

**The Wisdom of Thunder: Indigenous Knowledge Translation
of Experiences and Responses to Depression Among
Indigenous Peoples Living with HIV**

Randall Jackson

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AUTHOR: Randall Jackson, BA (Hons, Soc Sci, University of Ottawa), MA (Sociology, University of Manitoba)

SUPERVISOR: Dr. Roy Cain

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For Melody Nahmabin—

Who now does this wild dance across the Milky Way

Abstract

The translation of research findings, and the development of products has been identified as a research priority that may improve health outcomes for Indigenous peoples. Although knowledge translation is relatively new and emerging area in Indigenous science, Indigenous scholars have already been critical of Western defined knowledge translation theories and approaches as neglectful of Indigenous ways of knowing, being, and doing. Within Indigenous knowledge systems, the translation of research findings is best conceptualized as a ‘sharing what we know about living a good life.’ This dissertation explores and focuses on the use of Indigenous stories and storytelling as knowledge translation products that may be better equipped to share research findings with Indigenous peoples. Grounded in an earlier study exploring experiences and responses to depression among Indigenous peoples living with HIV, this dissertation reviewed the Indigenous knowledge translation literature, adapted narrative analysis to an Indigenous context using composite character development and a scared story (i.e., *Animikii* and *Mishebeshu*) to create an Indigenized research story titled “The Wisdom of Thunder.” Meant to inspire healing, this story was also meant to create space to rethink, reorder, and reimagine a world where HIV-positive Indigenous people who experience depression can learn and understand through Indigenous eyes. In ways connected to an oral body of stories, Indigenous stories, as an indigenized artful research translation practice, may make the findings of research more culturally accessible for Indigenous communities thereby promoting healing and wellbeing.

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Beginning in “a good way,” it’s cultural significant to me that I recognize and honour the traditional territory on which I worked as belonging to the *Mississauga* and *Haudenosaunee* nations. It is land protected by the “Dish of One Spoon” wampum, an agreement amongst all allied Nations to peacefully share and care for the resources around the Great Lakes. As an *Anishinaabe* person originally from Kettle and Stony Point First Nation (Southwestern Ontario), I am thankful to these nations of Indigenous peoples for welcoming me onto their traditional territory to pursue Ph.D. studies.

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Chapter One

Introduction

In Canada, most HIV research is supported with funding provided by the Canadian Institutes of Health Research (CIHR). This financial backing has supported the production of a wealth of multidisciplinary and scientific evidence that is shaping the ways in which we think about and respond to the prevention of new HIV infections, efforts to reduce AIDS-related deaths, and research that explores factors impacting quality of life for those living with HIV. Part of this vast body of research has focused on Indigenous peoples who represent a unique segment of the Canadian population where HIV is adversely concentrated. According to the Public Health Agency of Canada (PHAC), even though Indigenous people comprise only 4.3% of the overall Canadian population, “it [was] estimated [...] in 2011, Aboriginal people made up 12.2% of new HIV infections and 8.9% of those living with HIV in Canada” (PHAC, 2014, p. 1). The epidemic is further characterized in several important ways: (1) The dominant mode of HIV in Indigenous communities is linked with injection drug use (58.1%) compared to only 13.7% for non-Indigenous people; (2) Indigenous women (47.3%) are overrepresented compared to non-Indigenous women (20.1%); And finally, (3) more Indigenous youth (ages 15-29 years) are living with HIV (31.6%) versus non-Indigenous youth (22.2%). Between First Nations, Inuit and Métis, the face of HIV also differs. As PHAC (2014, p. 10) states: “Of

the 690 AIDS cases reported up to the end of 2008, 503 (72.9%) were among First Nations, 52 (7.5%), among Métis, [and] 22 (3.2%) among Inuit.”

In addition to this epidemiological profile, clinical HIV research adds an additional layer of complexity. Clinical research demonstrates that Indigenous peoples in Canada present later in the course of the illness than do non-Indigenous peoples (Stokes, Pennock, & Archibald, 2006), experience slower uptake of HIV antiretroviral therapy (Wood, Kerr, Palepu, Zhang, & Strathdee, 2006), and have less access to HIV-experienced physicians (Miller, Spittal, Wood, Chan, & Schechter, 2006). These features are thought to drive increased incidences of morbidity, and because of these, earlier death and a mortality rate that is three times higher in Indigenous communities compared to non-Indigenous populations (Benoit, et al., 2015; Del Amo, et al., 2013; Lima, et al., 2006).

Although this brief epidemiological and clinical summary are useful, it provides a limited view of the HIV epidemic occurring among Indigenous peoples in Canada. It obscures the structural determinants that shape vulnerability to and experience of HIV infection among Indigenous peoples. In this respect, Canadian HIV research has also focused on understanding why rates of HIV infection are disproportionately impacting Indigenous communities. The social determinants of health—the interrelated historical, political, societal, and economic factors—that work together to structurally comprise the health of a people provide a powerful explanatory model (Reading, 2015; Reading & Wein, 2013). It is widely

acknowledged that “colonization, racism, social exclusion, and the repression of self-determination act as [powerful] determinants within which Indigenous health is constructed” (Negin, Aspin, Gadsden, & Reading, 2015). Research exploring the determinants of health in the context of HIV and AIDS for Indigenous peoples have, for example: Explored experiences of poverty that impact quality of life and care (Allen, Murphy, Kiselbach, & Wiebe, 2015; Larkin, et al., 2007; McCall, Browne, & Reimer-Kirkham, 2009; Varcoe & Dick, 2008); unstable housing and homelessness (Lemstra, Rogers, Thompson, Moraros, & Buckingham, 2012; Miller, Spittal, Wood, Chan, & Schechter, 2006; Rachlis, Wood, Zhang, Montanner, & Kerr, 2009); mental health (Cain, et al., 2011; Cain, et al., 2013; Lemstra, Rogers, Thompson, Moraros, & Buckingham, 2012); addiction (Milloy, et al., 2011); traumatic childhood experiences (Hawkins, Loppie-Reading, & Barlow, 2009; Pearce, et al., 2008); and cultural determinants (Calzavara, Bullock, Myers, Marshall, & Cockerill, 1999).

Despite the obvious usefulness of this scholarship (e.g., improved understanding of disparities in health, advocacy, influencing public spending on health, etc.) that has explored the social determinants of health, Indigenous scholars are now asking for a more nuanced rethinking in ways that consider the value of Indigenous knowledges and ways of being (de Leeuw, Lindsay, & Greenwood, 2015). Critiques of the more normative social determinants of health approach in the context of Indigenous rest on two ideas: (1) Colonialism is not yet

adequately realized as a powerful and overarching determinant of health, despite being identified as important by Indigenous peoples; And (2), discussions of colonization as shaping disparities in Indigenous health have largely only considered this concept because of other, more generally accepted, determinants of health (e.g., housing, employment, education, etc.). These scholars (de Leeuw, Lindsay, & Greenwood, 2015) advocate for a more culturally relevant approach to explore Indigenous health, including considering colonization as a fundamental determinant of health. In doing so, they promote the use of Indigenous knowing as a more useful frame of reference to describe and understand the health realities of Indigenous peoples. In other words, in considering “beyond the social,” our attention shifts scholarship to “other” important Indigenous determinants of health, including the roles of spirituality, relationship to the land, geography, culture, language and knowledge systems, et cetera. This is a welcomed development and finds support in the context of Indigenous experiences of HIV and AIDS. According to a Public Health Agency of Canada report, *Population-Specific HIV/AIDS Status Report: Aboriginal Peoples* (PHAC, 2010), in speaking about future needs, it is vitally important “to identify and analyze cultural appropriate approaches to HIV/AIDS prevention, care, treatment and support that are specific to First Nations, Inuit, and Métis populations, as well as the specific needs of cross-populations, including women, youth and two-spirit, gay, lesbian, bisexual and transgender Aboriginal populations” (p. 91).

At the request of the Canadian Aboriginal AIDS Network (CAAN), which has been working towards refining its own research focus and approach, I became involved in a scoping review of Canadian HIV/AIDS literature focused on Indigenous peoples. Part of this review focused on the beneficial role of culture in the provision of HIV-related research and health services for Indigenous people living with and at risk of HIV/AIDS. In terms of the focus on culture, and towards closing the gap between Western and Traditional health approaches, preliminary findings of this scoping review revealed that the inclusion of Indigenous culture might enhance both health research and our understanding of Indigenous health, wellness, and the experience of illness. Health services that incorporate culture into their delivery, for example, can leave participants with a sense of empowerment, increase referrals to alcohol and drug treatment, reduce stress, and increase the number of clients in active care (Littlejohn, Bright, Mohammed, & Elliot, 2009; Littlejohn, 2002; Tu, Littlejohn, Barrios, & Tyndall, 2010; Benoit, et al., 2014). Inclusion of culture might also reduce stigma associated with living with HIV/AIDS (Eaglespeaker, 2006), support positive identity formation, and promotes cultural growth and intergenerational healing (Benoit, et al., 2014; McKay-McNabb, 2006; Wilson, et al., 2014). Here, the conceptualization of traditional health is thought to be tied to a holistic approach, oral traditions, culture and spirituality (Lennie, 1996). Attention to culture in HIV services also facilitates a sense of connection to the larger Indigenous community, and is

something used by Indigenous peoples living with HIV in responding to depression and other mental health challenges (Cain, et al., 2011; Cain, et al., 2013; Gorman, 2006; Jackson, et al., 2008; Prentice, et al., 2006). The Medicine Wheel, a symbol of Anishinaabe culture expressing the importance of connection and relation to all things in the environment, can be used in program delivery as a psychosocial intervention and as a counselling model in outreach to Indigenous youth. Here, evidence suggests that such approaches can, for example: Facilitate physician appointment adherence, provides support (Weiser, 1996); improved peer involvement (Peltier, Larkin, & Bilsborrow, 2011); improved care relationships (Milligan & Lavoie, 2012; DuBois, 1996); and can help build client self-esteem (Mill & Desjardin, 1996). Drawing on the strengths of Indigenous cultures, another project describes demonstrates how the inclusion of Indigenous knowing can facilitate sharing of relevant HIV treatment information (Boucher, Haight, Vincent, Peltier, & Stephenson, 2012). Here, Indigenous community control of programming incorporating traditional health practices is essential (Brassard, Smeja, & Valverde, 1996) and can be fruitful in terms of partnership with non-Indigenous programs which are knowledgeable and supportive of the importance of culture (Barlow, et al., 2008; Shannon, et al., 2006; Winsor, Stevenson, & Rivers, 2006).

In our CAAN scoping review, the use of culture was also not simply limited to health services. Several studies also addressed the use of culture in

research. In *Visioning Health*, a photovoice project focused on Indigenous women living with HIV, the method was combined with traditional ceremony to explore Indigenous women's perception of health (Prentice, et al., 2012). Arts-based approaches also used culture to facilitate youth expressions of HIV vulnerability, larger structural inequalities, and historical violence and trauma (Danforth, Koonsmo, Wilson, & Williams, 2012; Flicker, et al., 2011; Gahagan, et al., 2009; Smillie-Adjarkwa, et al., 2009; Yee & Koonsmo, 2011). Some have heralded arts-based approaches as essential to the process of decolonization (Wejr, 2006; Thomas, 2006). Storytelling (Everette, 2002; Nowgesic, 2014), the use of Indigenous languages (Rand & Kadlun, 2014), the inclusion of humour, and the use of Elders can also all improve the development and dissemination of health information into Indigenous communities (Flicker, et al., 2007; Flicker & Danforth, 2014; Flicker, et al., 2011; Forsythe, 2006; Fownes, 2002; Lambert, 2004; Mitchell, 2008; McLeod, Johnson, Gardiner, & Kakeway, 1996; St. Denys, 2011). And finally, the Medicine Wheel was used to analysis focus group transcripts to explore resiliency among two-spirit men living long-term with HIV (Jackson, Nobis, Zoccole, Brennan, & Georgievski, 2015; Zoccole, Brennan, Nobis, Jackson, & Georgievski, 2014).

The strengths of Indigenous culture, when embodied and practiced by Indigenous people, are thought to have a buffering effect in the context of negative outcomes related to social determinants of health. However, a focus on

factors that support Indigenous health and wellness are not yet adequately researched in HIV and AIDS. This is particularly true for knowledge translation efforts. Speaking broadly about the need for effective and culturally driven knowledge translation approaches, King (2011, p. 74) states, “we need more experience and more knowledge discovery to define the good practice that will allow the multitude of other First Nations, Inuit, and Métis communities, and urban Aboriginal populations to heal and gain wellness” (see also Jardine & Furgal, 2010). In Canada, the drive to translate research findings using Indigenous knowledge is still in its infancy and is constrained by, as acknowledged by the World Health Organization, a ‘know-do-gap’ (WHO, 2006)—referring to the lack social science researchers’ knowledge and skills vis-a-vis knowledge translation. Indigenous scholars across a variety of health contexts are similarly supporting calls to develop knowledge translation processes and products from within Indigenous world views (Estey, Kmetec, & Reading, 2008; Estey, Kmetec, & Reading, 2010; Jardine & Furgal, 2010). There is general agreement among Indigenous scholars that western theories and approaches may not meet the needs of Indigenous peoples (Jardine & Furgal, 2010; Smylie J. , 2011; Smylie, Olding, & Ziegler, 2014). Indigenous scholars and allies have called for the development of approaches that “[...] respect cultural differences and [that also recognize] the moral, historical, and legal rights of Aboriginal peoples to self-determination (Kaplan-Myrth & Smylie, 2006, p. 5). These scholars are beginning to define

what it means to enact knowledge translation from within specific cultural ways of ‘knowing and doing’ that are unique to Indigenous communities (e.g., decolonizing and participatory methodologies, support for self-determination, and that enact the moral and ethical principles of ‘sharing what is known with others’).

Goal and Objectives

The over goal for this dissertation is to explore Indigenous knowledge translation using story and storytelling towards a better sharing of research findings with Indigenous community members affected by and living with HIV and AIDS in Canada. Under this goal there were two related objectives: The first objective is to reconsider/re-examine a previous study I was involved in as a community investigator working with the Canadian Aboriginal AIDS Network (CAAN). Although now complete, this study focused on the experiences and responses to depression among Indigenous peoples living with HIV. The decision to choose this study for this project relates to the dearth of research exploring mental health specific to Indigenous people who experience mental health challenges, but also and equally important, it was a study that originally was not influenced by Indigenous knowing and doing. Perhaps it is time to look back, and explore, what it might mean to use Indigenous knowledge to translate findings for community use. As such, and this relates largely to my own development as a social science researcher, the second objective is to draw on and be influenced by

the ways Indigenous cultural knowledge might impact how research is performed and shared via knowledge translation activities with Indigenous peoples.

Indigenous Knowledge: My Personal Journey

I identify culturally as *Anishinaabe* from Kettle and Stony Point First Nation located in southwestern Ontario. I have worked for approximately twenty-plus years in the Indigenous HIV/AIDS movement in Canada and abroad. Part of this involvement led me to collaborate on a range of projects (see Chapter Five for details) as a community stakeholder, as a knowledge user, as a research participant, and as a scholar. The communities I live in and have worked with have inspired me to “look ... through the lens of Indigenous knowing and of the cultural forces that shaped the stories in the first place (McLeod, 2007, p. 17).

However, as an upcoming Indigenous scholar working in the field of HIV and AIDS in Canada, I was already acutely aware of the negative history of research on my people. Here research findings were often arrived at without the benefit of insiders’ knowledge. Research that was ‘conducted on’ rather than ‘with’ Indigenous peoples had a colonizing effect, and was largely informed by dominant Euro-Western values and norms (Smith, 1999). Perhaps it was Du Bois (1904), an early 1900s African-American scholar who said it best when he wrote; “It is a peculiar sensation ... this sense of always looking at one’s self through the eyes of others, of measuring one’s soul by the tape of a world that looks on in

amused contempt and pity” (p. 2). As such, part of the desire to explore the use of Indigenous knowing in social science research I have been involved in—including this dissertation—was intended to contribute to efforts to interrupt the continuation of these negative research approaches. It has been written by Indigenous scholars, for example, that we ‘walk in the two worlds’ of both academia and Indigenous communities (Tedlock, 2011). Jones and Jenkins (2008, p. 475), in writing about these two worlds, argue that this divide “is to be protected and asserted as a positive site of productive methodological work.” It is what led Walters and colleagues (2009) to challenge Indigenous scholars to “retraditionalize” their research effort. Indeed, Indigenous scholars had already begun to extensively map the terrain of Indigenous ways of knowing towards informing diverse ways of designing research, gathering data, and meaning-making in the research process (Chambers, et al., 2017).

I’ve been as much a participant in this development as I’ve been witness to the use of Indigenous knowing in critical social science research. In reflecting on the research that I’ve been involved in over the years in my work with CAAN, in the beginning we relied on allied academic researchers for help to conduct our research that we identified as relevant. My involvement in this early research was to assume responsibilities for research promotion, for participant recruitment, and assisting with—but not leading— analysis and knowledge translation. As our organizational research capacity grew, we began to apply for and manage our own

research funds, hire research staff, and engage Indigenous community stakeholders who contributed to defining the research approach. With each successive and successful project, the communities I have worked with have advocated and pushed for more strength-based rather than deficit-based inquiry. This push has added a welcomed dimension to Indigenous HIV/AIDS research. Indeed, as I reflect on my involvement in CAAN-led research over the years, our attention has shifted from describing the social context of challenges faced by Indigenous people to exploring the positive cultural factors and processes that might positively influence Indigenous health. I have become increasingly focused on concepts such as resiliency, the importance of ceremony in research, and the use of cultural mores as protective factors. It is this new orientation to thinking and doing research, inspired in large part because of my *Anishinaabe* culture as well as my involvement in the Indigenous HIV/AIDS community, that my interests have aligned with exploring a range of ‘wise practices’ that support, sustain, and grow Indigenous identity in health research.

Experiences and Responses to Depression among Indigenous peoples living with HIV

The experience of depression is common among those living with HIV and affects anywhere between 10% to 50% of the HIV general population (Ciesla & Roberts, 2001; Penzak, Reddy, & Grimsley, 2000). Given a variety of stressors that the HIV population face, this is not entirely surprising. Experiences of

depression among those living with HIV have been linked, for example: To disclosure of one's HIV status, lifestyle changes that accompany HIV illness, changes in health status over time living with HIV (Dickey, Dew, Becker, & Kingsley, 1999); experiences of HIV-related stigma (Herek, 2002); HIV antiretroviral medication side effects (Collins, et al., 2006; Power, Tate, McGill, & Taylor, 2003; Trepanier, et al., 2005); age, employment status, lack of social support (Catalan, Klimes, Day, & Garrod, 1992); and to alcohol and drug use (Komiti, et al., 2003).

Although this research presented a general overview of the experience of depression and HIV, the catalyst for focusing on experiences and responses to depression among HIV-positive Indigenous people in Canada was instigated by the suicide of well-known Indigenous person living with HIV. From a resolution brought to the floor of the Canadian Aboriginal AIDS Network's (CAAN) Annual General Meeting, Indigenous people living with HIV directed this national body to begin addressing their mental health concerns. At the time, I was working with CAAN as a national coordinator for the Indigenous peoples living with HIV/AIDS caucus. The focus on depression that Indigenous people experience was also bolstered by knowledge that much of the mental health research that was available at the time was grounded in a Western biomedical perspective that might not adequately represent the experiences of Indigenous people (Fenton & Sadiq-Sangster, 1996). Indeed, as Kleinman and Good (1985) argued, experiences

of depression, the emotions expressed, and how others respond may vary considerably from culture to culture (Cain, et al., 2011). It was not only important to respond to CAAN's members' concerns, but to do so from within the world views that they live their lives (McLeod, 2007).

Using a community-based research design, under CAAN's leadership, in 2004 we approached researchers at McMaster University to assist with the design of a study that focused on HIV-related depression with the goal to explore how Indigenous participants describe their experience of depression, the causes they attributed to depression, and how they made sense of their depression. Guided by a National Research Advisory Committee of Elders, Indigenous people living with HIV, and HIV community member representation, fifteen community organizations from across the country (Ottawa, Toronto, Vancouver, Edmonton, Winnipeg, and the Atlantic region) assisted with recruiting a purposive sample of seventy-two Indigenous individuals who self-identified as both living with HIV and having experience of depression. These individuals were invited to participate in an in-depth, semi-structured interview. With participants' permission, all interviews were audio-recorded, transcribed verbatim, and analysed thematically using Atlas.ti. The coding scheme related to several issues of importance, including family background, cultural issues, depression and HIV infection, formal and informal supports, identity, substance use, and recommendations. As the analysis emerged, these preliminary findings were shared at meetings and with

our National Research Advisory Committee. Underpinning the ways in which the study unfolded, the research team for this project was also guided by principles of Indigenous community ownership, control, access to, and possession (OCAP) of research data and findings. The idea driving the inclusion of OCAP to guide decision-making was to ensure that Indigenous cultural values, perspectives, and self-determination were respected throughout the research process.

Our findings demonstrated that depression, as experienced by Indigenous people living with HIV, was often described, not as feelings of sadness, but more as feelings emptiness, loneliness, distance, tired, guilty, scared, disappointed, messed-up, or lost. The expression of anger was a common way that participants described their depression. It was this anger that tended to focus on social relations—as mistreatment by family and community, difficulty trusting others, and discrimination and harassment. Depression, in other words, was a social phenomenon that was powerfully connected to feelings of social disconnection.

Summary of Chapters

Envisioned as stand-alone papers, each of the chapters included in this dissertation were compiled to highlight key stages in the research process and how each step contributed to the development of a story as a knowledge translation product—one grounded in Indigenous knowledge—about how Indigenous people living with HIV might understand their experiences and responses to depression. The concluding chapter in the series offers a personal

reflection of what it means to be an Indigenous person situated within the academy and use of Indigenous knowledge to shape scholarly research.

