



Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough



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ABSTRACT

Historically, Indigenous health research in Canada has failed to engage Indigenous peoples and communities as primary stakeholders of research evidence. Increasingly, research ethics and methodologies are being positioned as tools for Indigenous self-determination. In response, mainstream institutions have developed new ethical principles for research involving Indigenous people. While these transformations are necessary steps towards re-orienting research practices, they are not prescriptive. In this paper, we make visible three dilemmas from a case study in which Indigenous health research frameworks provided limited guidance or were unclear about how to balance community priorities with Indigenous research principles. We also discuss the strategies used to resolve each of these dilemmas.

We draw examples from a project that examined the lived experiences of children and youth living with FASD and their caregivers. This project was conducted in collaboration with Sheshatshiu Innu First Nation, an Indigenous community in Labrador, Canada. In doing so, we argue that knowing the key guiding principles in Indigenous health research is not always enough, and that the 'real-world' context of practices and relationships can lead to conflicts that are not easily resolved with adherence to these principles.

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1. Introduction

Historically, Indigenous health research in Canada has often failed to engage Indigenous peoples and organizations as primary stakeholders or beneficiaries of evidence from research. In a global context, *Indigenous* commonly refers to cultural groups that have a special relationship with traditional land, have distinct cultural knowledge and socio-political systems, share common ancestry with original occupants of a territory, form a non-dominant group in society, and self-identify as Indigenous (United Nations, 2009). In Canada, *Indigenous* and *Aboriginal* are often used interchangeably to refer collectively to First Nations, Inuit, and Métis peoples. Until recently, Indigenous community perspectives on research priorities, project development, and results were often ignored or marginal (Castleden et al., 2010; Ermine et al., 2004; Kovach, 2009; Schnarch, 2004, 1). In some cases, research proceeded without informed consent (Mosby, 2013), results were interpreted with

minimal context (King, 2015), and findings have helped depict communities as "desperate, disorganized, and depressed environments" (Tait, 2001, 105). A recent investigation by Mosby (2013) uncovered evidence of particularly egregious violations of research ethics in studies conducted in Indian Residential Schools and First Nations communities during the mid-20th century.

From 1948 to 1952, the Canadian federal government sanctioned a series of nutritional experiments on upwards of 1000 Indigenous children who were living in church-run residential schools across the country (Mosby, 2013). At the time of the experiments, the government and researchers had already recognized malnutrition was a systemic problem in the schools. Rather than attempting to remedy this, researchers used the deprived conditions as "laboratories" (162) to assess the impact of dietary, nutritional supplementation, and dental interventions (Mosby, 2013). These studies were carried out with little regard for either the consent or well being of the already vulnerable participants, and continued even when some results showed negative effects. It is unlikely that contemporary ethics review boards would approve such research. Nonetheless, unethical practices persist in some Indigenous health research, though they are not always as obvious

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as they were in the nutritional experiment. In an effort to transform research from a colonial project, to one that advances Indigenous self-determination, several community-centered research policy frameworks have emerged in Canada.

Over the last 15 years, principles embedded in research policies have helped reorient the way Indigenous health research is conducted. In Canada, two key policy frameworks guide research involving Indigenous people. These include the *Tri-Council Policy Statement (TCPS) 2* which contains a chapter specific to research with First Nations, Inuit and Métis People (CIHR et al., 2014), and the *Ownership, Control, Access, and Possession (OCAP)*[®], a registered trademark of First Nations Information Governance Centre, www.FNIGC.ca/OCAP (FNIGC, 2007) principles for research with First Nations communities. Together, these frameworks have helped institutionalize a new set of practices for Indigenous health research. Increasingly, national Indigenous organizations, local governments, and communities have also developed guidelines aligned with these frameworks, and reflect culture and community-specific values, knowledge, and protocols (Nickels et al., 2007). Transformations in research governance and methodologies have helped position Indigenous communities as leaders and collaborators in the research process.

At the core of the TCPS 2 and OCAP[®] are expectations that researchers be responsible for meeting specific ethical standards, fundamentally shifting the way projects are designed and carried out. Concepts and language that endorse community-based, collaborative, and participatory research as “best practice” for research with Indigenous communities are widespread. Such best practices commonly emphasize social justice and equitable relationships between researchers and communities (CIHR et al., 2014; Glass and Kaufert, 2007; Israel et al., 2003; Tobias et al., 2013). The field of collaborative research with Indigenous people has been critiqued for conflating community-based participatory research (CBPR) practices with decolonizing methodologies, and at times, reproducing colonial relations despite best intentions of “good” non-Indigenous researchers (Ahmed, 2000; de Leeuw et al., 2012). There is however a common thread in the literature emphasizing the importance of starting research from a foundation built on trusting relationships that prioritizes mutual accountability, meaningful outcomes, and community-driven projects (de Leeuw et al., 2012; Wilson, 2008).

