives of knowledge, and provide researchers and communities with models of research processes.

We embarked on a dialogical process to develop research agendas and priorities regarding TSCIs that are community driven and iterative. Continuing an iterative journey around the Medicine Wheel (Figure 1) and adhering to the principles of the Two Row Wampum Belt for relationship building (Figure 2) are essential to the research framework for this pilot project.

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