Chapter 2: Indigenous knowledge translation in Indigenous Communities

This chapter about Indigenous knowledge translation was influenced by the concept—*bimaadiziwin* (living well)—which urges Indigenous scholars to share what they have learned through their research with Indigenous communities (Kaplan-Myrth & Smylie, 2006). *Bimaadiziwin*, as I understand it, articulates a spiritual orientation to living a good life that is best practiced as living in ceremony. Although not explicitly stated, as an academic pursuit, the concept implies that scholarly work is best accomplished through the lens of a people who originally experienced the phenomena (McLeod, 2007). It is both a moral and ethical responsibility to work in this way when researching in Indigenous communities in Canada (Brant Castellano, 2000; Kovach, 2009; McLeod, 2007). As such, we draw on Indigenous knowledges to ground the translation of knowledge produced by our study on experiences and responses to depression among Indigenous peoples living with HIV and AIDS (Cain, et al., 2011; Cain, et al., 2013; Jackson, et al., 2008). Chapter Two reviews the literature focused on use of Indigenous knowledges to shape knowledge translation efforts for the benefit of Indigenous audiences. The literature defines Indigenous knowledge translation as an activity that is Indigenous led and that produces health information or products that are culturally congruent. The goal in conducting

knowledge translation, like mainstream processes, is to improve health outcomes for a people (Kaplan-Myrth & Smylie, 2006). Unpinning Indigenous knowledge processes are several important principles. These principles include drawing on Indigenous ways of knowing and doing, using a decolonizing approach coupled with a participatory methodology, and it will also express a commitment to support Indigenous self-determination. The review of this literature suggests that arts-based approaches typify knowledges translation in ways consistent with an Indigenous world view. Consistent with the goal of this thesis—to re-story through an Indigenous lens—the focus here is on the use of story and storytelling to share what has been the experience and responses to depression among Indigenous people living with HIV. This paper, written by R. Jackson (first author and responsible for data gathering and analysis) and R. Masching (second author with responsibilities for commenting, expanding the analysis, and editing) has been accepted in final form for publication in the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (June, 2017).

Chapter 3: Indigenizing composite narratives

The violent history of colonialization—including its links to spiraling rates of HIV infection occurring in Indigenous communities—demands a spiritual approach to combat resulting cultural wounds (Brant Catellano, 2015). It is this idea that provided the impetus to draw on our collective Indigenous spiritual histories—as practiced in ceremony in contemporary contexts—to develop our

approach to indigenizing an artful and composite narrative inquiry. In doing so, we responded to Basil Johnston's provocation: "Do you want to hear our side of that story (2007)?" In other words, when using Indigenous knowledge, stories and storytelling shift the ways in which we understand, respond to, and share knowledge about a given phenomena.

But the use of storytelling wasn't simply about sharing a distinct Indigenous perspective about what it means to live with both HIV and depression. Our use of story to translate research findings, and perhaps more importantly, was also meant to respond to Brant Castellano's (2015) deliberate query, "How do we move forward towards holistic health for Indigenous people?" Of direction offered by these two Elder scholars (i.e., Basil and Brant Castellano), stories and storytelling became our vehicle for translating findings back into Indigenous communities. In fact, our spiritual histories intuitively guided us to offer something 'beyond' the social determinants of health (Richmond, 2015). Indigenous stories possess pedagogical power that can also "affirm our relationship with our nations, our tribal communities, our family networks" in ways that capitalize on the notion of becoming "the stories we [listen to and] tell [...]" (Blaeser, p. 59). Indigenous stories are medicine, they teach Indigenous ways of being/doing, and are reflexive devices that potentially allow new and imagined possibilities to emerge. This paper, written by R. Jackson (first author with responsibilities for writing), C. Debassige (second author with

responsibilities for commenting on drafts and for expanding analysis), R. Masching (third author with responsibilities for commenting on drafts and for expanding analysis), and W. Whitebird (responsible for shaping the paper towards inclusion of Indigenous knowledge) is now published in an edited collection of scholarly work titled “*Artfully Social Work: Beyond Boarder and Boundaries*” published by Wilfrid Laurier Press (Sinding & Barnes, 2015).

Chapter 4: The Wisdom of Thunder

Meant to inspire healing among Indigenous peoples living with HIV and depression, *The Wisdom of Thunder*, incubated in numerous discussions over the years with Indigenous peoples living with HIV, with Elders, and with Indigenous community HIV educators and support workers. Following the footsteps of master Indigenous storytellers, in tandem with community consultations, the story also drew some inspiration from my own *dibajimoowinan* (personal narratives of family history and experience) to reflect a rich oral history of Indigenous stories, myth and legend (Simpson, 2014). In negotiating what it means to be Indigenous in the academy, it was an approach that I felt compelled to follow. As such it lays bare my own bias and this allowed me to shape the story using my Indigenous consciousness as an *Anishinaabe* person—a place of vulnerability—to make it visible to others.

As Chapter Two highlights, the stories shared by participants in the earlier study focused on experiences and responses to depression were repeatedly read.

The goal here was to listen for and draw out participants' impressions of the importance of relationship (e.g., the importance of land for community healing, etc.), connection (or disconnection from significant others, family, and nation, etc.), and use of ceremonial practices and cultural insights offered by participants. In doing so, composite characters emerged including those who were apprehended by the state (either fostered or adopted outside their communities), and those who use substances to respond to life's challenges, et cetera. While it might make sense to view the work as a partially fictionalized story, it is important to hold in account the notion of embedding oneself in the story, of remembering one's own cultural identity, and of using all cultural responses to tell an Indigenous story (Tedlock, 2011). In translating our earlier findings, I carefully and deliberately followed the footsteps of master Indigenous storytellers who came before. Like Simpson (2014), I drew on my own "*dibajimoowinan* (personal narratives of family history and experience) in ways that connect to 'our oral body of stories' to challenge listeners to also 'rethink, reorder, and reimagine the world' through Indigenous eyes. It is an approach that embodies remembering the past as connected to a future where social space is created where it might not have already existed. When we insert ourselves in our research (Tedlock, 2011), we avoid 'arm chair' research that might put us at arm's length from our research products—rather, this approach implores us to consider Indigenous consciousness as always highly personal and contextual (Simpson, 2014). This stand-alone paper

was solely written and conceptualized by R. Jackson and has been submitted (July 2017) to the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research for publication consideration.

Chapter 5: Indigenous Knowing in HIV Research

Meant as a personal reflection of what it means to draw on Indigenous knowing in social science research, in Chapter Five, I explore the idea of Indigenous cultural identity within the academy as a paradox that must be negotiated in ways that are far from straightforward, simple, or uncomplicated. It is largely a project that involves the renegotiation of personal identity that develops academic skills to challenge colonialism in research (Grande, 2008). The focus of this chapter uses reflexivity and articulates the value of theoretical overlap and building confidence to deploy Indigenous knowledge. Part of this is questioning the value of two-eye seeing—to push at its contours and boundaries—and to ask tough questions about its practice and use in research contexts. Finally, this chapter explores what makes Indigenous scholarship, Indigenous. Written and conceptualized by R. Jackson (sole author), this chapter has been accepted for publication in a forthcoming book edited by E. Mykhalovskiy and by V. Namaste tentatively titled “*Social Science and HIV/AIDS: Critique, Research and Engagement*” being published by the UBC Press, Vancouver, British Columbia.

Chapter 6: A Research Note

In the sixth chapter, for a variety reasons, it was important to discuss and highlight some of the ways Indigenous knowledge was used to resist dominant

and more normative approaches to Western social science scholar. It was vitally important to share this—to provide a felt sense—of what it means to be Indigenous and a scholar, to bring what I felt was beautiful about who we are as Indigenous peoples, and to use this as a way of countering less positive description and more Western understanding of what it means to be Indigenous and experience depression. In part, it is this active scholarly resistance that grounds much of the work I’ve been involved in, including this dissertation. The development of this chapter drew on an earlier work by D. Peltier (presenter), R. Jackson (presenter, drafted presentation), and E. Nowgesic (contributor) at a 2012 Ontario HIV Treatment Network (OHTN) conference (Peltier, Jackson, & Nowgesic, 2012). Before appearing in this dissertation, this earlier OHTN presentation was further revised and updated by R. Jackson and was also presented at a 2017 Metro Vancouver Aboriginal Executive Committee Policy Engagement Conference, Vancouver, British Columbia.

Chapter Two

Knowledge translation in Indigenous communities: A review of the literature

Randy Jackson¹ and Renée Masching²

¹McMaster University and the ²Canadian Aboriginal AIDS Network

Background

Although a relatively new field of inquiry for Indigenous scholarship (Smylie, 2011; Smylie, Olding, & Ziegler, 2014), there is general agreement that Western defined knowledge translation (KT) theories and approaches may not meet the needs of Indigenous peoples. Jardine and Furgal (2010, p. 119) argue, for example, that “insufficient attention has been paid to the development of knowledge translation within specific knowledge systems and ways of knowing” (see also Estey, Kmetic, Reading, 2008; Estey, Kmetic & Reading, 2010; King, 2011; Smylie et al, 2003; Smylie J. , 2011; Smylie, Olding, & Ziegler, 2014). As such, Indigenous and allied scholars have called for the development of KT approaches that express a “commitment [to and] respect [of] cultural differences and [for KT approaches that recognize ...] the moral, historical, and legal rights of Aboriginal peoples to self-determination” (Kaplan-Myrth & Smylie, 2006, p. 5).

At a pragmatic level, KT in Indigenous contexts “can be simply understood as *sharing what we know about living a good life*” (Smylie, 2011; italics in original). This suggests KT is already part of what the *Anishinaabe* (the people) refer to as *bimaadiziwin* (living well). Allowing Indigenous KT to be

shaped by *bimaadiziwin* suggests that KT processes, activities, and products can also be thought of as sacred endeavours and therefore in tension with Western models of KT. Knowledge development and translation as a spiritual pursuit is an idea not typically captured as part of Western scientific inquiry (Wenger-Nabigon, 2010). In ‘*sharing what is known*,’ Indigenous KT requires a comprehensive appreciation of Indigenous local knowledge, a connection to the promotion of health literacy, and a reciprocal relationship between researchers and community stakeholders (Kaplan-Myrth & Smylie, 2006) towards improving health outcomes. Indigenous scholars and communities involved in research also emphasize the importance of decolonizing KT processes, support of self-determination, and where Indigenous KT is best developed, a range of participatory methodologies (Barnes Moewaka, Henwood, Kerr, McManus, & McCreanor, 2011; Ermine, Sinclair, & Jeffery, 2004; Estey, Kmetic, & Reading, 2008; Estey, Kmetic, & Reading, 2010; Kaplan-Myrth & Smylie, 2006). If such principles are closely followed, it is felt that the fit between KT and dissemination products may result in a better response to Indigenous communities’ identified needs. In other words, Indigenous KT has the potential to support, nurture and sustain positive Indigenous identities for the foreseeable future. In this respect, Indigenous KT needs not only to be grounded in Indigenous knowledges but they should also be developed and evaluated from within that intellectual context (Denzin & Lincoln, 2008b).

As authors of this chapter, it is culturally important for us to locate ourselves. Jackson identifies as *Anishinaabe* from the community of Kettle and Stony Point in southwestern Ontario, Canada. Renée Masching has Iroquois and Irish blood lines and identifies as an adoptee raised in a home with a first-generation Eastern European father and an English/Scottish Canadian mother. We have both worked closely for many years with the Canadian Aboriginal AIDS Network (CAAN). Incorporated in 1997 as a national non-profit, non-governmental body, CAAN's vision is "a Canada where First Nations, Inuit and Métis Peoples, families and communities achieve and maintain strong, healthy and fulfilling lives and significantly reduce HIV and AIDS, HCV, STBBIs, TB, Mental Health and related co-morbidity issues where Aboriginal cultures, traditions values and Indigenous knowledge are vibrant, alive, respected, valued and integrated into day-to-day life" (CAAN, 2017). Our collaborative work under CAAN, for the past 20 or more years, saw us lead a variety of past and present community-based research projects. Inspired by the growth we've experienced as Indigenous scholars using both decolonizing and Indigenous methodologies, our interest in Indigenous KT marks an added feature where we wish to develop a more Indigenously grounded sharing of research findings in culturally appropriate and meaningful ways.

Indeed, we wish to add our voices to those of other Indigenous scholars, by sharing in their now generally accepted agreement, that any research with

Indigenous peoples must have a critical and comprehensive understanding of the use of Indigenous knowledge to shape knowledge translation. This includes a project, as one of several research examples we could have used, exploring experiences and responses to depression among Indigenous peoples living with HIV. It is a project that typifies our past approach to simple dissemination (as opposed to Indigenous KT). Although the experiences/responses to depression produced two peer-reviewed journal articles (Cain, et al., 2011; Cain, et al., 2013) and a community report (Jackson, et al., 2008), KT efforts beyond this have largely not occurred. It is also an example that highlights that we need to do better in terms of using decolonizing and Indigenous methodologies to shape KT. As a first step, our goal here, is to further explore meaningful Indigenous KT guided by the following questions: (1) What is, how, and why is Indigenous KT important? And (2), Are there any successful KT approaches currently being used in Indigenous communities and what might we learn from them? The larger goal for this paper was to gather knowledge about Indigenous KT that enables the transfer of findings from the depression and HIV study into a more culturally-grounded KT product.

Method

We drew on Randolph's (2009) literature review protocol as inspiration, following key instructions and adapting others. Like Randolph (2009), the goal of our review was to develop an understanding of Indigenous KT language and

theories, and to highlight some examples of Indigenous KT approaches. Although this review focused on peer-reviewed literature, in addition to these, several other key documents were also consulted and these include *Knowledge Translation for Indigenous Communities* (Hanson & Smylie, 2006) and *Sharing What We Know about Living the Good Life* (Kaplan-Myrth & Smylie, 2006). These ‘grey-literature’ reports, because they are often referenced and considered seminal works by other Indigenous and allied scholars, assisted with the development of our understanding of key issues and approaches to KT with Indigenous communities. For our purposes, a “review [of literature in this area] retrieves, appraises and summarizes all the available evidence on a specific (health) question and then attempts to reconcile and interpret it” (White & Schmidt, 2005, p. 55). A variety of search terms were used to access literature and these include the following: Aboriginal*, Aborigine*, Indigenous, native*, "first nation*", "first-nation*", "1st nation*", "1st-nation*", Metis, Inuit, Indian*, Amerindian*, “Māori”, and “tribal”. We created a list of Indigenous search terms, with librarian assistance, to capture KT articles specific to Indigenous peoples. We combined search terms specific to Indigenous with additional key search terms, including: “knowledge translation”, “knowledge transfer”, dissemination, “knowledge exchange”, “dissemination”, “implementation research”, “knowledge utilization” and “knowledge to action”. We entered search terms into several academic research databases including ProQuest, Web of Science and CINAHL. We also

adopted a forward and backward chaining (i.e., reviewing the reference lists of selected articles) for articles, book chapters or books specific to KT in Indigenous communities in Canada, the United States, Australia and New Zealand. The decision to limit the number of databases is based on the author's past research experience as likely to capture the majority of published Indigenous KT literature. Based on expertise, similarly, the geographic limit was applied as it was felt that this would return most articles on Indigenous population and KT theories, strategies or approaches. Finally, three inclusion criteria were used to select relevant literature. They included: (1) Does the article focus substantively on KT? Here, all conceptual, commentary, and empirical (both qualitative and quantitative research) were included. A second pass of all abstracts returned asked the following additional question: (2) Does the article include a substantive focus on KT with Indigenous peoples in Canada, Australia, New Zealand or the United States? The last criteria question we asked was the following: (3) Is the article available in the English language? Due to resources (i.e., time and funding for translation), only peer-reviewed literature in the English language were included. Aside from the two Indigenous-specific reports highlighted above, a comprehensive search of the grey literature was not included because of available resources (e.g., time).

Findings: Indigenous Knowledge Translation

Towards developing a better understanding of what is meant by '*sharing what is known about living the good life*' (Smylie, 2011; Smylie, Olding, & Ziegler, 2014), the literature defined Indigenous KT as an "Indigenously led sharing of culturally relevant and useful health information and practices to improve Indigenous health status, policy, services and programs" (Kaplan-Myrth & Smylie, 2006, pp. 24-25). Two key questions guided the development of our understanding of Indigenous KT. The first question urged us to consider key methodological components of Indigenous KT. A focus on the methodological aspects helped situate our understanding of Indigenous KT as a discrete process or approach as a fundamental feature of Indigenous science. Indigenous scholars who implement Indigenous KT have outlined several important methodological features. Indigenous KT: (1) draws on Indigenous ways of knowing; (2) is decolonizing in its approach; (3) supports self-determination; (4) is grounded in participatory approaches; and (5) enacts the ethical or moral responsibility to share research findings. In doing so, it became clear how Indigenous ontology (world view), epistemology (ways of knowing), and axiology (values) are critical for the development of effective Indigenous KT. These focuses lead us to pragmatically consider whether we are living the good life (focused on art-based approaches) in ways that exemplify successful Indigenous KT. The decision to focus exclusively on arts-based approaches in Indigenous KT relates to the focus

on the earlier study, experiences and responses to depression among Indigenous peoples living with HIV and AIDS, and particularly storytelling approaches that have been successfully used with Indigenous communities. We wanted to capture and learn more fully how Indigenous stories and storytelling as Indigenous KT act as medicine in ways that provide healing to Indigenous peoples (King, 2003; Peacock, 2013; Simpson, 2011; Simpson, 2014).

Draws on Indigenous Ways of Knowing

In 2007, the Canadian Institutes of Health Research (CIHR) issued a directive to health scholars conducting research with Indigenous communities to better understand, respect, and use Indigenous world views. This directive outlined for researchers their “responsibilities to the people and culture that flow from being granted access to traditional and sacred knowledge” (CIHR, 2007). It was an approach that was later taken up in a revised Tri-Council Policy Statement outlining ethical research with Indigenous communities (Interagency Advisory Panel on Research Ethics, 2010). As well, it promoted a research approach that aligned with the *UN Declaration on the Rights of Indigenous Peoples* that specified that, “Indigenous peoples have the right to be actively involved in developing and determining health, housing, and other economic and social programs affecting them” (Smylie, 2011). This approach suggests that Indigenous KT consider what, where, who and why Indigenous knowledges are important.

Indigenous knowledge systems are often described in the literature as relational, ecological, holistic, experiential, communal, oral and narrative-based (Brant Castellano, 2000; Crofoot Graham, 2002; Hart, 2010; Little Bear, 2000; Shiva, 2000). Although crucial differences have been noted across Indigenous knowledge systems, these overarching principles are thought to be shared across Indigenous tribal groups in Canada (Brant Castellano, 2000; Portman & Garrett, 2006). Brant Castellano (2000) in further describing key features of Indigenous knowledges notes the dynamism, diverse, localized, and intergenerational aspects of Indigenous knowledge. Similarly, Indigenous knowledge, according to Kaplan-Myrth and Smylie, is “alive, enfolded in nature, relationships, spirituality and everyday experiences” (2006, p. 7). Using and developing new Indigenous knowledge, in addition to these key features, almost always involves the interpretative involvement of healers and Elders, notwithstanding the importance of community-readiness to be involved in knowledge translation efforts.

Indigenous and allied scholars who actively cultivate cultural awareness are thought to be better able to recognize Indigenous knowledge, act on the information that has been gathered, and then use these to develop effective culturally appropriate KT. In this respect, Indigenous knowledges are widely accepted as rooted in the land, are given through spiritual revelation, in dreams, or are given through ceremonial relationships (e.g., Elders and healers) with others in the communities (Brant Castellano, 2000). Specific to Indigenous KT, scholars

also argue that gaining knowledge is also located in sharing knowledge. This sharing is conceptualized as multi-directional and KT is rooted in practical outcomes (Smylie, 2011). Knowledge translation in Indigenous communities is first-and-foremost a process that works to uphold principles of self-determination and is focused on collective consensus building, building a shared understanding, and produces dissemination in ways relevant to the socio-cultural contexts in which new knowledge is generated. As Kaplan-Myrth & Smylie (2006) state, “Indigenous [KT] is an Indigenously-led sharing of culturally relevant and useful health information and practices to improve Indigenous health status, policy, services and programs” (pp. 24-25). Rather than traditional Western approaches that emphasize the importance of interactions between scholars and knowledge users (Smylie, et al., 2003), Indigenous approaches espouse the view that “knowledge translation activities [best occur] within *the context in which knowledge is to be applied*” (Smylie, et al., 2003, p. 142; italics in original). In other words, a focus on the contextual settings of the knowledge user—or target population—and their world view and ways of knowing are necessary for successful knowledge translation (Jacobson, Butterill, & Goering, 2003; Smylie, Williams, & Cooper, 2006).

It is also important to understand who teaches Indigenous knowledge because their involvement in KT is critical to success. Important tensions are raised between Western and Indigenous knowledge systems when one considers

who teaches Indigenous knowledges. As Kaplan-Myrth and Smylie (2006, p. 24) state, “the Western scientific canon—all about empirical, objective, rational truths—does not classify personal experience and spirituality as ‘knowledge.’” Rather, within Indigenous knowledge systems, knowledge is gathered through individuals, family, and community relationships, given in or obtained in ceremony, found embedded in songs, works of art, and stories, and/or obtained through Elders who provide spiritual and interpretative guidance. In this respect, “Elders are the most highly knowledgeable members of communities” and they are recognized by community members as assuming “responsibility of intergenerational knowledge translation” (Kaplan-Myrth & Smylie, 2006, p. 24; see also Begoray & Banister, 2011). Accessing Indigenous knowledge through multiple sources are key for successful Indigenous KT—and again—Indigenous and allied scholars who take the time, who approach Indigenous sources of Indigenous knowledge with an openness and willingness to learn, and then act on cultural information to weave these ‘traditional teachings’ within Indigenous KT may have more success in term of promoting health for Indigenous people.