While research institutions are slowly recognizing the need for building trusting relationships before conducting research, many communities, Indigenous scholars, and participatory researchers have worked together to develop innovative ways of integrating Indigenous-specific ethics into research practices. A recent mixed methods study about the impact of climate change on health in a Labrador Inuit community is an instructive example of such practices (Cunsolo Willox et al., 2012). The project was initiated and co-led by community members and university-based researchers, licensed by municipal and regional Inuit governments, and university research ethics boards, and addressed community-defined priorities (Cunsolo Willox et al., 2012). Furthermore, the project helped generate contextualized evidence that was both validated by and relevant to the community as a primary stakeholder.

Dilemmas arising in health research involving collaborations between Indigenous communities and academic institutions are likely commonplace, even with established procedural benchmarks from both research policy and practice. Scholarship related to the broader epistemological, political, ethical, and methodological challenges and innovations in this field is increasingly prominent (Bartlett et al., 2007; Boffa et al., 2011; Brunger and Wall, 2016; Chatwood et al., 2015; Healey and Tagak Sr, 2014; Kovach, 2009; Smylie et al., 2004). However, discussions about the micro, individual-level challenges emerging from day-to-day

relationships in Indigenous health CBPR are less evident. Over the course of a project, dilemmas may emerge that challenge relationships between researchers and communities. While ethical and methodological frameworks in Indigenous health offer theoretical underpinnings, they do not always provide sufficient guidance for how to apply these in real-world settings of CBPR and decolonizing research.

In this paper, we share contextualized examples of research dilemmas that may bare similarities and relevance to others who are involved in Indigenous research. The dilemmas required pauses, critical reflections, and seemingly awkward conversations to foster solutions. The primary objective of this paper is to identify and discuss unexpected dilemmas that arose within a collaborative project with an Innu First Nation community in Labrador, Canada. We illustrate pragmatic approaches to implementing guiding principles for research with Indigenous communities and discuss some of the relational tensions that arose in the process. We argue knowing the key guiding principles for research with Indigenous peoples is not always enough, and suggest transparency in Indigenous health research practices is necessary to improve how guiding principles are translated into day-to-day research practices.

2. Context

2.1. Indigenous health, colonization, and reconciliation

In Canada, and indeed globally, Indigenous peoples experience dramatic health disparities compared to non-Indigenous populations (Anderson et al., 2016; King et al., 2009; Reading and Wien, 2009; United Nations, 2009). These disparities are connected to inequitable social conditions and other intergenerational legacies of colonization (Anderson et al., 2016; Gracey and King, 2009). The Canadian residential school system, for example, was a systematic effort to separate Indigenous children from their families to weaken cultural ties and assimilate Indigenous people into a “dominant Euro-Christian Canadian society” (TRC, 2015a, v). This system was built along with a policy mandate to establish geographical areas, known as reserves, where Indigenous communities were settled, creating conditions that discouraged or penalized traditional ways of living. The ripple effect of these and other colonial policies play a pivotal role in many aspects of health and well being of Indigenous people in Canada.

In contemporary Canadian society, colonialism persists in obvious and insidious manifestations. For example, there are disproportionately low levels of funding for education, health, and social services, elevated exposure to environmental contamination, degraded community infrastructure, and discriminatory treatment within the health system (Allan and Smylie, 2015; Gracey and King, 2009; King et al., 2009; Reading and Wien, 2009). In this context, many Indigenous communities also experience disproportionately high rates of involvement in the child welfare and justice systems (Blackstock, 2011).

In 2015, the Truth and Reconciliation Commission (TRC) of Canada released its final report and a list of recommendations (TRC, 2015a,b). The TRC’s report was a watershed moment in Canadian history in which colonization is both acknowledged and a path forward is charted. The TRC Calls to Action contains 94 recommendations including “adequate resources to enable Aboriginal communities and child-welfare organizations to keep Aboriginal families together where it is safe to do so, and keep children in culturally appropriate environments” (1) and “eliminate the discrepancy in federal education funding for First Nations children being educated on reserves and those First Nations children being educated off reserves” (2). Two of the recommendations specifically address Fetal Alcohol Spectrum Disorder (FASD), the topic of

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