Last, it is important to also understand why Indigenous knowledge is important in Indigenous KT. Aside from the fact that being Indigenous matters (Ball, 2004), the loss of Indigenous knowledge as a negative consequence of colonialism is but another important reason for embedding Indigenous knowledge in KT. In this vein, “[Indigenous KT] is inherently political” and is “fundamental

to the exercise of self-determination” (Kaplan-Myrth & Smylie, 2006, p. 28). Indigenous KT is viewed both as an effort to support and affirm the importance of Indigenous identities but it is also seen as an exercise in confronting Western power and control to define what is meant by ‘good KT science.’ Indigenous KT that draws on Indigenous world views is framed by scholars as an Indigenous responsibility or ethic. As Kaplan-Myrth and Smylie (2006) share, “Indigenous knowledge is kept alive through respect for Elders” (p. 29; see also Begoray & Banister, 2011) and this is viewed as both an individual and collective responsibility. Indigenous KT translation thus expresses Indigenous peoples’ endurance “that Indigenous knowledge will not vanish as long as Indigenous people pass on what they know to future generations” (Kaplan-Myrth & Smylie, 2006, p. 29). In this sense, Indigenous research is the development of new Indigenous knowledge and Indigenous KT fulfils the promise of sharing such knowledge in ways that Indigenous communities might benefit.

The importance of Indigenous knowledge to successfully translate health and other information, with communities as equal partners, is demonstrated by assorted studies. In one study reviewed, for example, Bisset and colleagues (2004) used case analysis to describe a community-readiness model where diabetes was promoted as a community health issue. Community-readiness involved flooding the community with information that transformed diabetes from “*something to live with to perceiving diabetes as something to prevent*” (Bisset, Cargo,

Delormier, Macaulay, & Potvin, 2004, p. 321; italics in original). In using Indigenous ‘traditional ways’ to disseminate information (e.g., KT decisions were guided by notions of holistic health and the Seventh-Generation teachings of love, courage, humility, honesty, truth, wisdom, and respect), findings demonstrated that raising community consciousness was aided by the “cohesive and assertive tendencies ... [of service providers that facilitated] the community’s ability to ‘pull it together’” (Bisset, Cargo, Delormier, Macaulay, & Potvin, 2004, p. 323).

Strives to Decolonize KT

Supported by several key recommendations (e.g., the Royal Commission on Aboriginal Peoples and the revised Tri-Council ethical guidelines), the development and use of decolonizing methodologies has experienced tremendous growth over the last sixteen years (Brant Castellano, 2000; Denzin & Lincoln, 2008a; Smylie, 2011). Like other areas of Indigenous social and cultural life, Indigenous pathways involved in sharing knowledge have been disrupted by the negative effects of colonialization. It is within this vein that decolonization has been identified in the literature as key for successful KT in Indigenous contexts (Smylie, 2011). According to Smith (1999), decolonizing approaches in KT are focused on returning research findings “back to the people in culturally appropriate ways and in a language that can be understood” (p. 15). Developed by the *Knowledge Translation and Indigenous Knowledge Research Group*, according to Smylie (2011), decolonizing KT rests on several interrelated

assumptions. First, successful Indigenous KT acknowledge that Indigenous communities already have effective health systems (e.g., ceremonies, medicines and foods) that can be used in designing KT approaches. This assumption has guided a range of successful Indigenous KT approaches in addressing the health of Indigenous communities. Dell and colleagues (2011), for example, explored a culture-based resiliency model of providing care to Indigenous youth experiencing solvent use. By connecting youth with Elders and providing access to traditional foods, this model promoted healing by reconnecting youth with their communities and affirmed their cultural identities. Second, decolonizing approaches to KT acknowledge that Indigenous health systems include diverse ways of being and that knowing the world as connected with the land. Recognition of this suggests successful Indigenous KT in one community may not transfer in the same way in another community (Kaplan-Myrth & Smylie, 2006). In reflecting on Dell and colleagues' article (2011), King (2011, p. 73) observes, "If we improve the health of a small community, that is important, but, for every group there are hundreds or even thousands like them but different." Traditional foods in one community may not exist in another so what is it about the traditional food offered to Dell and colleagues' participants that worked? How might findings from this study inform solvent use services in other Indigenous communities? The answer to this question is not yet available and because of this,

according to King, Indigenous “knowledge translation is a vital part of our scientific arsenal that still needs refinement” (2011, p. 73).

These first two decolonizing principles—i.e., recognition of Indigenous strengths and attending to Indigenous diversity—links with other principles of decolonizing KT for use in Indigenous communities. It is widely recognized that Indigenous health is rooted in local environments and ecosystems and as such embodies crucial differences (Smylie, 2011). Successful Indigenous KT considers this diversity and attempts to understand knowledge translation as specific to one locale. In one study, for example, scholars compared the use of one KT strategy in three Indigenous communities in Canada. They found that “each of the three participant communities [had] unique and context-specific values, practices, and social structures that influence the pathways of health information” and that because this, it is “important to [draw on] Indigenous knowledge [from] within local geographic ecosystems” to account for Indigenous diversity (Smylie, et al., 2009, p. 443). This principle also recognizes that “these systems [are] epistemologically distinct from modern biomedical scientific traditions, which purposefully decontextualized knowledge from local contexts to discover generalizable health principles and cures” (Smylie, 2011). In fact, it is widely acknowledged that Indigenous peoples conceptualize health and wellbeing in ways consistent with their cultures. In other words, the decontextualized nature of Western health information may not always be amendable in diverse Indigenous

cultural contexts where the focus in the later is rooted in the local environment. Another similar decolonizing principle recognizes that successful Indigenous KT makes a connection with the political context in which Indigenous health knowledge is used in health services and programs. Here, Indigenous KT is conceptualized as inherently political in terms of articulating self-determination. Connected with these principles, successful Indigenous KT approaches recognize the ways Indigenous knowledge systems of health were damaged by state policies that suppressed Indigenous ceremonial and health practices. It is an Indigenous KT approach that actively works to redress the negative impacts experience by Indigenous peoples in Canada and that continues to reverberate in Indigenous communities by affirming the cultural values of Indigenous peoples as important to community health and wellbeing.

Successful Indigenous KT strategies that embed a decolonization orientation, that draw on the strengths of Indigenous culture, may serve to increase trust in proposed health services and programs where other approaches fail. Eighth, “contemporary health knowledge and health behaviour among Indigenous individuals and communities is influenced by an interplay of precolonial systems of health, historic, and ongoing processes of colonization, and exposure to non-Indigenous systems of health—the nature of this interplay is diverse and varies according to individual and community experiences, locations,

migrations, and kinship systems” (Smylie, 2011). Understanding local experiences are important towards crafting effective Indigenous KT that is meaningful to them. Ninth, and last, “a decolonizing process involving critical examination and dismantling of individual and systemic assumptions and power relations, including the suppression of Indigenous knowledge, is required to improve the health of Indigenous communities” (Smylie, 2011).

Supports Self-Determination

Indigenous KT is also a process that works to uphold principles of self-determination. This directs KT scholars to implement consensus building strategies, build shared understandings, and devise KT approaches that are relevant within the socio-cultural contexts in which knowledge was originally generated. In other words, a focus on the contextual settings of the end user—or target populations—is essential for knowledge translation activities to be successful (Jacobson, Butterill, & Goering, 2003; Smylie, Williams, & Cooper, 2006). In short, Indigenous KT supports Indigenous peoples’ conceptualization of health (Smylie, Williams, & Cooper, 2006). As an example of self-determination in KT for Indigenous peoples, Smylie, Williams and Copper (2006) asked participants at the *Canadian Conference on Literacy and Health* the following question: “What exactly are culture-based approaches to literacy and health, and how can they be effectively and practically applied in given Indigenous contexts?” (p. S22). In responding to this question, participants highlighted the

importance of self-development, understanding and embedding Indigenous knowledge in KT messaging, fluency in terms of cultural knowledge, and a focus on holistic health (e.g., attending to physical, mental and emotional and spiritual) and Indigenous wellbeing. However, despite wide acceptance of self-determination in health literacy as a goal in Indigenous KT, significant gaps in knowledge continue. These gaps include a lack of systematic reviews of research of Indigenous KT, examples of best practice engaging communities in KT practices, best practices in health services using Indigenous KT, evaluations of Indigenous KT approaches, and barriers to effective Indigenous KT (e.g., lack of appreciation of Indigenous knowledge, racism, poverty, etc.) (Smylie, Williams, & Cooper, 2006).

Grounded in Participatory Methodologies

Using decolonizing approaches coupled with support for self-determination for Indigenous peoples, the Indigenous KT approaches reviewed here draw on a range of participatory methodologies to achieve successful transfer of knowledge from the academy to community. According to Smylie (2003; 2011) and others (Barnes, Henwood, Kerr, McManus, & McCreanor, 2011; Begoray & Banister, 2011), “methods of Indigenous knowledge generation and application are [often] participatory, communal and experiential, and reflective of local geography” (2003, p. 141; see also Masching, Allard & Prentice, 2006). Participatory methodologies emphasize a ‘by ‘us’ for ‘us’ and about ‘us’

approach, are directed by communities in leadership positions, privilege local and experiential knowledges, involve the community in equal partnership, and ‘retraditionalize’ the research process (Ball & Janyst, 2008; Cahill, 2007; Evans, Hole, Berg, Hutchinson, & Sookraj, 2009; Jacklin & Kinoshameg, 2008; Walters, et al., 2009). According to Wallerstein & Duran, “[Community-based participatory research] is an orientation to research that focuses on relationships between academic and community partners with principles of co-learning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts” (2006, p. 312). In terms of Indigenous KT, participatory methodologies allow self-determination to emerge by both making room for Indigenous peoples to be involved in constructing knowledge but also for their involvement in disseminating research findings (Smylie, Williams, & Cooper, 2006). These are approaches that embody the principles expressed in a range of participatory methodologies. These approaches also suggest a critical appreciation of and the desire to use Indigenous knowledges in crafting culturally appropriate models of KT.

Although participatory methodologies were taken up by a variety of authors in this review (McShane, Smylie, Hastings, Martin, & Centre, 2006; Masching, Allard, & Prentice, 2006; Martin, 2006), Pierre-Hansen and colleagues describe a participatory model that drew on the strengths of an Indigenous community towards developing appropriate culturally-grounded palliative care

practices. Focused on developing a culturally responsive model of care, this example involved consulting an Elder's council, community members and leaders, and a traditional healer. Focused on developing an understanding of barriers to effective KT and how best to overcome these in working with Indigenous communities, they found that Indigenous governance models that integrate cultural values, practices and norms and an organizational culture aligned with health research best exemplify principles needed for successful Indigenous KT. For these authors, the involvement of community in research processes was important because "the major sources of health information are from within the Inuit community, principally through Elders, family, friends, staff of the Inuit Family Resource Centre, and family doctors" (McShane, Smylie, Hastings, Martin, & Centre, 2006, p. 298). Understanding effective Indigenous KT is about recognizing community strengths to produce and share information and this supports principles of self-determination. As McShane and colleagues (2006) state, "Compared to the model of knowledge translation put forth by the [CIHR], the results suggest a need to for a direct link between knowledge users (i.e., community members) and the knowledge products." Typical knowledge products (i.e., pamphlets) may need to be replaced by information sources linked to Inuit oral, direct communication traditions (i.e., audiovisual recordings) where knowledge users have been directly involved in the preparation and presentation of health knowledge flowing from research.

Is Ethical Responsibility

Like principles of two-eyed seeing (Hatcher & Bartlett, 2010; Iwama, Marshall, Marshall, & Bartlett, 2009), the idea of an ‘ethical space’ emerged as a key principle when working with Indigenous communities on knowledge translation activities. Ethical space is defined as “the common space between two disparate knowledge systems, cultures, and world views” (Jardine & Furgal, 2010, pp. 110; see also Ermine et al, 2004). It is a space where dialogue about intentions, values, perspectives and assumptions is valued in ways that promotes “amicable research agreement between researchers and Indigenous communities” (Jardine & Furgal, 2010, p. 110). The idea of an ‘ethical space’ helps to advance the argument that Indigenous KT is grounded in, supports, and builds on Indigenous perspectives and values (Smylie, Williams, & Cooper, 2006). It is also within this ‘ethical space’ that Indigenous and allied scholars have critiqued Western knowledge generating systems for not being open to Indigenous ways of sharing knowledge (Duran & Duran, 2000). A comparison of Western and Indigenous knowledge translation systems demonstrates fundamental differences that need to be accounted for and when interfacing between divergent systems. It means that “knowledge translation methods for health [...] research must be specifically developed and evaluated within the context of [Indigenous] communities” (Smylie, et al., 2003, p. 142). Considered theoretical development, the two-community frameworks espoused here as an ‘ethical space’ envisions

new ways of developing and sharing new Indigenous knowledge (Lester, 1993; Smylie, et al., 2003). In this respect, and as described above, Indigenous KT is found to be consistent with the family of participatory methodologies that urges scholars to design KT with community relevance and community control in mind.

Several articles included in this review describe Indigenous KT as embedded in and consistent with the philosophies of community-based research methodologies (Elias & O'Neil, 2006; Masching, Allard, & Prentice, 2006). In this way, Indigenous KT is conceptualized as a moral obligation within Indigenous societies. Smith (1999) provides a powerful statement about methodology, and particularly, the importance of decolonizing research and towards Indigenous knowledges in an Indigenous KT research process as an ethical stance. As Smith states:

Methodology is important because it frames the questions being asked, determines the set of instruments to be employed and shapes the analysis. Within an indigenous framework, methodological debates are ones concerned with the broader politics and strategic goals of indigenous research. It is at this level that researchers have to clarify and justify their intentions (p. 143).

From an indigenous perspective, it is therefore ethically and vitally important to consider the ways ontology (i.e., theory of the nature of existence), epistemology (i.e., nature of knowing), methodology and methods shape the

scientific enterprise (Wilson, 2008). These approaches to conducting research also shape methodology and method as they relate to Indigenous KT. All aspects of Indigenous knowledge interact to shape the knowledge production and dissemination process and begin with the notion of idea worthiness, the questions asked, the ways questions are asked, and how data is analyzed and interpreted (Wilson, 2008) and shared. For Indigenous peoples, as Smith (1999) states, “the ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the worlds’ colonized peoples” (p. 1). Further, it is a move that supports “the imperatives inside the [Indigenous] struggles of the 1970s [towards a ...] survival of [a] peoples, [their] cultures and languages, [and supports] the struggle to become self-determining” (Smith, 1999, p. 142).

Arts-based Indigenous knowledge translation: Are we living the good life?

A key question as it relates to Indigenous knowledge translation is whether we ‘are living the good life’? In other words, are scholars sharing health research findings with diverse Indigenous audiences in ways consistent with their knowledges? As Christensen (2012) notes, the processes and the products used in Indigenous knowledge translation are often not recognized or supported within the academy. Western methods (e.g., journal articles and formal research conference presentations) for sharing information tend to have better traction and tend to also dominate the research landscape as the only acceptable and more

worthy forms of KT. Increasingly, however, qualitative scholars who are critical of the objectivity and rationality biases in the sciences have become increasingly interested in a variety of arts-based approaches for use in KT (Bazeley, 2006; Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012; Coemans, Wang, Leysen, & Hannes, 2015; Austin & Forinash, 2005). Not only can arts-based approaches drive the ways in which health knowledge is generated, they are research approaches that influence dissemination strategies in ways that challenge Western notions about what counts as evidence. Collectively, arts-based approaches are contributing to a new “appreciation for the complexity and multi-dimensionality involved” in translating findings for use across a variety of populations or audiences (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012, p. 2).

In fact, the social sciences are beginning to recognize the potential of arts-based approaches to powerfully reveal important aspects of the illness experience and what is meant by health and wellbeing. In other words, as Boydell and colleagues argue (2012, p. 2), “by incorporating art forms in the research process it is possible to evoke emotional responses and to construct alternative forms of representation that promote dialogue and shared storytelling.” The value of arts-based approaches is premised on the “subjective nature of human experience, an interpretative philosophy *vis-à-vis* knowledge production, including a creative process and a representation of that experience made available to others”

(Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012, p. 2). Gergon and Gergon (2011) also argue that art-forms in the social sciences creates interest, generates action, directs critical assessment towards health issues, and are better than traditional academic forms of knowledge translation where the latter is thought of as a limited model for communicating research findings across audiences.

Congruent with critical, Indigenous, and decolonizing methodologies (Denzin & Lincoln, 2008a; Denzin & Lincoln, 2008b), arts-based approaches can be defined as “method[s] in which the arts play a primary role in any or all of the steps of the research method. Art forms [...] are essential to the research process itself and central to formulating the research question, generating data, analyzing data, and presenting the research results” (Coemans, Wang, Leysen, & Hannes, 2015, p. 34; quoting Austin & Forinash, 2005). These relatively new approaches draw on a number of different artistic and visual methods. Visual methods for dissemination are used across a variety of arts-based approaches, including photography, collage and painting. One exemplar of arts-based KT used photography to explore food security in the lives of Indigenous children. This photovoice project produced a photobook and that this was “a powerful means for disseminating findings and creating opportunities for individual and community-led change [that] positioned youth as health and cultural advocates, and valuable community assets” (Genuis, Willows, Nation, & Jardine, 2014, p. 606).

Indigenous KT using arts-based approaches can also focus on performance (e.g., film and theatre). Willox and colleagues (2013) explored the use of digital storytelling, as an example of performance in KT focused on the impacts of climate change. Findings from this study suggest digital storytelling helped to not only preserve but to promote Indigenous oral wisdom for wider community benefit. Although digital storytelling has been criticized as a method that does not faithfully represent Indigenous traditional knowing (Hopkins, 2006), it can still positively update and shape the ways traditional knowing is presented (Iseke & Moore, 2011). Beltrán and Begun (2014), for example, effectively argue that digital storytelling offers an opportunity for healing, is potentially transformative, and is a method that can potentially disrupt the experience of historical trauma suffered as a result of the negative effects of colonization.

Finally, narrative methods (e.g., poetry, fiction and non-fiction) as arts-based approaches to knowledge translation can also be effectively used to disseminate findings affecting positive social change. Several narrative approaches stand out as examples of positive and effective knowledge translation strategies. Blodgett and colleagues (2011) used vignettes as a narrative strategy to address some the incompatibility of Western methods in social research with Indigenous ways of knowing and sharing information. Drawing on participatory action research principles coupled with cultural praxis, they found the approach “particularly salient within the Aboriginal community as stories are a traditional

way of passing on knowledge and preserving cultural values and teachings” (Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011, p. 529; see also Begoray & Banister, 2011). In the words of one of the community authors from this study, “*in using the traditional pathways of storytelling, the spirit of our research will continue to be alive for those researchers who will follow.*” (Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011, p. 529; italics in original). Similarly, and in another study, Christensen (2012) focused on the written word as a valuable arts-based approach towards translating knowledge. Drawing on his dissertation findings of Indigenous homelessness in the Arctic region, Christensen used his research findings to create a fictionalized account of one women’s experience of homeless. The value in this approach not only heightened confidentiality, but was enthusiastically and resoundingly well received by participants because it provided them with a way to view their experiences of homelessness as an account of resiliency and agency. As Christensen (2012) states, “Not only do creative representations of research have the potential to engage research participants in new ways, [but] they [...] also [serve to] influence participants’ understandings of their experiences” (p. 237) and in a more positive light.

Typically, arts-based research methods influence the ways data is gathered, how data is understood, and relevant here, how arts-based approaches are used to disseminate findings. Specific to the later of these, arts-based methods “are [being] used as a medium to translate an outcome of a particular research

project, replacing a traditional research report and moving away from the traditional focus on textual dissemination of research findings” (Coemans, Wang, Leysen, & Hannes, 2015, p. 34). Again, research findings are being re-imagined or represented by visual, narrative or performance art projects. Blodgett and Schinke (2015) explored the role of culture in athletes’ experiences in ‘mainstream’ sports venues through the use of mandala drawing (i.e., a circular drawing meant to inspire healing in ways that depict one’s inner world and outer reality) coupled with conversational interviewing as a promising arts-based form. They found that their research approach “open[s] space where Aboriginal athletes could more deeply and meaningfully share their stories” (Blodgett & Schinke, 2015). In another study, Dell and colleagues (2011) explore the transformative power of storytelling for use in clinical settings with First Nations and Inuit youth experiencing solvent and other substance use. Use of storytelling in clinical settings was identified as more “respect[ful of] local values and traditions” (Dell, Sequin, Hopkin, & Tempier, 2011, p. 80) and more connected with community processes related to providing care and supporting healing and wellbeing.

Our recent research experience, not unlike the empirical studies described above, suggests also that the value and use of cultural symbols (e.g., Medicine Wheel) or cultural approaches (i.e., storytelling, video) to sharing and transferring knowledge can offer unique ways to write, speak about, and present findings in ways more congruent with Aboriginal worldviews (Jackson, Brennan, Georgieski,

Zoccole, & Nobis, 2015; Amirault, et al., 2015). The use of cultural symbols, such as the Medicine Wheel, potentially facilitates the goal of knowledge translation, exchange and uptake of research findings in communities of interest because it presents findings with active community involvement and draws on the cultural strengths of sharing to present research findings in ways that make sense to participants. Along with the development of printed project reports, which are familiar formats for policy audiences, the projects I have been involved with have incorporated a variety of arts-based approaches, for example, data visualization as a way of visually representing oral tradition. This project which I participated as a co-investigator, explored resilience among two-spirit men, and visually represented research findings using an *Anishinaabe* Medicine Wheel. Drawing on principles of data visualization and information architecture, we created an online web space where community members (as well as other audiences) can interactively explore resiliency in ways that made sense to them (see <http://www.oahas.org/2shawls/>). In another project, we undertook a scoping review of the global decolonizing and Indigenous methodological literature to explore Indigenous knowledges with the aim to better understand ways of embedding this knowledge in our research processes, in generating new knowledge, and in disseminating findings of research back into the populations in which we work. Drawing on the aesthetic of oral storytelling and the power of documentary film to disseminate findings, this scoping review project hosted a

research team sharing circle where we video-recorded our dialogue and then selected key themes to share with wider audiences (visit <https://www.youtube.com/user/CdnAboriginalAIDS>). In feedback from people whom we talked with, many regarded the videos as enormously valuable, more accessible and engaging than written formats. Building on these examples, the first author (i.e., Jackson) of this paper has become increasingly interested in use of storytelling as an effective Indigenous KT dissemination strategy.

Storytelling as an Arts-informed KT Approach

Storytelling, as a knowledge translation strategy, is thought to be congruent with Indigenous knowledges supporting Indigenous self-determination, healing from colonial trauma, and the resurgence of Indigenous cultures and lifeways (Begoray & Banister, 2011). Moreover, as Christensen writes, “within an Indigenous sociocultural framework, storytelling is the central medium of knowledge transmission and is also an important educational tool” (2012, p. 232). Smylie also supports the use of storytelling as an Indigenous KT dissemination strategy because as an arts-based approach, “Storytelling [... is one] important way that local knowledge, values, and skills were transferred within and among communities and across generations” (see also Kaplan-Myrth & Smylie, 2011; Lawrence et al, 2006; Little Bear, 2000). The primary reasons for support of storytelling as a KT strategy in Indigenous communities is derived from the understanding that stories embed the cultural protocols of a specific Indigenous

peoples (Lavallee & Poole, 2010), are powerfully linked with the power of oral tradition (King, 2003), and are grounded in different ways of knowing (Walker, 2001; Wenger-Nabigon, 2010). According to Smylie and colleagues (2003):

“In Indigenous knowledge systems, [... the development of] knowledge [often] starts with ‘stories’ as the base units of knowledge; proceeds to ‘knowledge’ [and the ...] integration of the values and processes described in the stories; and culminates in ‘wisdom,’ and experiential distillation of knowledge.’ This process is cyclical, as ‘wisdom’ keepers in turn generate new ‘stories’ as a way of disseminating what they know. Traditionally local forms of knowledge dissemination were [often] interwoven with social, political and kinship structures [in ways that ...] reinforce individual and collective wellbeing [...] to ensure the protection and sustainability of the physical environment” (p. 141).

In exploring Indigenous adolescent girl’s health, Begoray & Banister (2011) advocate conceptualizing an effective knowledge translation approach as associated with community-based research methodology. As such, effective knowledge translation with Indigenous girls focused on issues of contextuality, collaboration, reciprocity, relationality, and reflexivity. Storytelling as a KT approach thus reflects “the intrinsic connection of everyday pragmatism to metaphysical and symbolic realities [as] a common feature of Indigenous

worldviews” (Smylie, Williams, & Cooper, 2006, p. S22). The productions of these stories are grounded in community-based research approaches in ways that attend to “the culture and context of the participants” (Kelly, Mock, & Tandon, 2001, p. 348; see also Christensen, 2012). Here the objective is to locate ways to present research findings in immediate and engaging ways that inspire change by using the cultural lens of participants that reflect the ways depression might be perceived, experienced, and understood—not only by the participants—the general public as well. According to Christensen (2012), storytelling has the potential to transcend cultural borders making it a powerful vehicle that “appeal[s] to the heart of diverse audience” (p. 232).

Discussion and Conclusion

The Indigenous KT literature offers some important direction for developing research dissemination approaches with Indigenous communities. First and foremost, this body of literature directs KT scholars to foreground Indigenous worldviews. Understanding the nature of Indigenous knowledges, and implications for Indigenous KT, means translating research findings will be attentive to local conditions and ways Indigenous communities understand and use cultural wisdom. Understanding that Indigenous knowledges are rooted in specific ecosystems, means KT scholars will avoid “ineffective” approaches that are not grounded in “locally specific, community generated understandings” (Smylie, et al., 2009, p. 443). In this respect, Indigenous communities are well

positioned to contribute to KT efforts. Attention to Indigenous knowledge is also considered important because when grounded in Indigenous knowledges, scholars will understand that Indigenous peoples do not operate as if there is a separation between knowledge production and knowledge dissemination. Rather, scholars will understand that “KT [is] nothing new for Indigenous peoples” where possession of knowledge has always been “inextricably linked to action both philosophically and practically” (Smylie, Olding, & Ziegler, 2014, p. 17).

Drawing on the wisdom embedded in Indigenous knowledges—and consistent with key research policy directives—the development of effective Indigenous KT is decolonizing and participatory. As Begoray and Banister (2011) state, health “programs would be more effective, especially if Indigenous [local community representatives ...] were founded upon community-based knowledge translation principles.” Collaboration engages community members, shares power, and draws on local community knowledge. In this vein, community involvement not only centres KT within Indigenous world views, ways of knowing, and ways of learning, it is a process by which Indigenous KT contextualizes community-based KT as specific to a local Indigenous population. Connected to local conditions, Indigenous KT processes strive to build trust, shift power to community to decide on actions, and embody a synergistic and reciprocal relational ethic (Begoray & Banister, 2011). In other words, as Barnes Moewaka and colleagues (2011) write, Indigenous KT avoids “knowledge-rich

research experts delivering outputs to knowledge-needing end users. Such expert-driven models fall short of meeting the complexity of the research-user interface, particularly in relation to Indigenous communities.”

Finally, Indigenous KT draws on the power of decolonizing and participatory approaches aimed at creating “ethical space” where collaboration, reciprocity, and meaningful community and academics relationships “resonate with the tenets of Indigenous ways of knowing” (Begoray & Banister, 2011). As a model that informs the ways that power-sharing occurs within the context of knowledge production and knowledge use, as Ermine and colleagues state, these are process where “empowerment and benefits [...] become central features of any research entertained and conducted” (Ermine, Sinclair, & Jeffery, 2004). It is a conceptual space—a place to negotiate partnerships, that acknowledges the political nature of knowledge production and dissemination, redresses loss of Indigenous knowledges, contributes to the resurgence of Indigenous lifeways grounded in local cultural perspectives, and strives to enable individuals, families and communities to live a good life (Kaplan-Myrth & Smylie, 2006). In short, ‘ethical space’ capitalizes on the ideas of “equity and mutual respect for different ways of knowing” as critical for success (Smylie, Williams, & Cooper, 2006, p. S25).

Despite this direction, however, Indigenous KT theories do not yet adequately inform nor provide sufficient direction to researchers, and this

continues to be problematic (Smylie, 2011). This raises important questions about translating research findings of an earlier study exploring experiences and responses to depression among Indigenous peoples in Canada (Cain, et al., 2011; Cain, et al., 2013; Jackson, et al., 2008). The literature reviewed acknowledges storytelling as healing in Indigenous contexts because they are literary devices that are grounded in experiential learning. They are interactive, build on the oral tradition, and serve to “translate information among and across generations about their history, origins, and spirituality” (Begoray & Banister, 2011). However, little information is provided about how these stories might be developed from research findings. Questions about what is Indigenous storytelling, how are Indigenous stories created, how might stories be used in knowledge translation remain. Nonetheless, storytelling is frequently cited as the most reported and used type of communication in Indigenous communities and the involvement of Elders in Indigenous KT can model positive action as central toward promoting effective translation for Indigenous community benefit.

Chapter Three

Towards an Indigenous Narrative Inquiry: The Importance of Composite, Artful Representations

Randy Jackson, Corena Debassige, Renée Masching, and Wanda Whitebird

Do you want to hear our side of that story? (Johnston, 2007)

When pondering how to use Indigenous knowledge to think across unsettling difficulties when working within the rigid tenets of Western social science, we were inspired by Thomas King's Canadian Broadcasting Corporation (CBC) Massey Hall Lecture Series, *The truth about stories: A Native narrative* (2003). In these lectures, King provides us with sage advice that bolsters how we pivot our understanding of ways narrative inquiry can be reimagined through Indigenous knowledge. King does this by offering the following: "The truth about stories is that that's all we are" (2003, p. 2). Although stories can help us better understand the world, they can also uncomfortably govern our lives. In fact, they are both miraculous and troublesome. You see, we divide the world up with stories, and sometimes the only differences we can find in something are the stories we are told by others or ones we quietly whisper to ourselves. King also describes himself as a "hopeful pessimist," and he writes "knowing that none of the stories [he tells will] change the world. But [he writes] in the hope that they [will]" (2003, p. 92). It is a position where a promise is offered; as he says when

he quotes Okri (1997, p. 46), “If we change the stories we live by, quite possibly we change our lives.”

Today's Indigenous peoples are learning ways to “restory” the world by grounding our resistance to contemporary and historical conditions through our knowledge of traditional stories and teachings. Tedlock (2011) points out that this resistance is accomplished in ways that implicate the “Other,” and is tethered to, and flourishes in, space that encourages use of one’s double consciousness. Our use of the idea of double consciousness refers to two worlds—the shared space in research occupied by competing world views. It is space occupied by privileging neither a Western nor an Indigenous perspective; rather, they create and are connected to a third space that draws on both world views in an artful expression located within narrative inquiry. We find the concept of double consciousness similar to principles of “two-eyed seeing” advocated by Indigenous scholars. Here we are urged to use both eyes to locate the strengths of each perspective and to use them together in blended ways to illuminate aspects of the social world that are of interest (Hatcher & Bartlett, 2010; Iwama, Marshall, Marshall, & Bartlett, 2009). Tedlock, herself Indigenous, says that double consciousness is a reminder that she “should walk in balance along the edges of these worlds. ‘There is beauty and strength in being both: a double calling, a double love’” (Tedlock, 2011, p. 337).

Tedlock (2011) discusses double consciousness in the context of preformed ethnographies that are expressed through memoir and creative nonfiction. In the case of narrative approaches to social inquiry, however, double consciousness carefully and cautiously urges the use of the aesthetic of oral storytelling in synergistic, musical, and poetic ways, bridging critique with written forms (Gilbert, 2006; King, 2003). Denzin and Lincoln argue “that everything is always already performative. The performative, in addition, is always pedagogical, and the pedagogical is always political” (2008a, p. xi). It is an approach that reminds and challenges us to continue *dibaadadaan*—an *Anishinaabe* word meaning to tell stories—for if we stop, we’ll soon discover that “neglect is as powerful an agent as war and fire” (King, 2003, p. 98).

This chapter focuses on the use of narrative inquiry filtered through an Indigenous knowledges perspective. Our primary goal is to use conventional narrative inquiry as a springboard, weave Indigenous knowledges within and around, and work towards having composite narratives as a useful research tool to ground Indigenous participants’ voices into a single literary, oral, and artfully representative *dibaajimowin*—an *Anishinaabe* word referring to “teachings, ordinary stories, personal stories, histories” (Simpson, 2011, p. 50). Our use of a composite approach to narrative is meant to push us past critiques (i.e., a critical perspective) focused solely on the negative consequences of colonialism, paternalism, and imperialism. Rather, we wish to move into a space that actively

envisions and fruitfully grounds the artful practice of Indigenous epistemologies and ontologies through *dibaaJimowin*. Composite narratives, for us, are meant to be interactive and attentive to the audience (King, 2003; Tafoya, 2000), maintain oral tradition (Kovach, 2009), and draw on ancient Indigenous tribal wisdom through traditional stories (Tafoya, 2000; Tafoya, 2009). In our practice, we also set composite narratives in context by connecting them to critiques of contemporary health theory (Murray, 2002). Such an approach, as Anderson (2011) and Borrows (2010) argue, supports, sustains, and grows Indigenous knowledges (Wilson, 2008). The composite we encourage, like other forms of storytelling and narrative imagination, is as Simpson argues, “at [its] core decolonizing, because it is a process of remembering, visioning and creating a just reality where Nishnnabeg (meaning “the people”) live as both *Nishnnabeg* and *peoples*” (2011, p. 33; italics in original). Such stories are powerful for they embody our relationship with our ecologies. When we voice these stories, we locate ourselves within them: we establish ourselves and our ecologies as inseparable in ways that can’t be severed by colonialism (McLeod, 2007).

Before we begin, however, there is a caveat. We, the authors, were reminded as we wrote this chapter that coming to know Indigenous knowledge and finding useful applications for it is always a journey. With Indigenous knowledges as our opening, we began first with personal experience. It is a position that required each of us to “go to the centre of [one’s] self to find [our]

own belonging” (Kovach, 2009, p. 49). It is highly personal work in the sense that it is unique to the individual, and as a result, it doesn’t “lend itself to a check-box, universal approach” (Kovach, 2009, p. 50). As Indigenous peoples who live, work, and contribute to our communities, our approach has ultimately been shaped by our own “intertribal experience” (*Anishinaabe*, Delaware/Cayuga/Irish, Cree, and *Mi’kmag*) and by our professional lives as support workers, researchers, and Elder. Our approach is also constrained by the “semantics of the English language,” and it represents, as we see it, simply “one view of reality, a perspective that needs to be evaluated in the contexts of other stories by other members of the community” (Brant Castellano, 2000, p. 32). As such, our writing about composite narrative in Indigenous contexts is not meant to be taken as prescriptive, but is presented here as one approach—among many others—that we feel is useful for understanding the complexities of stories shared by Indigenous peoples.

In this chapter, we are especially intent upon developing a means of understanding the complexities of stories shared by Indigenous people who live with HIV and AIDS as they explain to themselves (and to us) the roots of their depression, how they experience depression, and ways in which they respond.

Research that centres Indigenous knowledge

Although a lengthy description of the essential features of Indigenous knowledge is beyond the scope of this chapter, we must understand the essential

elements of Indigenous knowledge before we can centre it in a composite narrative. Considered by many to be a relational perspective (Barton, 2004; Crofoot Graham, 2002), the ways in which Indigenous knowledge is used in research contexts is varied, owing to the diversity among Indigenous peoples.

Kincheloe and Steinberg describe Indigenous knowledges as:

a lived-world form of reason that informs and sustains people who make their homes in a local area. [Indigenous peoples] construct ways of being and seeing in relation to their physical surroundings. Such knowledges involve insight into plant and animal life, cultural dynamics, and historical information used to provide acumen in dealing with the challenges of contemporary existence (2008, p. 136).

In addition to these key features, Brant Castellano (2000) notes that the use and development of new Indigenous knowledges almost always involves the interpretative involvement of healers and Elders. Indigenous knowledges are thought first to be personal, always correct, oral, experiential, holistic, and conveyed in narrative and metaphorical language. For knowledge to have social validity in ways that support the participatory involvement of communities in research, it is “validated through collective analysis and consensus building” (Brant Castellano, 2000, p. 26; see also Battiste & Youngblood Henderson, 2000).

Moving towards centring Indigenous knowledges in ways that speak to participants in research—in ways that Western ontology often avoids (Kirmayer,

Brass, & Valaskakis, 2009)—Anderson (2011), in her study of life stages of Aboriginal women drawn from interviews with Elders, writes about how “allegorical stories underpinned the narratives and events of their own lives” (p. 19; see also Tafoya, 2000 and Tafoya, 2009). It is in both space and place—rather than time—where allegory assists Indigenous people to non-intrusively derive meaning, to add to their personal body of tribal wisdom, refract memories of older and ancient times, and where this can be interpreted in light of shifting experience and context (McLeod, 2007). In other words, Indigenous knowledges offer “maps of meaning [...] located at the centre of a community’s identity” (Kirmayer, Brass, & Valaskakis, 2009, p. 442). Using Indigenous knowledges can also provide opportunities—in shared cross-cultural spaces and places—for mutual participation (King, 2003; Kirmayer, Brass, & Valaskakis, 2009). They potentially shift the research landscape to support Indigenous identity and consciousness, and enable cultural meaning to move further to the surface in ways that can be understood by a variety of readers, irrespective of their cultural identities.

This approach is premised on deep listening, quietness, and stillness, so that we are better able to hear the reverberations from the past in contemporary contexts. This listening draws on principles of “spiritual history” that simply urge “us to try to engage the narratives through the lens of those who originally experienced it” (McLeod, 2007, p. 17). It also suggests that we incorporate these

ancient ways of deriving understanding about contemporary experiences of illness by acknowledging “their relations to a world in which nonhuman persons play an active role in the lives and fate of human beings, either through their visible actions or in an invisible spirit realm” (Kirmayer, Brass, & Valaskakis, 2009, p. 442). Inquiry into the illness experience is best approached with attention to the notion of *all my relations*, for it recognizes that Indigenous knowledge continues to operate in Indigenous lives because it has been “ongoing, and [has been] sustained through relationships, respect, and responsibility” (McLeod, 2007, p. 18). Accessing meaning and interpretation through Indigenous knowledges premised on composite narrative means “participating in a ritual [and] seeking spiritual wisdom” that is “not subsumed by material or psychological levels of explanation” (Kirmayer, Brass, & Valaskakis, 2009, p. 489).

Research as Ceremony

Benham (2007) and Wilson (2008) both previously outlined that doing research—or, in our case, narrative inquiry—in Indigenous contexts means one must address the thorny issue of how best to retain the sacred and the spiritual aspects of ceremony. We acknowledge that the single most important feature of an Indigenous centred, decolonizing methodological approach rests in “the *process* of doing [... which is] as important as what is *produced* at the end” (Anderson, 2011, p. 15; see also Cochran et al., 2008; Brant Castellano, 2000). To achieve this we understand, as Brant Castellano (2000, p. 29) writes, that “all of

the senses, coupled with openness to intuitive or spiritual insights, are required in order to plumb the depths of Aboriginal knowledge.”

In the project we describe here, we focused our efforts from the outset on becoming spiritually ready to receive knowledge, and moved towards an approach that openheartedly (Simpson, 2011) incorporated ceremony (Wilson, 2008) into the design of the project. This means that we acted in ways in which the doing of research respected “the core values, beliefs, and healing practices of the Indigenous community [...] throughout the research process” (Lavellée, 2009, p. 23). Lavellée (2009) also offered specific directions towards enacting these commitments: working collaboratively with Elders as equal partners who provided stories of traditional knowledge and assisted with interpretation through that lens (Anderson, 2011; Baskin, 2005; Brant Castellano, 2000; Kovach, 2009); incorporating or mirroring Indigenous ceremony (e.g., focus groups were modelled on the basis of a sharing circle format; see also Baskin, 2005; Lavellée, 2009; Poff, 2006); offering tobacco to participants as a gift that symbolized the “Creator” was present and witnessing the exchange (Kovach, 2009); and as far as was possible, using Indigenous symbols to elicit stories from informants about their understandings of Indigenous knowledges (Lavellée, 2009).

However, Shahjahan (2010) documented how the usual approaches to curriculum development often do not capture the key features of the personal work scholars engage in towards embedding spirituality in their own lives prior to

engaging in their social justice work. The same is also likely true of our research endeavours. Nonetheless, as we understand research practice through an Indigenous lens, conducting research involves adopting a process focused wholly on aspects of “personal work that must be done by the researcher in conjunction with [their] own world (both inner and outer)” (Kovach, 2009, p. 50). From an *Anishinaabe* standpoint, it directs one to seek out Elders, centre the holistic nature of knowledge, and participate in activities such as ceremony and prayer as means to access inward knowledge. As Kovach noted, “[We] need[ed] to open ourselves to those teachings and then give ourselves time to integrate them so that we can be of use to our community” (2009, p. 50). This process of becoming ready to hear stories in Anishinaabe contexts is referred to as *debwewin*—meaning “to know with one’s heart”—so that the connection contemporary stories have with ancient and wise ways of knowing the world is more clearly understood (Simpson, 2011). It is a process that sustains and honours *n’ginaajiwimi*—our essence is beautiful (Peltier, Jackson, & Nowgesic, 2012)—and works to incorporate this notion in context with difficulties and challenges faced by Indigenous people in contemporary settings. Further, as Kirmayer, Brass, and Valaskakis (2009) write, spirituality becomes an interpretative strategy meant to further our understanding beyond biological, or even psychological understanding towards a deeper appreciation of ways in which spiritual meaning is assigned by participants to their experience. It is a process that “recognizes that the meanings conveyed by

myth are not only personal but also concern larger webs of connection that draw in culture, history, the social world, and the environment” (Kirmayer, Brass, & Valaskakis, 2009, p. 443).

Our research as ceremony: Method

We first sought to ground our reflections about narrative inquiry in an Indigenous context. Adopting a community-based research strategy, in collaboration with partner agencies (2-Spirited People of the 1st Nations, the Canadian Aboriginal AIDS Network, and the Ontario Aboriginal HIV/AIDS Strategy) who provided recruitment assistance, Indigenous people living with HIV or AIDS were invited in September and October of 2012 to participate in one of three focus groups. The focus group with men had six participants, the one with women had six participants, and the one for transgender people had three participants. Of the fifteen participants, twelve self-identified as First Nations and three declared Métis status. Three women self-identified as transgender, five as heterosexual, and one as bisexual. All the men asserted their two-spirit identities. The majority of participants reported they had been living as HIV-positive for between seven and twenty-two years. One participant stated they had tested positive for HIV in the past two years.

Modelled on the basis of an Aboriginal sharing circle (Baskin, 2005; Lavellée, 2009; Poff, 2006; Rothe, Ozegovic, & Carroll, 2009), following a brief presentation focused on Indigenous knowledge (i.e., creation story), focus group

participants were asked a broad series of questions about their individual understanding of Indigenous knowledge, how they use Indigenous knowledge in their lives, and how Indigenous knowledge might best be used in research. The use of a sharing circle as inspiration was meant to reflect the central importance of oral tradition and storytelling for Indigenous people (Poff, 2006; Rothe, Ozegovic, & Carroll, 2009). This format structured the gathering of stories about Indigenous knowledge by providing a cultural signal to participants that the consultation was premised on egalitarian, supportive, non-confrontational values meant to solicit collective identification of problems and solutions (Rothe, Ozegovic, & Carroll, 2009). The sharing circle was moderated by a fully disclosed, HIV-positive Indigenous person and an Elder in an effort to gain trust and to reduce any potential power imbalance. The central goal in adopting this approach was to create a “mutually respectful, win-win relationship with the research population—a relationship in which people are pleased to participate in research and the community at large regards the research as constructive” (Poff, 2006, p. 28). Research plans were vetted through community representatives prior to submission and approval by McMaster University’s Research Ethics Board.

All stories gathered during the focus groups were audio recorded and transcribed verbatim. Later, consistent with recommendations offered by Onwuegbuzie, Dickison, Leech, and Zoran (2009) for analyzing focus group data, we used constant comparison to weave their stories together. Following processes

similar to those developed by Strauss and Glazer (1990), Onwuegbuzie et al. (2009) described three stages of analysis. Open-coding was employed in the first stage, which refers to “the part of analysis that pertains specifically to the naming or categorizing of phenomena through close examination of data” (Strauss & Glazer, 1990, p. 62). In this first step, we grouped smaller units of our data that expressed similar properties and assigned a code (e.g., talk with Elders, stories). In the second stage of coding—axial coding—we grouped the codes “back together in new ways *by making connections between a category and its subcategories*” (Strauss & Glazer, 1990, p. 97; italics in original). So, for example, we grouped “talk with Elders” and “stories” under the broader category of “sources of Indigenous knowledge.” In the final stage, selective coding, a theme was developed to highlight the content of each group. Selective coding is the process of “selecting the core category, relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (Strauss & Glazer, 1990, p. 116). Here, our core category became “knowledge from stories,” and validity was established by linking our codes and categories with direct quotes that spoke about the continuing importance of Indigenous knowledges in our participants’ lives. As the paper was finalized, we again sought out focus group participants, who wished to remain involved, for a member-checking process structured to assess the validity of what was written and to further ensure the trustworthiness of the findings.

Knowledge from stories: Findings

Our conversations with the focus group participants powerfully demonstrate ways the participants feel disconnected from their Indigenous knowledges. Many participants highlighted how Indigenous knowledges were important to them. However, accessing and respectfully using Indigenous knowledges was problematic. Several participants commented how they continue to hear that Indigenous knowledges are worthless or without value—and not something learned. Others spoke of how they felt personally unworthy to apply their knowledge by participating in ceremony because of active personal substance use. Still others shared how little they knew, or how they were disconnected from or stripped of their knowledge because of difficult childhoods. Participants discussed these difficulties as being connected to a history of colonialism that included experiences of racism, protocols about active substance use in relation to ceremonial participation, and constrained access to traditional people from whom they could learn Indigenous knowledge.

For the longest time, actually, I wouldn't even admit I was Native.

When I was in [name of community] where the majority of people were Native—cause where I grew up in [home community] they would call me squaw. So yeah, I'm like, yeah, I'm Indian [laughter] from [name of community]. I tried to get involved. But for the longest time there were things I didn't understand (about how to use our

knowledges). Then I'd feel embarrassed about it so I, but with you [i.e., the Elder facilitating the focus group], I don't feel embarrassed. I feel like I can ask you. 'Cause before, I would wonder what we were saying (Elizabeth, interview).

I just moved and have wanted to smudge my new home. But I can't 'cause I use drugs and alcohol. Mind you, I don't do that like I use to [i.e., use drugs and alcohol] but I still do. Still, you aren't supposed to smudge for 48 hours (after your last drink). So I don't smudge (Lisa, interview).

So, yeah, right, Indigenous knowledge to me is making sense of colonialism. [...] And, well, hum, my Indigenous knowledge is what's kept me alive. It's where [crying] the hope comes from in a hopeless world. And the metaphor of the water for me [pause] is the tears and the feeling like I'm drowning in assimilation and [in] the [...] consequences of those stupid fucking policies (Brad, interview).

As authors of this chapter, we approached our work as Anderson (2011, p. 5) did, believing that, despite challenges, “vestiges of [...] traditional knowledge [...] were still operational.” The stories that many participants shared as each

focus group progressed revealed the variety of ways in which Indigenous knowledges continue to shape our participants' lives. Participants shared how they work to instill Indigenous knowledge in their children, how they were engaged in processes to recover their Indigenous knowledge, or how they might—despite continuing challenges brought into their lives by colonial intrusion—continue to honour the gifts they received through stories shared by *nookosiag's teachings* (those of their grandmothers). For many, Indigenous knowledges are a touchstone and something they experience as they make sense of their lives. Participants shared the following comments in recognition that Indigenous knowledge has always been a part of who they are as Indigenous peoples:

It's what I do with my kids. I pass along our grandfather teachings. I wasn't taught, well basically, I was taught the seven-sacred teaching like honesty, humility, courage, respect, you know, it's something I try to instill in my kids (Samantha, interview).

It's hard to kill the Native spirit and the knowledge that is inside of us. So, for me it was a[n] [un]conscious kind of learning thing. It got me through that childhood I had. But what I think—it was that Native spirit and that innate knowledge—that came forth once I needed it. When I was finally exposed to my Native culture, and once I became aware that I was Native, I started to practice my Native culture. It felt

so comfortable and right. It was amazing and empowering as well. I can't explain how, 'cause it was like I was reconnected to something I was separated from (Russell, interview).

I talked with a lady who is an Elder here—and we talked about—she's the typical grandmother kind of person, you know? I can't remember her name but she was just wonderful. When we did the smudge, she made me turn around or something like that, but I didn't ask her why. And then I kinda felt something ... and I thought, I guess I'm someone special (Lisa, interview).

I woke up to my native spirituality six weeks after I was diagnosed—I went to a sweat lodge. At some level, my Indigenous knowledge [was] awoken for me on that day and I've been able to use that for healing, or start to deal with it (Brad, interview).

In the focus groups, we also asked participants to reflect on the value of Indigenous knowledge in research. From the perspective of participants, research practice does not always adhere to Indigenous knowledge in ways that mirror learning styles in Indigenous communities. One participant shared the following:

You know, what I'm most thankful for is when I'm learning about my Aboriginal [heritage]. You know, I always participate in those white men studies but when I come across something like this [focus group/project] I find it much more important to me. You learn things you didn't know (Rhonda, interview).

We contend that in order to make research more relevant for Indigenous people, approaches to research need to centre and embed Indigenous knowledge mindfully throughout their processes. Several participants, for example, felt that research in its current form offered little opportunity for learning. This has unintended consequences, such as shutting people out, or degrading Indigenous people by making them feel worthless or without value. Several participants shared the following:

I would love to go to a conference where I could understand what they are saying. They say come—be with us—but I feel like I have to [have a better education] to at least understand what the hell's going on. I don't want to know about statistics, this and that, and those endless five-letter words—I don't understand that and I don't want to understand that—I go because I want to know the knowledge but if

they want to talk in another language it defeats the purpose (Albert, interview).

It makes me feel stupid—that I need to have all this education—and I went to this conference and asked them to tone it down a bit ... just don't talk down [to us] (Russell, interview).

Towards this end, one participant talked about the need to retain and to bring back the ways in which Indigenous people learn—through *dibaaJimowin*, through talking/sharing circles, through other Indigenous teaching practices such as interactions with Elders—as necessary towards creating research that is understandable and meaningful to them. As one participant shared:

But it's time to retain all that stuff, like the stories. You know, I have to hear things a hundred times before, you know, before I'm able to share it. But it would be nice to be able to tell a story like that, something from being Aboriginal, so that it doesn't get lost cause it's already really kind of lost for me (Elizabeth, interview).

For many—as powerfully demonstrated in the quote below—Indigenous knowledge can assist people to move on, to heal, and to understand the negative impacts of colonialism. Perhaps our responsibility as scholars working

collaboratively with Indigenous people is to both heal from the effects of colonization through our research, and to bring out aspects of Indigenous knowledge that assist people with their own healing, as was powerfully captured by one participant:

And I've been beat-up, fucked over, lied to, cheated, fucking betrayed, and there's been a level of anger in me that [I] don't know what to do with. But my teachings are teaching me what to do with it. And they are teaching—and I'm seeing the more that it gets out of me—the clearer I get. So, yeah, right, Indigenous knowledge to me is making sense of colonialism (Brad, interview).

The themes described above, which were drawn from excerpts of our dialogue with participants, suggests the use of Indigenous knowledges in research is an important consideration. Focused on stories, storytelling, and narrative inquiry, our project provides a more culturally grounded research process for Indigenous peoples. It presents a research approach that, potentially, could be more relevant and meaningful to Indigenous communities concerned with HIV/AIDS. Next, we offer a discussion of composite as an Indigenous aesthetic, why it is important to adapt this approach for an Indigenous context, and present our Indigenous composite narrative approach.

Composite narrative as Indigenous aesthetic

The magic of narrative inquiry when it embeds and centres Indigenous knowledges, like the literature King (2003) writes about, “is not in the themes of the stories—identity, isolation, loss, ceremony, community, maturation, home—it is the way meaning is refracted by cosmology, the way understanding is shaped by cultural paradigms” (p. 122). As we considered story as an artful composite representation—one that weaves into as well as challenges principles of narrative inquiry—and as we considered the importance of Indigenous knowledge, the following questions became our guideposts. How can *dibaaJimowinan* (stories) from multiple and diverse participants interact with one another, merge, and braid into a single *dibaaJimowin* (story)? In what ways do composite narratives, in artful ways, reflect the sacredness of stories and the diversity in which Indigenous participants’ cultural identities are lived? We contend that narrative research, when mindfully centred through Indigenous knowledge, can assist with the creation of a composite *dibaaJimowin* that is both written voice and an aesthetic pursuit (Blaeser, 1999; Gilbert, 2006). In addition, and bridging this approach with other mutually compatible social scientific discourses, our use of a composite is intended to mirror an Indigenous understanding of story. Inherent in this approach is the “researcher-as-storyteller” reflexively connecting the past (using traditional stories) with the present (set in the literature specific to the phenomena and in stories shared by participants), with an eye to the future (to

imagine and awaken Indigenous realities). Like other critical approaches in social science, composite narratives can act as mediators that trigger positive social transformation by resisting colonial practices. As Blaeser (1999) states:

Through speaking, hearing, and retelling, we affirm our relationship with our nations, our tribal communities, our family networks. We begin to understand our position in the long history of our people. Indeed, we become the stories we tell, don't we? We become the people and places of our past because our identity is created, our perspective formed, of their telling (p. 54).

Using Indigenous knowledge and how people understand and use this knowledge in the contemporary world, stories from research participants are blended, woven, and tied together to form a single wedded account in ways that describe and enhance not only our understanding (Collins & Barker, 2009) of Indigenous knowledges, but also the challenges and triumphs that Indigenous people living with HIV and AIDS encounter in everyday life. Composite narrative offers “a chance to use the traditional art of storytelling to teach and to heal” (Nerburn, 2007, p. xv; see also Blaeser, 1999). They are opportunities “to share the stories [that] help rebuild the narratives by which the Native people were understood” (Nerburn, 2009, p. xvi). It is an approach that is respectful of the fact that “people learn by story, because stories lodge deep in the heart” (Nerburn, 2009, p. xvi), and it is a perspective widely shared among Indigenous scholars.

Framed by critical race scholarship as one of several possible counter-stories (Solórzano & Yosso, 2002), a composite approach to narrative inquiry is a literary pursuit (Coulter, 2009), a synthesized account (Arrington, 2004) meant to highlight some of the more representative ways participants organize personal stories, make sense of, and provide meaning in their lives (Borrows, 2010; Collins & Barker, 2009). This unifying approach—meant to add further texture and richness—is woven with the “reflective understandings of the researcher in the telling of a composite narrative” (Wertz, Nosek, McNiesh, & Marlow, 2011, p. 5896). Embedded within a cyclical process of development, they are often times “conceived of and written in layers,” and “stretch back” (Borrows, 2010, p. ix) across time to the stories shared by Elders and wise ones in Indigenous communities. As McLeod (2007, p. 11) wrote, “Old voices echo; the ancient poetic memory of our ancestors finds [a] home in our individual lives and allows us to reshape our experience so that we can interpret the world we find ourselves in” (see also Anderson, 2011; Borrows, 2010; Simpson, 2011). From an Anishinaabe perspective, Simpson (2011) offers us additional perspective. Referred to as *biskaabiiyang*—a verb meaning to look back—this process provides an approach to return to ourselves in ways that allow researchers to evaluate the impacts of colonization. It opens space in research to incorporate aspects of Indigenous culture (e.g., philosophies, stories) that were lost to colonial practices. In other words, *biskaabiiyang* is about decolonizing the mind prior to

research, and learning new ways of incorporating Indigenous knowledges into research. As Simpson writes:

The foundations of Biskaabiiyang approaches to research are derived from the principles of *anishnaabe-inaadiwiwin* ([...] ways of being). These principles are *gaa-izhi-zhawendaagoziyang*: that which was [given] to us in a loving way (by the spirits). They have developed over generations and have resulted in a wealth of *aadizookaan* (traditional legends, ceremonies); *dibaaajimowin* (teachings, ordinary stories, personal stories, histories) and *anishnaabe izhitwaawin* ([...] culture, teachings, customs, history). Through *Biskaabiiyang* methodology, [...] research goes back to the principles of *anishnaabe-inaadiziwin* in order to decolonize or reclaim *anishnaabe-gikendaasowin* (Geniusz, 2009; as cited in 2011, p. 50).

In this way, the product of a composite narrative is simultaneously “current,” in the sense that it is grounded in a contemporary context; at the same time, it “predates” itself by drawing on ancient Anishinabek knowledge to develop an understanding (Borrows, 2010, p. ix). Indigenous scholars also work with community stakeholders, using participatory research approaches, to create composite narratives. The composite narrative advocated here, rather than an original approach, has existed in the social science literature for the past decade, where researchers from a variety of disciplines have drawn upon it to explore a

variety of issues. Composite narratives have previously been used to explore Anishinabek legal traditions (Borrows, 2010), Indigenous self-determination in the context of homelessness for an urban-based population in Canada (Walker, 2005), and stories of *Anishinaabek* women's lifecycles (Anderson, 2011). As these sources used composite narrative approaches, stories are woven to add depth, and to acknowledge the multiple layers of stories and the multiple sources of knowledge— oral, dreamtime, and written. Such an approach is premised on deep listening, quietness, and stillness so that we are better able to hear the reverberations from the tribal past in contemporary contexts.

Composite narratives: A method for weaving stories

*They are all we have, you see,
all we have to fight off illness and death.*

You don't have anything if you don't have stories (Silko, 2006).

For many Indigenous peoples, stories work as if they are like medicine. Stories in Indigenous communities possess pedagogical value, and are reflexive devices that allow listeners to imagine new possibilities through Indigenous world views (Peacock, 2013). They provide a lens through which colonialism is challenged, and as Simpson suggests, a means of

envision[ing] our way out of cognitive imperialism, where we can create models and mirrors where none existed, and where we can experience the

spaces of freedom and justice. Storytelling becomes a space where we can escape the gaze and the cage of the Empire, even if it is just for a few minutes” (2011, p. 33-34).

Reverberating with collective tribal memory handed down by Elders, stories are meant, with each subsequent telling, to assist Indigenous peoples in making sense of experience, giving meaning, and explaining both the known and the unknown aspects of the social world. In this way, stories can be viewed as embodying a living spirit that offers wisdom in dealing with the contemporary challenges of life (Peacock, 2013). Stories are meant to deepen our understanding of who we are as cultural and social beings by affirming our tribal identities. They allow us to experience the similarities between ourselves and others in ways that focus attention on priority issues that may not be addressed in the literature (Banks-Wallace, 2002). Composite narratives include characters, and draw on the direct quotes of participants to support dialogue and discussion. They are intended to do this in ways that frame the key issues as originally identified by community through Indigenous knowledges. The focus of composite approaches in narrative inquiry is intended to shift “the analytic gaze away from excessive attention to structural elements [within narratives] and towards the capacities of stories (i.e., inform, teach, and to learn from)” (Garroutee & Westcott, 2013, p. 64).

What follows is our method for writing a composite narrative. The goal here is to explicate the ways our approach is grounded in Indigenous oral tradition

and world views. This process includes several overlapping categories that include: (1) narrative elements that inform a composite narrative; (2) living with and getting to know the stories of participants; (3) movement from individual stories to braided account; and (4), writing the composite narrative.

Elements of our composite narrative

Our approach to the development of a composite narrative used several disparate elements to weave into a single story. Our primary data source narratively explored the experiences and responses to depression by Indigenous people living with HIV/AIDS across seventy-two in-depth interviews. In analyzing these stories, we used an adapted narrative inquiry framework to reveal the importance of relationships, connection, the intergenerational continuity of knowledge, use of ceremonial practices in responding to depression, and cultural insights that participants drew to make sense of and find meaning in depression (Cain et al., 2013; Cain et al., 2011; Jackson et al., 2008). Focusing on these key areas, a composite narrative can assist with decolonization. In Cree communities, for example, McLeod writes, “narrative memory is an ongoing attempt to find solutions to the problems we face today, such as breakdown of families, loss of language and general loss of respect for ourselves and others” (2007, p. 91). Stories of oral history are Indigenous knowledges in action that offer culturally grounded acumen in ways that inspire change for the better (Anderson, 2011).

Supplementing our growing understanding of experiences and responses to depression among our participants, we also reviewed the literature in this area. We searched the social science literature (e.g., sociology, social work, psychology, anthropology) for research reports highlighting experiences and responses to depression among Indigenous people living with HIV. However, we found the literature generally lacking. As a consequence, we expanded our review to include the broader areas of depression and Indigenous peoples. In conducting this search, our goal was not only to explore ways of piecing our cultures back together, but it was also about learning to work our composite narrative as if this story were medicines (Anderson, 2011). We also separately searched through the humanities literatures (e.g., critical literary studies) to explore the writings of scholars who work with Indigenous stories. Our goal here, consistent with an approach described by Banks-Wallace (2002), was to define the boundaries of what we mean in using a composite narrative as an Indigenous story. Findings from these separate reviews were folded into our composite narrative.

We also drew upon traditional stories that focused on mental health in Indigenous communities. These stories came from our own oral knowledge of our cultures, were shared with us by the Elder who is represented on the project, and last, gathered from the literature. Here, as Ong (1982), writes, “Originality in oral cultures [...] consists not in the introduction of new materials but in fitting the traditional materials effectively into each individual, unique situation” (cited in

Ballenger, 1997, p. 783). Ballenger (1997) also notes ways in which this oral history blends the past and present to influence the future. Our exploration of the experiences of and responses to depression among Indigenous people living with HIV/AIDS represented an opportune time to be informed by these oral histories in our developing understanding of depression among Indigenous people living with HIV/AIDS. Traditional stories informed our developing interpretation, and in turn, refracted one way in which Indigenous knowledges were reconstituted in our composite narrative. Our use of a composite narrative approach reflects several important precepts of Indigenous knowledge—that the world is alive, dynamic, and relational. Thus, exploring experiences and responses to depression among Indigenous people living with HIV through traditional stories was necessary and appropriate in our contemporary context.

Finally, we also wove our own reflexive understanding with participants' accounts of experiencing and responding to depression in the context of HIV/AIDS. When composite narratives include the author's reflexive self, the reader is provided, potentially, with a "felt-sense" (Wertz, Nosek, McNiesh, & Marlow, 2011) of participants' experience with depression in the context of HIV illness. Favret-Saada (1980) writes: "To understand the meaning of this discourse [...] there is no other solution but to practice it oneself, to become one's own informant, to penetrate one's own amnesia, and to try and make explicit what one finds unstateable in oneself" (cited in Tedlock, 2011, p. 334). This approach

rested on the principle that we embed our own stories of experiencing in ways that we felt personally deep down in our cores. Composite narratives potentially provide “a rich double portrait” (Tedlock, 2011, p. 335), one that makes explicit our own experiential knowledge of listening to participants’ stories. It is an approach that links to broader social and political issues, assumes that the primary audience is larger than academic audiences, and that locates the reflexive gaze of the scholar as protagonist, as s/he critically links theory with vivid descriptions of participants’ lived experience (Gray, 2003).

Living with the participants’ stories

A composite narrative is a single braided story meant to mirror the lives and social world of participants. It is not simply a re-telling, but represents the interpretative work undertaken by a researcher. It draws on the social scientific literature of interest (e.g., depression among those living with HIV), embeds participants’ understanding of the phenomena, and draws upon the reflexive understanding of the researcher. It rests on the principle that “the author is the active part of the story, a person so enthralled by hearing his own voice and listening to others telling the tale that he cannot remove himself from the narrative” (Tedlock, 2011, p. 332). In this way, a composite narrative

connects with universal human qualities so that the reader can relate personally to the themes; is a story that readers can imagine in a personal way; attempts to contribute new understanding about the phenomenon;

and is not exhaustive, but allows the topic to be seen more clearly. It aims to illuminate, to allow the reader to have an increased sense of contact with the phenomenon without fully possessing it (Wertz, Nosek, McNiesh, & Marlow, 2011, p. 5884).

The development of a composite narrative, in our case, is buttressed against the content of seventy-two interviews with Aboriginal peoples living with HIV/AIDS in Canada (Cain et al., 2013; Cain et al., 2011; Jackson et al., 2008). In our context, interviews were treated as narratives (Chase, 2008), where participants' stories about their experiences with and responses to depression were represented as "a distinct form of discourse. Narrative inquiry is retrospective meaning making—the shaping and ordering of past experience" (Chase, 2008, p. 64). And, like other forms of scholarly work, it is the basis upon which also to understand "the narrator's point of view, including why the narrative is worth telling in the first place" (Chase, 2008, p. 65).

A first step in the development of a composite narrative involves reading and re-reading each of the in-depth interview transcripts. In reading each of the interviews, in an approach consistent with Gray (2003) and Gray and Sinding (Gray & Sinding, 2002), we highlighted various key issues that were particularly revealing about experiences of and responses to depression among Indigenous people living with HIV/AIDS. After reflecting on each of these key issues identified across different interviews, we focused on particular themes (e.g.,

finding out HIV status, experiencing depression, the benefits of blending ceremony with contemporary approaches when responding to depression), and provided these a central place in our composite narrative. Our approach in identifying these issues was to reflect on the ways experiences and responses to depression connected with and could be understood through Indigenous knowledge (Barton, 2004; Barton, 2008). These judgements about how best to handle the data are influenced by the actual content of the interviews. Decisions made along the way were carefully recorded using Atlas.ti (a qualitative research data software program), and reported in ways transparent to readers.

As we became more and more familiar with the narrative landscape of our own project's data, we increasingly noticed, as did Anderson (2011), that "the process of collecting oral history was much more an exercise in learning how story medicines can work, and [of] gradually finding [our] place in [this] work" (p. 15). Consistent with approaches to narrative inquiry as well as principles of Indigenous knowledge, the development of understanding during this phase avoids imposing one's world view on another. Rather, we learn "to both live in and write about other cultural settings [and we worked to create a] space [that could] accommodate multiple individuals with various cultural and ethnic identities who interact and in so doing change while maintaining certain of their unique qualities" (Tedlock, 2011, p. 333). As an analytic approach to understanding participants' lives, this is consistent with Indigenous approaches,

where we generate understanding through critical reflection and examination (McLeod, 2007; Simpson, 2011), and where this is woven together with participants' stories and into the "experience for both storyteller and the audience" (Simpson, 2011, p. 104).

From participants' accounts to the braided story: Life story approaches

Our research questions weave with the life story approach. In narrative inquiry, the life story approach refers to "the study of how individuals move through 'crises' that accompany each distinct phase of the human life cycle" from birth to older adulthood (Baddeley & Singer, 2007, p. 177). These pivotal moments of crisis are felt to transform the subjective meaning of an experience profoundly, in ways that shape identity. Our study was focused on soliciting our HIV-positive Indigenous participants' descriptions of experiences and responses to depression. As a life course approach does, the mental health literature also defines several crisis points that span a life lived with HIV/AIDS. These key points include: knowledge of HIV status; disclosing one's HIV status to others; confronting HIV stigma and responding to discrimination, stress, and the role of social support; and the impact of comorbid mental health challenges on quality of life (Walkup & Crystal, 2010). Through in-depth interviews, we were concerned with how participants understood the roots of their depression (e.g., if it was connected to HIV or not, or the result of a foster/adoption experience), how they experienced depression (e.g., the shock of an HIV diagnosis), and the ways they

responded (e.g., substance use, Western mental health interventions, use of ceremony). Originating in psychology, life course approaches in narrative inquiry generally share a focus on the autobiographical, attention to the sociocultural factors that shape identity, adopt a life span perspective, and are open to multi-method ways of exploring the stories of participants in research contexts (Baddeley & Singer, 2007). In other words, the life course approach offers a way of organizing and understanding critical moments over the course of living with HIV from participants who confront feelings of depression.

How, then, is life course narrative research conducted? What are the key steps in conducting life course research? In using this approach, researchers often draw on open-ended interviews to elicit participants' stories. These interviews are transcribed verbatim, and individual transcripts are read and re-read. As researchers develop an understanding of a participant story, they also identify key quotes that offer "compelling texts" that illuminate the general patterns of the story (Riessman, 1993, p. 27). These quotes are incorporated into written summaries for each of the participants' stories in the study. In preparing these summaries, researchers attend to differences in sequence and the influence of a story's plot. Stories are the sequence of "the raw, temporally sequenced, or causal narrative of a life" that are ordered to reflect "the expected arrangement" according to social convention (Riessman, 1993, p. 30). An event occurs, for example, that propels an individual to seek out a HIV test. Upon diagnosis, this

leads to decisions about treatment, how to best handle disclosure, and how to deal with the emotional stress of illness, and so on. The plot, on the other hand, “emerges from the unexpected twists in the narrative that draw attention to differences from the conventional story” (Riessman, 1993, p. 30). Sequences with attention to plot demonstrate ways in which meaning shifts, and identity is reframed. Examples that potentially mix up this expected sequencing include plots or stories about how depression is not the result of HIV, how Indigenous experiences of HIV and depression is both similar and different to other cultural groups, or how social support is best when it is grounded in ceremony. As summaries—including identification of relevant theoretical issues and key substantive themes—are prepared, these are used by the researcher to draw “a comparison across a series of first-person accounts” (Riessman, 1993, p. 30). This comparison focuses on

locating turning points that signal a break between the ideal or real, the cultural script and the counter-narrative. The investigator searches for similarities and differences among the sample in discursive strategies—how a story is told in the broadest sense (Riessman, 1993, p. 30).

Focused on the comparison, evidence for a researcher’s interpretation is grounded in the direct quotes identified earlier.

From participants' accounts to the braided story: Indigenizing life story approaches

The life course approach in narrative inquiry offers, potentially, a useful framework for working with Indigenous peoples' stories of experiencing and responding to depression in the context of HIV/AIDS. In using life story as our narrative approach, we framed our encounter with this method in ways that embedded our emerging understanding of Indigenous cultures, world views, stories, and storytelling. Our goal in shifting the gaze—where life course remained a useful framework for organizing our own interpretations—was to develop a composite narrative that illuminated the world views of our Indigenous participants through their stories. That is, “rather than offering a chronicle of events, Indigenous oral history typically works to confirm identity and remind the listeners of the social and moral code of their society” (Anderson, 2011, p. 18). In other words, the idea of truth value is about who Indigenous peoples are, rather than a focus on the truths about what happened. This approach is widely acknowledged in the literature. The goal is not to see how a story is set apart, but rather, the purpose of a story is so that individuals can “find themselves in their people, to discover this shared reality” (Ballenger, 1997, p. 796).

The shift in our attentive gaze begged us to approach our participants' stories with a different mindset than offered by a life course approach. First, in our composite narrative we pivoted our attention, not to the “compelling texts,” but rather, we searched each of the transcripts for evidence of the ways in which

participants framed their stories in ways that reflect their cultural identities. This focus was not about the facts or events over an individual's HIV life course story. Rather, as Anderson states, it was about reflecting on how participants were "coming to grips with the personal meanings of broadly shared knowledge and converting those meaning to social ends" (2011, p. 19). Like the life course approach in narrative inquiry, we too searched through our participants' interviews for captivating quotes. However, our approach was focused on the ways participants' words and phrases, "work[ed] like arrows," acting as piercing missives sent out to "make you live right" (Cruikshank, 1999; quoted in Anderson, 2011, p. 19). These arrows acted as a symbol for the dissemination of knowledge in ways that connect the past with the present and remind listeners of the value of wise old teachings. As Noori states, "In its tip are stories, epiphanies, and glimpses of eternity, passed from one generation to the next. These intergenerational ways of understanding are complex, interconnected, and reflected in both Anishinaabe texts of long ago and text being written today" (Noori, 2013, p. 35).

It was also an approach that begged us to ask different kinds of questions about participants' stories as we scrutinized our interview texts. We envisioned the stories shared by our participants as part of the broader Indigenous world. That is, we envisioned they would provide us with vivid descriptions about the Indigenous world views of our HIV-positive participants, as told through their

stories of experiences with, and responses to, depression. Stories have the function of helping us to make sense of the world and our place in it. Stories help us shape our consciousness, and as a result, they help us shape our choices. In other words, as Garrouette and Westcott write, “[Stories] engender ‘ways of being in the world’ that attend to specific possibilities” (2013, p. 73). So, rather than focusing on events or facts within our participants’ stories, our approach is one in which we listened for how participants were using cultural knowledge as strategies for improving their lives (Anderson, 2011). Similar to a life course approach, our reflection on each individual story is also recorded as a summary. Following advice offered by Banks-Wallace (2002), who drew on Indigenous literature to frame her research encounter in African tribal communities, our approach—rather than focusing on sequence and plot—also asked specific questions about participant’s stories, including: “(a) What is the point of the story? (b) How does this story foster healing, nurturing, or communion? (c) What other purpose or function does this story serve in this context? And (d) what key words and/or phrases are used to tell the story?” (Banks-Wallace, 2002, p. 416). These questions guided the development of participant summaries that incorporate each of the compelling quotes that were identified in reading and rereading each of the individual transcripts. These first-person accounts, as in life course approaches to narrative inquiry, are then compared against other participant

stories, with attention to how stories are told. From this, a single composite narrative emerges in ways grounded in our participants' stories.

Writing the composite narrative

Through reading and re-reading, and as our knowledge of participants' accounts living with HIV and depression grew, we became more and more interested in the ways in which individual stories might weave with one another in ways that reflect cultural identity. Reflecting Indigenous oral tradition as it did, we discovered that our composite narrative best shared space with principles of creative nonfiction. In this non-standard way of academic writing, our approach mirrored new approaches in the social sciences that were focused on the development of innovative ways of presenting and sharing research findings (Gray, 2003). Although writing from a narrative ethnography perspective, Tedlock writes,

Creative non-fiction [...] is factually accurate, and written with attention to literary style: However, the story is polyphonic with author's voice and those of other people woven together. In creative nonfiction, the story is told using scenes rather than exposition, and [...] the author-as-character is either the central figure or the central consciousness, or both (2011, p. 336).

In this way, the composite narrative focused our attention to a relatively new way of representing research findings. For us, there were three reasons

driving the development of our composite narrative approach. The first reason was that in weaving several or more participant stories with one another, we felt we were further protecting the identities of participants by disguising identifying details (Gray, 2003). Second, our intent was to celebrate Indigenous identity by developing an interpretative understanding grounded in their Indigenous world views. Contributing to the struggle to decolonize, we were especially interested in how a composite narrative might refract Indigenous knowledges in the stories of our participants. In this, despite the negative consequences of colonization, we held steadfast to the notions that elements of Indigenous knowledges continue to influence the lives of Indigenous peoples (Anderson, 2011). And last, we hoped that our approach might honour Indigenous ways of sharing and learning that occurs through story. In other words, we recognized that our approach to “reporting inevitably shape[s] knowledge” (Gray, 2003, p. 178). It was thus our hope to return research findings in ways that made dissemination more congruent with Indigenous cultural heritage; that is, we wished to avoid further colonization with our written composite interpretation of participants’ stories.

Creative non-fiction also privileges narrative techniques in the sense that their purpose is to inform, describe and explain, provide arguments, and cite appropriate sources (Tedlock, 2011). The difference between traditional scholarly approaches to the dissemination of findings and creative non-fiction approaches to narrative inquiry is that one is embedded in the literary tradition. Used by what

Gray and Sinding (2002) call “performance science,” this approach maintains a profound connection with the data and its original meaning. As Gray states, “accounts should provide abundant concrete detail, so that they express a sense of the everydayness of lived reality” (Gray, 2003, p. 183). Creative non-fiction, considered a new form of narrative, has “characters, action, and shifting points of view. They follow a story-like narrative arc with a beginning, middle, and end, as well as high and low points of dramatic development including moments of tension and revelation. They also have an emotional arc consisting of inner conflict that meshes with the narrative arc” (Tedlock, 2011, p. 335) in ways that make this world visible to the reader. Our composite narrative drew on the direct quotes and stories of our participants in ways that mirrored our comparative understanding of the data. Our composite narrative reveals Indigenous identity by exploring the many complex challenges faced by Indigenous people who also live with HIV and depression.

Our hope in using principles of creative nonfiction was to present our findings narratively in ways that made them more visible and meaningful to our participants. We did this by refracting Indigenous knowledges through our interpretation and then writing about it in a woven, braided, and blended way as a composite narrative in ways that tied it to traditional stories. Drawing on methods of creative nonfiction (Forché & Gerard, 2001; Gutkind, 1997), with the writer assuming a reflexive role (Cook-Lynn, 2008), we discovered that it was possible

to “use oral tradition and storytelling while [...] simultaneously engag[ing] with the contemporary reality of a dominant white world” (Schorcht, 2003, p. 7). Stories that draw on creative non-fiction principles value accuracy in their writing (i.e., faithful representation). Creative fiction does not typically use real-life places or events to impact reader audiences; “[creative] nonfiction, conversely, must not only ring true, it must be true” (Gutkind, 1997). The hope here—using the findings of the narrative approach described above—was “to emphasize that there is not a single [HIV and depression] story, but rather a multiplicity of experiences” (Gray, 2003, p. 183) in ways that highlight not only the common experiences but also the enigmas (Benham, 2007; King, 2003). Although we can say such approaches promote “alternative ways of speaking, reading, writing in ... inquiry [called] critical storytelling” (Dunlop, 1999, p. 3), in the end, “The ultimate test of the validity of knowledge is whether it enhances the capacity of people to live well” and these “new formulations of old wisdom can best be tested in the crucible of everyday life” (Brant Castellano, 2000, p. 33).

Parting thoughts

What’s important are the stories [we’ve] heard along the way. And the stories [we’ve] told. Stories we make up to try to set the world straight (King, 2003, p. 60).

This chapter has focused principally on the use of Indigenous knowledges in ways that not only challenge but support the use of narrative inquiry, so as to better understand experiences and responses to depression among Aboriginal people living with HIV and AIDS. It advocates a position that experiences with illness, such as HIV and AIDS, are best understood from the cultural perspectives of those who originally experienced it (McLeod, 2007), and thus, best expressed using their cultural practices of storytelling. One way to achieve this was to merge participants' stories into a single story—a story that incorporates and challenges existing theories of health while using traditional stories in ways that draw forth the cultural meaning. The composite narrative approach discussed above is an Indigenous, critical, and decolonizing approach that suggests transformation and healing is possible in ways that support Indigenous identity in the context of research (Anderson, 2011; Simpson, 2011). As the quote above suggests, our approach embraces the notion advocated by King (2003): if we challenge (or change) the ways in which Western research constructs stories about Aboriginal people living with HIV and AIDS in Canada, perhaps we also shape our understanding about ways culture, knowledge and identity are important to experience of illness.

However, we might have opened space for use of an indigenized narrative inquiry, we also understand that this space is problematic in ways that may also engender criticism. Perhaps Indigenous peoples—the primary audiences for which

we write—may find our approach not nearly Indigenous enough. Our non-Indigenous audiences might find we’ve pushed Indigenous too far. Perhaps, as well, Western narrative researchers may criticize our approach as too literary, or literary theorists may find us “too bound by research convention” (Coulter, 2009, p. 608). Whatever the challenge, in thinking through ways in which narrative might be indigenized, perhaps we’ve only affirmed the notion that working with Indigenous knowledges is thorny, knotty, and fraught with challenges that make its application within narrative inquiry not easily resolved. Whatever the eventual criticism, and recognizing this is a journey about learning the ways and uses of Indigenous knowledge in research contexts, we are buoyed by the notion that such approaches are “foundational for the construction of an anticolonial, egalitarian social science” (Cannella & Manuelito, 2008, p. 56).

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Chapter Four

The Wisdom of Thunder

Randy Jackson

Author's Note

“*A Thunder’s Wisdom*” draws on the craft of Indigenous storytelling to create, what is hopefully considered, a compelling Indigenous knowledge translation (KT) product (Jackson & Masching, 2017). It is a KT product that is meant to assist with restorying, in healing ways, the experience of sadness that results from colonial violence experienced by Indigenous peoples (Anderson, 2011; King T. , 2013; McKegney, 2007; McLeod, 2007; Nerburn, 2007; Vizenor, 1994). The story that follows, grounded in research findings (Cain, et al., 2011; Cain, et al., 2013; Jackson, et al., 2008), presents a literary interpretation of lived experience using an Indigenized composite narratives approach (Jackson, Debassige, Masching, & Whitebird, 2015). Exploring experiences and responses to depression among Indigenous peoples in Canada who live with HIV, the story also embeds Indigenous knowing and being, and does so in ways heavily influenced by a well-known *Anishinaabe* traditional story about an epic battle between thunderbeings and water serpents. Although comparable stories exist in most Indigenous and Western cultures, these mythological creatures—who many Indigenous people believe exist—was a story I first heard as a child growing up. It

was shared with me as a way of teaching about how best to understand one's personal struggles through an Indigenous lens. The personal experience of this traditional story was further developed to guide the development the story the follows by drawing on the anthropological and humanities literature (Johnston, 1995; McKegney, 2007; Smith, 1995), in a conversation with an Elder (Whitebird, 2014) and with several Indigenous people living with HIV (Peltier, 2012). This traditional story provided an Indigenous storytelling framework, as a way of connecting contemporary experiences with the interactive ecologies where Indigenous peoples live their lives.

Introduction

Even though my *Nookomis* (grandmother) died when I was ten I can still hear her voice. “When we utter their names,” she would say, slowly pronouncing so that I might learn, “*Ani-mi-kii* (Thunderer) and *Mis-he-be-shu* (Water Serpent), it’s the sound of those words that always begin this story. It’s an ancient story,” she would add, “one full of truth and instruction, and it survives because we share it with one another. We share it ‘cause it might help us heal.” When the sound of thunder began to rumble quietly off to the west, *Nookomis* continued, “Listen to that. Can you hear it? *Nana ’b’oozo* (trickster) is likely calling *Animikii* for help. And that storm approaching,” she paused as much for effect as for clarity, “that’s those *Manitous* (spirits) speaking to one another.” Looking up at the darkening clouds, *Nookomis* lowered her voice to a whisper and gestured towards the horizon. “*Animikii* is close. I can hear him and I can even feel his presence. I bet you that the storm we hear coming is *Animikii* fighting *Mishebeshu*. You know, when that storm happens, out there over the lake, we’ll be still. We’ll be quiet. We’ll listen to that storm’s *dae’b’wae* (truth). You know that *dae’b’wae*—well—that’s those *Manitous* teaching us about *bimaadiziwin* (living well).”

The phone felt heavy in my hand as I pushed back from my desk and slumped down into my chair. Someone had just told me that our mutual friend,

Edward, jumped to his death from his tenth-floor apartment. I won't lie to you. It felt like the air had been punched from my stomach. Edward was someone I met years earlier on the Indigenous HIV conference circuit and he would regularly ring me to chat. Although our conversations were mostly focused on plain-old catching up, sometimes we also shared with each other our struggles of living with HIV. Over the course of several years, as a way of trying to understand why he was prone to such consuming sadness, Edward would tell me bits of his life history. When he was young, Edward and his family got caught in the 60s Scoop. It was an infamous time in Canadian history when many Indigenous children were taken from their families and often placed in non-Indigenous foster homes or adopted out to non-Indigenous families. Edward's family struggled with poverty, partied too much, and often left Edward alone to fend for himself. When the child protection workers came, he was stolen and placed with a *zhaaganaash* (English-speaking, Caucasian) family. Although awareness of the importance of cultural pride has slowly improved, Edward's new 'family' didn't yet fully appreciate the value of keeping Edward connected to his *Mi'kmaq* culture. They didn't understand that a sense of connection—that relationships to his family, community, to the land, and to all the spiritual entities that live in the cosmos—were essential to his health and wellbeing. Having never learned his *Mi'kmaq* culture, Edward's emotional pain ran deep. It often festered, coloured his taste for life, and Edward struggled to dislodge it without ever fully succeeding.

As an adult, Edward worked hard to reclaim his culture, to receive teaching from Elders, and to learn how to practice the sacred teachings through ceremony. It is because Edward threw himself into learning about his culture that he understood its importance better than anyone. “Without my cultural identity,” he once told me, “I’m just dead. I’m so dead inside. I think I’m this way because the only thing I can think about is how angry I am at both my birth and adopted families, how angry I am at the world, at how angry I am at everybody.” I treasured our visits. Even though we both struggled with feelings of disconnection from culture, our talks always help me feel less alone, more connected, more in awe at the beauty of our respective Indigenous cultures. Indeed, hearing of his death, I was left wondering whether a stronger sense of connection to his culture might have helped Edward heal? As I contemplated this, for a few moments, I began to slowly and sadly realize that Edward likely never managed to find the connection he really needed. Culture might have sustained him, held him up, and might have provided him some comfort.

It was a doubly sad day for me learning of Edward’s untimely death as his suicide also reminded me of my own past struggles. In fact, as I now understand it, Edward’s life story is a sadly commonplace and ordinary one. His story, like my own, was remarkably like many of the men and women whom I met on the Indigenous HIV conference circuit. Like Edward’s, like the lives of these other Indigenous men and women, my past life was also filled with partying and wild

sex with far too many anonymous partners. They were things I did, that still have the power to make me feel worthless. My erratic and careless behavior was driven by a sense of never being enough, not for anyone, and least of all not for myself. These feelings of worthlessness were wedged into my unconsciousness and propelled me into a life of unhealthy behaviors and poor decisions. Those feelings of worthlessness almost always came with the same niggling thoughts of ending my life. But somehow, deep down, I knew that I wouldn't ever try to commit suicide. Nevertheless, it scared me to be so close to those feelings, to always struggle with them. I just couldn't help but feel them.

It was through the Indigenous HIV community that I too, like Edward, became open to the possibility that I could work to be more firmly connected to the vibrant and healing *Anishinaabe* (the people) culture that I was born into. Even though Edward never quite found the solace he was looking for, his life and his friendship pushed me in that direction. It took my learning of his death for me to focus once again on my own healing journey, to work like Edward did, to reclaim my culture. That was the one thing I could do to remember and honour Edward's life—for all that he'd given me.

Almost ten years ago, and long before I met Edward, I had checked myself into an Indigenous-run residential healing lodge in southern Ontario at the urging of my family doctor. It was the first program of its kind, catering to people living with HIV who struggled with a variety of mental health issues. Although I was

feeling nervous about being at this healing lodge, on my first night, attending dinner in the cafeteria, I sat down at a table with three old timers by the names of Bill, Jared, and Rob. It turned out to be an excellent choice! They had been to this healing lodge before and over dinner, we shared a bit of our lives with one another.

It was Bill, a skinny, older Cree guy from northern Manitoba, who first suggested to me that if I truly wanted to heal, I should get into the next day's 'talking circle', 'cause that my friend, will be your first full step out of the shadows."

Agreeing with Bill, Jared chimed in. "Yeah man, channel your energy into something good instead of negative—and pray."

Even Rob, who I later learned liked to listen more than talk added, "It's up to us to create our own reality, so make the most of your time here." And I wanted to just this—to make the most of it. I wanted to learn more about my culture. I wanted to also learn how to activate this knowledge through ceremony and practice. Edward's recent death continued to ring like thunder in my ears—it seemed like he had gotten himself trapped in the battle between *Animikii* and *Mishebeshu*. Without his culture to help him understand, he bumped up against those *manitous* and lost the story of his life.

Edward's story, one might say, was about how unfathomable sorrow could get blocked deep in one's heart. Although sadness was something Edward had

lived with since being taken by his family and placed into child protective custody, he once told me how much worse it had been since he was diagnosed with HIV. “Since I’ve had this news, it’s been more, I don’t know, hard to cope with. I’m feeling down in the dumps a lot. My feelings of sadness seem to have gotten worst.” But as I reflected on the kind of person Edward was, what rose to mind was that he was a good man who lived a simple and uncomplicated life. He was a man of pure heart. Some would say he was generous to a fault. Thinking about Edward made me wonder whether being Indigenous mattered when he was faced with his own profound grief? Did he fully understand the violent way colonialism had shaped his life? Most of all, I wondered if things could have been different if he had his family and was able to truly reconnect with his community and nation. Would having learned the power of his culture have helped him heal? It seemed, at least on the surface, that Edward occupied that ‘racialized’ space reserved for Indigenous people struggling with life—it is sometimes a space we create for ourselves, but more often than not, it is simply a space created for us by a colonial society that seeks to confine, restrict, and leave us languishing in our unhappiness.

It’s Where We Live

“But,” *Nookomis* explained, “to understand this story, you gotta’ know the lay of the land.” She lowered herself on shaky knees to the level of the water at the edge of the lake. “It begins here,” she said, “with the underworld. That’s where *Mishebeshu* lives.” Standing up, *Nookomis* continued. “That’s the sky realm,” she pointed. “Up there.

That's where *Animikii* lives. But here," she said, with her arms spanning out towards the lake and then back to the groove of trees, "all this here is the land, our earthy home. It's where we live, where it's best for us to live our lives." And offering a clue to the mystery of our existence, she continued, "All these directions, what's above, what's below, it's important to know that there's this energy that flows between them. It's what keeps us healthy. This place takes care of us, just as we are meant to care for her, our Mother Earth. It has a bottom that holds us and it has a top that covers us. These things protect, shield, and, well, they are meant to keep us safe. Everything, seen and unseen, is held together by this energy. Everything works together. It's about connection."

Just as breakfast was finishing up at the beginning of my first full day at the treatment lodge, I heard our counsellor, another *Nookomis* calling out from the front of the cafeteria. "*Aaniin, boozhoo*" (hello, greetings), she said with a beautiful ear-to-ear smile. "Come for a walk, down by the lake. I've got an *aadizookaan* (traditional story) for you. Let's go offer some tobacco, smudge, and share some of our stories with one another. Let's go talk about what brought us here—okay? So, let's go smudge and cleanse ourselves."

Although it was still early in the morning, the air was already heavy, unmoving, and a thick moisture hung in the air. The day's forecast was calling for an early afternoon cold front, approaching from the west. The forecaster warned that it was likely that when the cold front finally hit the warm air it would produce booming thunder, spectacular lightening, and heavy rain.

But for now, hearing the counsellor greet us, I smiled, for she reminded me of my own *Nookomis* who was fond of saying, "Thunderstorms are so much more. Those storms are letting us know powerful beings are among us—the

Animikii and *Mishebeshu* —and this is good. You know, those *Manitous*, they affirm our relationship with them and to one another.” She also liked to add that those *Manitous* had come to help. “You know those *Manitous*, they look all over. They have the power to see whether everything’s alright.” *Nookomis* was someone recognized as a traditional *debaajimojig* (storyteller). “*Aadizookaan*,” she reminded us, “are our medicine. When we share sacred stories, even when we simply listen, they can heal us. They remind us of our *Anishinaabe* ways. Stories affirm our identities and we share these sacred stories over and over because if we don’t, well, it’s a neglectful thing.” Without traditional stories helping a people to learn *Anishinaabe* knowledge, my own *Nookomis* taught me, we might find ourselves struggling, confused, and flailing about like fish out of water.

This counsellor, not unlike my own *Nookomis*, was a short, wrinkled, older, red-skinned lady whom everyone also called *Nookomis*. This other *Nookomis*, like my own grandmother, was also a storied traveler in our multi-leveled universe. Like my own *Nookomis*, this counsellor was also a respected traditional *debaajimojig*. It was through stories that she provided vivid descriptions of the ways the universe layers itself, and the ways it works as a cohesive whole. She told us of the characters in those stories whose role is to guide and teach us, characters like *Animikii* and *Mishebeshu*. I was often reminded of the close relationship between these sacred stories and my own experiences. “Stories,” my own *Nookomis* was fond of saying, “offer practical

advice about living well. They express the nature of *Anishinaabe* reality. They give our lives meaning.” In words that I have since learned, stories help to decolonize the mind and spirit in ways that bolster *bimaadiziwin*. “Stories open space to think differently” my *Nookomis* often said. “If we deeply listen to the main thrust of those stories, they offer guidance about how to live a more fully connected relationship with everything that makes up reality.”

The healing lodge was situated on the southern shores of *Naadowei-Gichigami* (Lake Huron), and in the morning’s drenching humidity, it seemed that this great lake spread itself out in all directions, flat as any mirror, frozen in place. Off in the distance, rising towards the hill bordering the healing lodge, stood a large grove of birch, cedar, and pine trees. With the light humid breeze gently blowing off the lake, you could hear those trees rustling up against each other—checking in and visiting one another—they too were alive and connected. I desperately wanted to be like those trees. I no longer wanted to numb myself with alcohol, with sex, or with drugs. I didn’t want to miss any more of this land’s grand lessons. I wanted to stand tall like those trees! I wanted my relatives, to check in and visit, just as those trees were doing with one another. “Those trees have a consciousness that speak, you know, they have many things to share, many things to teach.” my own *Nookomis* shared. My *Nookomis*, like the healing lodge counsellor always managed to coax the ‘real me’ to the surface.

This is exactly, what I needed, I thought. Somewhere natural, like this place. It was a space where the colonial damage done to me could safely find a solid surface. The land, all the life it contained, could be so profoundly healing. Like the counselor, my *Nookomis* would often gently encourage me. “Bring it out into the light,” she would say. “Let those memories finally breathe the fresh air. It’s healing to share. Don’t try to hide in it.” Encounters with these grandmothers always seemed to leave me feeling like I’d just encountered a powerful Warrior—someone whose words could send an arrow high into the sky that would fall back again to *Shkaakaamikwe* (Mother Earth). They were words that never failed to cause me to sit up straight, listen, absorb a lesson, and then propel me in a new direction.

When our talking circle group arrived at the lake, with *Nookomis* still and always smiling, it seemed that everyone began to sense that this wise woman deserved our mindful presence, our love, our respect, the full truth of our lives, our trust, our courage, and our humility. As I returned her smile, my eyes scanned the horizon for any sign of the thunderstorm predicted in the morning radio weather report. *Nookomis* instructed us all to lower ourselves close to where the earth met the water. We were reminded of when we were children, receiving a first lesson in respect and humility as each one of us were encouraged to offer the water, the land, our surroundings, and *Nookomis* herself, a handful of traditional tobacco. After we each had had our turn, *Nookomis* said, “I have this vision of

survival I want to share with you. It's a story that might help us re-think and re-story ourselves. It's a story, I hope, that will help you consider the violence that colonialism has caused in your life." Gesturing with her arms spread out towards the lake, she nodded at us. "It's the story of *Animikii* and *Mishebeshu* and of an epic battle that plays out over *Naadowei-Gichigami*."

Introducing Animikii

"Who is *Animikii*? Well, he's a powerful *Manitou*," my *Nookomis* began. "He serves *Shkaakaamikwe* (*Mother Earth*). Those Thunderers, they've created the same clouds they hide behind. It was *Kitchi-Manitou* (Great Spirit, Creator), answering the prayers of *Nana'b'oozo* (trickster), who called on *Animikii* to look after Mother Earth." Sensing the need to slow down, to check in *Nookomis* asked, "Aren't those *Animikii* clever?". "You know," she continued, "*Animikii* provides *Shkaakaamikwe* rain when she is thirsty, keeping her refreshed and fertile." *Nookomis* then turned to look at the woods bordering the lake, "Those *Animikii*, with lightning flashing from their eyes, they use their wings to fan the fires that re-birth the bush." Stopping, with a solemn look on her face, she added, "So, you see, we owe them our respect—not simply 'cause they care for *Shkaakaamikwe*—but we owe them our respect 'cause they also possess the power to destroy."

The healing lodge counsellor, *Nookomis*, began again. "To understand why we experience sadness, why we've used alcohol or drugs, why we are angry for having been stolen, or why we've shared our bodies indiscriminately, it's important for us to understand who *Animikii* is and their role in the *Anishinaabe* world view." As I listen to this *Nookomis*, my eyes are drawn skyward and I watch a *migizi* (eagle) dive towards the water. When *migizi* is only two feet above

the lake, heading east towards the shore, she spreads open her wings as wide as possible, and glides half a metre over the water. Noticing my gaze, *Nookomis* laughs out loud. “Looks like *Nana 'b'oozo* beat me to the punch and summoned *Animikii*. Perhaps,” she continued, “he got a message for us from *Kitchi-Manitou*, about *bimaadiziwin*.”

Not yet believing, I began to think, “No, *migizi* just has her eyes on those large invasive lake carp. She’s likely hunting food for her babies.” Her wings were almost horizontal to the earth, her body long and majestic, her bright white head was a contrast to the deep brown on her neck and tail.

Perhaps *Nookomis* knew I didn’t quite yet believe. Her response made me blush. “Oh, that *Animikii* is real enough. It’s so important,” *Nookomis* told us, “that we develop a respectful relationship with these powerful beings. Without relationship, we won’t be able to live in good ways.” Sensing the need to reassure us, *Nookomis* also added, “*Animikii* is a charitable being. *Animikii*’s role is to bring balance and harmony. The work that he performs, well, it helps connect the spiritual energy of the upper world with the energy of the lower world. *Animikii* makes our struggles visible by means of the thunderstorm.” Laughing, *Nookomis* added, “He’s like us. He’s real. You know, look at those clouds, up there above the lake. Make your own struggles visible, so *Animikii* might see. Share your sadness, anger, and share what it’s like to languish outside of culture. When we share like this, we reconnect ourselves.”

Even though it was our first day at the lodge, upon hearing this, we began to feel considerably more at ease. As our nervousness about being in a group about to share intimate details of our lives slowly dissipated, our healing group became intensely focused on sharing what it was like to live with unrelenting sadness. Everyone seemed to want a turn to speak. The kind of stories we heard that day were feelings of profound sadness, anger and grief from having been ripped from our families and our community. For many of us, we revealed feelings connected with colonial violence in ways that predated life with HIV. For others, the sadness came in stories about learning of having contracted HIV. Sadness was connected to how things got layered—they were stories about being treated badly for being Indigenous, for abusing ourselves by using street drugs or drinking too much alcohol, for being two-spirit, and for being HIV-positive. Because of all of this, sadness, it seemed, was the only thing life offered to us. These feelings made up our ‘normal’ existence. It seemed like these stories have always been part of us—our lives have been cruelly twisted by sadness in ways that have made breathing, that have made good living, an almost impossible feat.

Around the cafeteria table that morning, the first to share was Bill. He introduced himself as *Coast Salish*, sixty years old, and living with his wife of 25 years. Bill said that—fifteen years ago both he and wife were diagnosed HIV-positive. A survivor of residential schools, an alcoholic and user of drugs, HIV only made him angrier. He was angry at the untimely prospect of a much shorter

life. Bill told us that he simply didn't know "how to deal with these feelings. I—my old lifestyle was—I would—I would fight, and drink heavy, and do a lot of drugs. That was the only way I knew how to deal with it. I don't even feel good anymore about going back to the reserve. I feel like they treat me like a leper." Alluding to fact that "like a leper" was typical of the way he'd always been treated, Bill continued. "Even when I was small there was a lot of this sort of prejudice in the town. People on our reserve were always considered to be so dirty, to have lice, and they had whatever, they talked like they had, what they consider like a Native accent, the way they talked sort of slow and kind of like—you know—backwards kind of people and that's how they were treated, and we lived in the town."

Bill's anger inspired stories from other participants. Jared, two-spirit, Cree, shared how it had been twenty years since he had been diagnosed with HIV. He was raised in his culture, was active in the two-spirit movement, but struggled with anger from HIV. "That's the extent of how depressed I am," Jared said. "I get violent, malicious, and spiteful. The other side of the depression is just complete deadness." Jared believed he got HIV participating in the gay party circuit, by cooking heroin and shooting up with other guys. Having trouble understanding the complexity and intensity of his emotions, he continued with tears streaming down his face. "I feel like I'm worthless, that I can't really do things right. In the last couple of weeks, that's how I've been feeling, and I have

been feeling it right to the bone. I just don't know what's going on. My mind is so messed up. I don't know if I'm angry or sad or happy sometimes. It's mostly anger and unhappiness though. Um, yeah, just messed up. Right messed up in the head." Highlighting how things came to a head, Jared added, "Yeah, last year after a guy broke up with me, my heart was crushed and everything. I went to a different healing program, but then when I was there I realized, oh, my God, I felt I had to hide it a lot and I couldn't tell them the truth of why I was there to deal with the loss of that one person. And it felt, it was sad because I couldn't talk about it. It was very difficult because I didn't feel welcome there, because I'm two-spirited."

Moved by seeing Jared in tears, it was Rob who spoke up next. Rob was a thirty-six-year-old *Métis* man who had been living with HIV for the past 17 years. "Oh, you're lucky. I could not, I basically didn't—I had to learn how to cry—I had to learn how to be angry. I could not show anger". Hearing stories of anger, Rob shared similar experiences, but in his case, his was anger turned inward. "I hate myself sometimes for being sick. For letting myself ... for letting that happen to me. I thought before that I wasn't angry, I didn't get angry, and when I found out I had HIV, I didn't get angry, I didn't get ... you know, I didn't freak out or nothing, I just acted like, you know, ok you have it, deal with it. So, maybe that's what I'm dealing with now, the anger. I don't know." Continuing to unpack his story, he added, "You know, like Jared, this is the second time I've been in

treatment. The first time I went, last year, they actually told me I'm too messed up to heal right now." Chuckling to himself, he continued. "They said, 'this program is not right for you.' And it was a Native Healing Lodge and they told me that this program is not good for you right now because you're just—you're more messed up than we thought, pretty much." Rob was laughing harder now. Humour, Rob said, was his way of keeping himself from going crazy. For Rob, like for many Indigenous peoples, humour had the power to blunt the anger and softened the hard edge of emotional pain. Laughter, like it is for many Indigenous people, was Rob's emotional lifeline. Even though the use of humour in such a serious situation seemed odd, we all accepted that humour served a good purpose. Rob added, "I liked being the clown. I loved having the centre of attention. But really, deep inside, I was sad. So, I would extend myself beyond what I was capable of doing and I would get nothing back and this perpetuated even more negative reactions and negative things continually happening all the time. So, it was embarrassment, like I said, there was scared, embarrassing," in a voice that trailed off, "Yeah, ummm."

Even though I understood Rob used humour to soften sharp edges, I had to add more seriously, "Yeah, me too. When I got back here to this healing lodge, this nice gentleman asked me, 'well, what do you think caused you to go out and drink again?' And I said, 'well, I guess I wanted to. I wanted to drink. I was getting tired of being alone all the time, and I didn't have support and I was tired

of this and tired of that.’ But my counsellor, that nice gentleman, turned around to me and he said, ‘You know what? I don’t think so. I think you gave up on yourself. That’s why you started drinking again.’ And he was right ‘cause I then looked at it totally differently. I hadn’t seen it that way at all before. After a while I thought about what he said and that’s why I relapsed the first time—because I gave up.”

Nookomis responded encouragingly to our stories, “You know, *Animikii* isn’t simply symbolism. He’s real. We get to interact with him, to be in relationship with him, through that thunderstorm that is approaching. But he can also exist in your words, in the testimony each of you have offered. *Chi-miigwech* (thank you very much) for sharing your stories—that took honesty and courage.” *Nookomis* told us that she had said *chi-miigwech* because it’s important that we understand that when we work to represent *Animikii* in our life world—in our stories about how we feel, here, now—that what we’re really participating in is the refinement and the extension of our cultural beliefs, values and sacred teachings. “It’s through sharing that we’re all now walking that Red Road. But,” she continued, “life is a kaleidoscope. So, when we explore this part of the story, it’s important to remember that we’ve done so through a lens of sorts. We must be careful that we don’t talk about *Animikii* in a way that might limit our vision. What we have here is a partial story—there is more to this story, there are more characters, more events to add to the timeline.” *Nookomis* paused for a minute,

seemed to reflect, and then continued. “If I haven’t already told you, it’s always important to remember that *Animikii* depends on *Mishebeshu* the water serpent. The two make each other who they are and they provide each other their purpose in life. In other words, the part of story that focuses on *Animikii* shields us from what *Mishebeshu* might offer. Their relationship with one another—*Animikii* and *Mishebeshu*—works to protect, to balance, to be restored. Let’s explore that! Okay?”

Introducing Mishebeshu

“Do you want to know about *Mishebeshu* now?” my *Nookomis* asked pointing to the middle of the lake, “You know, that underwater monster who comes from out that big hole out there, at the bottom of the lake? Once, years ago, my Dad and I spent the day fishing on the lake. It was very hot and humid when we dropped our fishing lines, and when we did, out ahead of our boat, we noticed what looked like this big black sturgeon. Its back would break the water’s surface before it dove. This went on for some time—again and again—it would dive and surface, dive and surface. We sat quietly in the boat and watched. But you know what? It wasn’t a sturgeon, ‘cause this thing, this serpent, it had a triangular back, almost diamond shaped.” *Nookomis* raised her hands to the top of her head to demonstrate. “It had small horns that protruded from the top of its head. And it was larger than any sturgeon we had ever seen, probably fifteen or twenty feet long. It was frightening ‘cause that fish was much bigger than our boat. I asked Dad if we could leave. I wanted so badly to get off the water, get back on shore, and it couldn’t happen quickly enough, you know? But Dad, oh he knew better, alright. He understood *Mishebeshu* in a way I didn’t. He told me, ‘*Mishebeshu* is allowing us safe travel on the water.’ My father was a straight-shooting, matter-of-fact kind of guy, and when *Mishebeshu* surfaced again he told me, ‘Now there’s a gift for your eyes. You know,’ he said, ‘*Mishebeshu* is a powerful being. It’s ‘cause of this that we might think he’s the terrible one. But, he’s not. He’s not so bad.’ You’ll see.” Offering yet another riddle, *Nookomis* continued. That name *Mishebeshu*, well, it suggests medicine. That’s what my Dad told me that day, that *Mishebeshu* has extraordinary power, just like *Animikii*. That medicine, well, *Mishebeshu*, he’s also about giving our

lives meaning.” It happens through that struggle—when *Mishebeshu* battles *Animikii*—it’s that battle that helps to ‘right’ the imbalance in the world.”

After listening to our stories, the counsellor *Nookomis* shared a bit of her own story of survival. Long before becoming a counsellor, she too had many horrific experiences that flowed because of colonialism, the worst of which was her abduction by the state and church into a residential school at the age of only eight. Having experienced this as a profound loss of culture, family, and connection, she told of her own sadness, her own struggles to be a cultural person, and of eventually picking up and using alcohol to cope. Nookomis smiled and added, “That’s when I hitched a ride on the back of *Mishebeshu* and I traveled with him to the edges of the known universe.” For those of us who gathered by the lake that morning, hearing the counsellor’s own story, inspired us to share again in a second round of the talking circle. “Tell me how you understand those feeling of sadness. How are those feelings connected to your experience?”

It was Bill who, again, first spoke up. “I wasn’t raised Aboriginal and I wasn’t allowed to hang around with—believe it or not, me being Native—with Native people.” Sharing how his family didn’t teach him his culture, he continued, “You know being Native, and having my culture, and traditions and stuff. I don’t know anything about that! I don’t know anything about that at all. I’m from the north. And my band doesn’t have, they don’t have, they’re starting to come around, but I don’t know anything about my tradition, traditional or, I just, I just

feel like I'm lost." Not quite finishing his sentences, like parts of his stories were cut out of him, it was eventually HIV that provided Bill with an important reason to explore his culture: he desperately needed to be spiritually strong to live with the physical illness. Bill described what it was like finally finding space in his life to reclaim culture. "My very first time I picked up an eagle feather and I was like wow! Just this overwhelming feeling of joy that came over me." With tears streaming hot down his face, Bill continued. "Wow, I'm holding the feather of an eagle! It was so powerful being Indian it was just ... and the eagle feather I got was from the chief. Now for me it was, wow, okay, an Indian chief gave me an eagle feather. I said, whoa, ok ... I still have the eagle feather today. I want ... I'll die with that feather. I will die with that feather on me."

For Jared, like many others, crushing poverty, housing instability and unemployment were what devastated him living with HIV—they were his monsters. Following Bill, Jared shared how the financial end of things affected him. "The money bit ... well, that is extremely depressing, because I'm not making the money I used to. I'm living below poverty now, on my pension, and I just feel that the opportunities aren't there for me anymore, you know? Because of my physical body. I don't know anything else but how to use my physical self. So, I'm just sort of going to try to reeducate myself. Just start, start over again." Prior to coming out and living as a two-spirit man, Jared once had a girlfriend and they started a family together—a daughter and a son. "I can't do nothing for my

kids ‘cause I don’t have the money, that’s another thing. ‘Cause I don’t have money to do things for, for family. Makes me feel ... I don’t know, less ... less as a father? You know, kids need stuff, and my girl is having a hard time, and ... with her boyfriends, and I just feel really bad. I can’t do nothing.” Expressing how he’d love to change this, Jared added, “if there was a way of bettering myself financially, I would, ‘cause I believe that if you have money, you know, you can make a change in your life. But if you don’t have money, you’re limited to what you can do.”

Following Jared, Rob had a different story to share about how he understood his feelings of sadness. “When I think of depression, it isn’t so much related to HIV in the beginning as it is now, but it’s mostly due to coming from a family of alcoholics. Verbal abuse, emotional abuse, stuff like this. So, I never had the support as a child.” Adding how this wasn’t the only experience that drove his experience of feeling overwhelming sadness, Rob added, “It’s a mixture of things, it’s just a whole combination of stuff. I had a tough childhood, but I had some good. Well, I had a dream when I was a kid that I was supposed to be a hockey player and I was a pretty good hockey player when I was a kid. But I didn’t have any support there either. And I was abused as a kid, and I learned as a kid, just, I think I’m still sad about being a really crappy kid and having a really crappy childhood!” Turning towards the sky and as much to *Nookomis* as to the Creator, Rob continued. “You know some of our community members were able

to heal themselves and emerge as “well” people, as healers. I know this one guy, like you, *Nookomis*, he works to help our Native brothers to deal with the issues of HIV and AIDS—but in the prisons. So, we can emerge and heal ourselves from these experiences and through sheer determination of will, you know. And for me that sheer determination of will is, you know, it’s, you’re never, they’re never going to do that again to you. You will emerge and will not be suppressed and oppressed by people, I think the worst thing that can happen to us. It’s like someone holding our spirit, holding our spirit in a cage you know?”

It was now my turn. The only stories I had about depression were connected to the drugs and alcohol that I used. It came, for me, because of being sexually abused when I was a kid by my uncle. “To be depressed for me, I just don’t know how to deal with it. My old lifestyle was that I would, I would, fight and drink heavy, and do a lot of drugs.” This included becoming very promiscuous, I told them. “I got into a really depressed state, I wanted to um ... I wanted to die, so I ... so I got very self-destructive. I started doing things to hurt myself. I decided to die because I didn’t want to live anymore, so I would put myself in dangerous situations with bikers. I’d try to get shot, I’d try to get stabbed.” Unfortunately, the medication to treat HIV only compounded feelings of sadness. “I was on a HIV drug called Sustiva, which caused a lot of psychological issues to come up, issues of thinking that I was being persecuted by people, my parents, my family, my friends. I became very paranoid, very, very,

angry, malicious, mean...all the exact opposite of how I usually am. Very unhappy.” But, I told them, things were beginning to change. Maybe it was age. Maybe it was a growing maturity, but I just started to “kind of grow, grow out of it, type of thing, to me. There’s ... there was a time in my life when alcohol was, I mean when I could really, it’s hard to believe in a guy as young as me, but I mean I drank, and... drank and drank. Had every symptom of the...the classic alcoholic right from you know, right from the top to the very bottom; pushing bottles around in a cart to go get more booze type of thing.” I chuckled to myself sharing this, and then quickly added, “It sounds funny, but it isn’t. It’s really tragic.”

Nookomis began her story again, “You know, it’s those Thunderers who have the power. They will work to right the imbalance that *Mishebeshu* has caused in our lives. When those *Manitous* come together, when *Mishebeshu* breaks that water, *Animikii* will use those air currents to dive toward that serpent. You know,” *Nookomis* continued, “I want you to also begin to understand that many of you shared stories that aren’t the result of who you are as a person.” Pausing, *Nookomis* added, “You know, those social conditions you spoke to, loss of culture, housing, and what not, these things aren’t your fault. They are rooted in colonialism. You are not to blame. Colonialism results in a cosmic imbalance that is meant to cause us personal harm, you know? The Thunderers and those serpents—our grandfathers—they work constantly to protect us from this imbalance and from the harm we cause ourselves because of that imbalance.”

At that moment, it started to lightly rain, and our small group ran and took cover under the nearby gazebo. You could see the lightening, still off at a distance, getting closer. “Maybe it’s time to tell you about that storm approaching from the west. Here, it’s important to keep in mind that the storm—that the battles it depicts between *Animikii* and *Mishebeshu*—is not a contest between good and evil, light and dark, or right and wrong. Oh no, it’s not. To view the battle that way is a Eurocentric error. That storm. That battle. I find it helpful to think of the storm as an epic war between the forces of balance and imbalance. That’s what those *Manitous* bring us when it storms. They are teaching us to reconnect, to be in relationship, that the land and all her beings are her to assist us with our troubles.”

Storm on the Lake

Looking towards the sky, my *Nookomis* asked, “What about that approaching storm? That sound of thunder in the distance, it reminds me of this story we share only in summertime. It’s a story, the old ones told me, about something that happened a long time ago. It’s about this man, a hunter for his community, who was trying to get across the lake to where the wild game had migrated. The hunter was walking along, trying to figure how he’d get quickly across, ‘cause he didn’t have his canoe with him. He walked for some time before he came to this fat, long, black snake lying near the shore. Although that snake was frightening, the hunter was thinking about the hunger his community might suffer, so he guardedly asked the snake, ‘Will you carry me across the lake? I need to hunt over there, where the animals have gathered.’ Much to his surprise the snake agreed. ‘Yes, I can take you. But those thunder clouds are a worry. They are beginning to look menacingly black and I’m afraid of the thunder and lightening. Will you tell me if it thunders or begins to lightening while we are crossing?’ The hunter promised he would and with that he got on the snake’s back. Once the hunter felt secure, that big snake began its slimy slither into the warmth of the lake water. As they went along, the clouds began to

darken even more. The thunder, once distant, rumbled deeper and louder than it had before. The storm was almost over top of them. And with that, a fierce light hissed and crackled in a series of volleying flashes, and began hitting the now churning water. Whimpering with a fear that was quickly closing in on all sides, the snake said to the man, ‘Wait, I think I hear *Animikii*. It feels like he’s very close. I can hear his low rumble grow stronger. I can even feel the electricity. We better get ourselves out of the water, and quick.’ Not waiting for the hunter to respond, the snake turned around and began to head back to shore from where they had come. Just as they reached the shore, at a spot near the rocks where the hunter could leap to safety, a stroke of lightening hit the snake. The snake withered in pain, curled up, wrapping around itself in a tight coil. But this protective move had no benefit to him. The hunter was shocked to see the lightening hitting the snake again just as he reached the rocks near the shore, and it broke the snake into a million pieces. Those snake pieces, well they, too, began swimming about before finally making land. So, you see, that great black snake wasn’t killed after all. His pieces saved him. They turned into many smaller snakes that we continue to see all around here, even today.”

Back in this realm, under the safe cover of the gazebo, this other *Nookomis* brought our attention to the clouds over this lake. The clouds were coalescing, darkening, and beginning to menacingly roll over top each other. You could see, hear, and feel those clouds gathering strength. Standing at the shore and looking west out across the lake, *Nookomis* proclaimed, “Wow, that *Animikii* is truly a magnificent *Manitou*! Feel that wind, look at those black clouds billowing over one another, and see that wall of rain approaching trying to make shore. I’ve been listening to your stories about feeling sad, or angry, or not being able to feel anything at all. And I was thinking, perhaps *Animikii* and *Mishebeshu* will help us remember relationship and connection.” Don’t we all want to experience healing? Through my own struggles—like that thunder and lightning—I can tell you that

those thunderstorms happen all the time around here. The wise old ones told me, ‘these battles happen again and again—they are like life, a circular thing. Its nature that reminds me how it might be foolish to seek resolution—but just like *Animikii* and *Mishebeshu* have done—we are here to find ways of bringing balance into our lives. Let’s allow *Animikii* and *Mishebeshu* to show us.’”

No sooner had *Nookomis* spoken those words than the dark clouds, heavy with rain and the weight of the world, began to dip dangerously low over the lake. Clearly, everything was aligning towards the moment. “Lay your tobacco again,” urged *Nookomis*. “It’s time to ask *Animikii* for help. He’ll come help you do battle with that part of yourself—that *Mishebeshu*—that keeps you disconnected and unbalanced.”

As we finished laying our tobacco, the thunder clapped loudly, lightning flashed, and this brought heavy, unrelenting rain. As the thunderstorm played out before us, it created space for our own flood gates to open. Everyone in the talking circle, it seemed, had something to share about their journey to find balance. It was Bill who first spoke. “I really know that you are telling us what we really need to know. And it’s always, it’s who you are kind of ... what happened to you when you were small kind of thing. Why a lot of people get depressed, because they are hiding a lot of shame, guilt or whatever, right? And so, then you leave that unattended, you end up getting depressed, because it bothers you, and you don’t know why, and some people are like, “why, why, why?” Because they

don't really know like you know, about themselves, their inner selves, why. But, ignoring it ... will take its toll."

"How do we connect?" *Nookomis* responded. How do we find balance? Share your wisdom! You know this. Those ancient ones, they planted these things in you long ago, it's in your blood memories. Dig for it. It's already a part of you. That storm—that battle between *Animikii* and *Mishebeshu*—that battle, that thunderstorm, it reminds me, it teaches me that I'm also to be in relationship with myself. That storm, you know, it brings about medicine that will help us heal. Don't fight the battle, don't push back against. Let it wash over you! Learn to let it. Share your thoughts," *Nookomis* said in this third round of the talking circle, "cause to share is to connect and heal. Share with *Gichi-Manidoo*, make your struggles visible like that thunderstorm, cause when we do, we heal, and maybe, just maybe, we'll help heal others too."

With this license to share, Bill once again began to speak. "I don't feel as lonely, as alone, or empty anymore. I know that when that depressed feeling comes on, I know that I can go somewhere." He paused for a moment, "I can do something about it to make myself feel better. One of the things I do, and I know many of you do too, is I do speaking about HIV. We drive all over the place. I've worked the food bank, I've worked the drop-in centre, I'm the vice-president of an AIDS service organization—I just keep really busy, to keep my mind off things. Whenever I find myself sitting at home, or being alone, which is pretty

common, I start falling into the really extremely depressed state, and then I have to get busy and that's about the only way I deal with it right now."

Jared agreed with Bill. "Yeah, coming back to that AIDS service organization and connecting with people, and the other clients and stuff here, helped a lot, too. It really did. Maybe a big difference, because sometimes you feel so focused on your own self that you forget there's other people around you that have problems too. So yeah, I see a psychiatrist too," Jared added, "and she's the one who told me or helped me realize that I needed to identify myself with other Indian people and learn to become more Traditional. So, that's why I'm here."

"Yeah, I like that Traditional stuff too," Bill responded. "When I got to the lodge and I sat down in this healing circle ... and we have sage, and cedar, and sweetgrass, and tobacco and this is what they mean and this is why we put them in the direction that they are," he paused, "I feel more at ease, relaxed ... it's focused more on the Aboriginal. Us!"

Rob added a layer of complexity with what he shared next. "I asked this other counsellor, 'Do you think it would be alright if I came out and told everybody else that I was gay? HIV?' The other counsellor said the Elders were not quite ready for that. So, I couldn't tell anybody. So, I know that there's still that stigma when it comes to being gay, HIV, especially in the Aboriginal community." Listening to Rob, it was a reminder to all of us, that focusing on

ways forward can be difficult. We sometimes get stuck. Being around others, learning from their example might help turn the tide.

Finally, it was my turn to speak, “You know, you think that you’re depressed because you’re sick and you can’t move and you’re in a compromising position and then all of a sudden ... it’s just humour. I don’t know. I have a natural ability to make myself laugh at the worst times possible.” Talking about humour like this, made me smile. It reminded me that the Creator has a sense of humour too. “Perhaps,” I thought to myself, “humour provides a lesson to learn a life lesson.”

Nookomis, smiling and taking her time to look each of us in the eye, said, “You know, although we’re finished for today, I do want to leave you to think about one last thing. The story of *Animikii* and *Mishebeshu*, well, that’s a story that never ends. Our sacred stories—this *aadizookann*—it isn’t simply myth, ... don’t you know? Those stories are meant to offer meaning and value to our lives. Just like the snake who was broken into a million pieces, *Mishebeshu* will manage to regenerate himself and *Animikii* will always come back to do battle with him. When the water churns because of *Mishebeshu*, I want you to remember how we began today. We each offered the waters, the land, our Elders, a bit of traditional tobacco. I want you to remember, moving forward, that *Animikii* almost always responds to a tobacco offering. If you find yourself in a storm on a lake—and I’m speaking metaphorically—I want you to be confident that the Thunderer will

answer your prayers. Because much of what caused our feelings of sadness are social—like colonialism, poverty, racism, housing, unemployment—it’s important to understand that *Mishebeshu*, well, he’s unpredictable. He’ll take your tobacco but may not be appeased by it. The battles these colonial forces inflict on our lives, for many of us, will continue. It’s like the story of *Animikii* and *Mishebeshu*—it’s a story that never really ends. It’s like the story of colonialism that hasn’t ever really ended—and until those outsiders learn to ride *Mishebeshu* and encounter *Animikii*—these will likely continue. But hearing about *Animikii* and *Mishebeshu*—well, it plants a different story that will grow.

“That story is in us now, plain and simple, it’s part of us,” Nookomis smiled and I was reminded once again of the wisdom and the medicine of my grandmother. “But you know something even more important? Even though there are many Indigenous people who believe that *Nana ’b’oozo* retired—he’s hasn’t, you know? He’s simply sleeping. He waits for us to evoke his presence, when we convince him to carry our prayers to *Kitchi-Manitou*, have no doubt that support and help will come in your battles.”

Chapter Five

Indigenous knowing in HIV research in Canada: A reflexive dialogue

Randy Jackson

Introduction

One of my first remembered experiences of how scientific knowledge can offend came in the form of an early morning call—some 20 or more years ago. An Elder in my community, also my mother’s aunt and my great aunt, had just passed to the spirit world. In the years leading up to this moment, I was aware my aunt was concerned about the loss of traditional knowledge upon her death. She agreed to track back into the bush with a Western trained botanist. On the surface, all seemed in order. The botanist was ahead of current Western research protocol that now informs research encounters with Indigenous¹ peoples. The botanist negotiated community access through the band council, spent the appropriate time in and getting to know the community, secured individual consent, collected the necessary information, produced a community report of findings, and left.

Many years later, long after the death of my aunt and well into my Western academic training, while shopping in a bookstore my mother stumbled upon a publication written by this once visiting botanist. The manuscript

¹ The term Indigenous is used in this chapter as an umbrella term and is inclusive of First Nations, Inuit, and Métis peoples who are legally defined as Aboriginal under the Canadian Constitution (1982) as the original inhabitants of the territory now known as Canada. The term Indigenous is also used to refer to global Indigenous communities who hold similar or shared knowledges and values vis-à-vis Indigenous peoples in Canada.

showcased the sacred knowledge of flora and fauna in my community's traditional territory. Absent from this publication are either any recognition of community involvement or acknowledgement of authority to publish what my mother considers traditional knowledge. It is published solely under the botanist's name and my mother is deeply offended. For my mother, the publication represented a theft of Indigenous knowledge. For me hearing my mother speak, I too began to lose my own sense of naïveté about Western research.

Perhaps this is an unremarkable and far too common story of how Western science can offend. For me, however, it is the moment where I begin to recognize the West's appropriation of Indigenous knowledge, made possible by the subjugation, marginalization and oppression of Indigenous peoples. These are features of Indigenous experience that can continue to promote the advancement of colonialism. The botanist story is but one example of "researchers extracting data from Indigenous communities and then publishing 'their' research with little benefit to the people" (Kovach, 2009, p. 32). The stories of the West encountering the exotic 'Other' are plentiful. Like the experiences of other marginalized and oppressed groups, the West devours knowledge from this 'Other', and does so largely for its own benefit. Hearing about the botanist is when I also first recognized that as an Indigenous person I must not only negotiate my cultural identity as an *Anishinaabe* person, but that I must also do so as a member of the Western academy. In practice, this recognition is best described as far from

straightforward, simple, or uncomplicated, but it is a paradox I'm nonetheless compelled to negotiate. As Grande (2008, p. 234) states, "the colonial tax of Native scholars not only requires a renegotiation of personal identity ... [but] by virtue of living in the Whiteman world, Indigenous scholars have no choice but to renegotiate the forces of colonialism, to learn, understand, and converse in the grammar of the empire as well as develop the skills to contest it."

Many Indigenous scholars have embraced critical approaches in the social sciences that embed decolonizing and Indigenous methodologies. Using these approaches, Indigenous scholars advocate for a critical social science more inclusive of their cultural ways of knowing. A focus on this goal highlights the Western bias in research, the erasure of Indigenous knowledges, and the 'pathologization' of Indigenous peoples (Bond, 2005; Peltier, et al., 2013; Reading & Nowgessic, 2002). Taken together, they have also demonstrated how Western research that represents Indigenous peoples negatively shapes the ways in which we think about and respond to their health. Decolonizing research, on the other hand, recognizes the negative force of colonialism on the health and wellbeing of Indigenous peoples, emphasizes the reclamation of ancestral ways of knowing (Crowfoot Graham, 2002), the relevance of local cultural knowledges (Brant Castellano, 2000), interpretation and meaning making processes that reflect cultural knowing (Jackson, Brennan, Georgieski, Zoccole, & Nobis, 2017), culture as intervention (Hall, Dell, Fornssler, Hopkin, & Mushquash, 2015), and

holistic and relational models of health care (Brant Castellano, 2000; Denzin & Lincoln, 2008a; Kovach, 2009; Smith, 2014). Taken together in ways that dovetail with the family of participatory methodologies (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009), over the past decade-plus, social science researchers have begun to fruitfully and meaningfully involve Indigenous organizations and communities in their research programs.

The goal of this chapter is to explore what it has meant to me to be engaged in Indigenous HIV research. I emphasize how reflexivity, as part of one's critical disposition (Smith, 1999) is an active feature of decolonizing and Indigenous methodologies. In this sense, a critical decolonizing and Indigenous methodological approach in HIV research rests on and compels not only external, but, also, internal epistemic reflexivity. But to engage reflexively recognizes that any learning comes from a deeply personal place (Loppie, 2007), and as Tomaselli, Dyll and Francis (2008, p. 368) state, "[to write reflexively] is to implicate [one's self] in the production of knowledge." This chapter provides an overview of decolonizing and Indigenous methodologies and, drawing on a decade of Indigenous HIV research experience, explores some of the strengths and the pressing tensions associated with these approaches in HIV research with Indigenous communities in Canada. From a decolonizing perspective, reflexivity is vital because it serves to remind us that if we are not mindful, our research may inadvertently promote the continued rise of hegemonic power structures in

research (Cannella & Manuelito, 2008). In part, reflexivity in Indigenous research contexts is meant to support Indigenous self-determination, and as Smith states (1999, p. 124), it assists Indigenous and allied researchers “to imagine a world in which indigenous peoples become active participants, and to prepare for the possibilities and challenges that lie ahead.”

The Promise of Decolonizing and Indigenous Methodologies

Critical social sciences that take up decolonizing and Indigenous methodologies are flourishing on a global scale. These conceptual approaches to social science research recognize colonialism as a troubling force in the lives of Indigenous peoples. Decolonizing and Indigenous methodologies are meant to work together to interrupt colonialism in social science research by holding space that privileges Indigenous culture, voice, and knowing. In other words, decolonizing critical social sciences are committed to “acts of reclaiming, reformulating, and reconstituting Indigenous culture and languages [...] to become self-determining” (Smith, 1999, p. 142).

For me, the use of decolonizing approaches coupled with community-based research principles, have always been at least partially focused on the development of techniques of inquiry that strive, taking up the call offered by Walters and colleagues (Walters, et al., 2009; see also Wilson, 2008), to ‘retraditionalize’ the research process through inclusion of Indigenous knowledges. Indigenous knowledges in research are not meant to reflect the

“future centered hope of the Western imagination, but rather, [they express] a hope that lives in contingency with the past—one that trusts the beliefs and understandings of our ancestors as well as the power of traditional knowledge” (Grande, 2004, p. 28). Although it is important to recognize diversity of Indigenous knowledge, there is general agreement that these systems are thought to be dynamic and ever evolving (Brant Castellano, 2000; Loppie, 2007); that they are oral knowledges that stretch back generations; and that they are localized in ways specific to one’s Indigenous heritage. Indigenous knowledges are also thought to embody a cosmological orientation, and where knowledge is revealed, the teachings derived almost always involve the interpretative support of a community’s healers, Elders, or other spiritual leadership (Brant Castellano, 2000; Evans, Hole, Berg, Hutchinson, & Sookraj, 2009; Kincheloe & Steinberg, 2008; Kovach, 2009; Peltier, et al., 2013; Smith, 1999; Wilson, 2008). As Battiste (2008, p. 499) defines it, “Indigenous people’s epistemology is derived from the immediate ecology; from people’s experiences, perceptions, thoughts and memory, including experiences shared with others; and from the spiritual world discovered in dreams, visions, inspirations, and signs interpreted with guidance of healers or elders” (see also Brant Castellano 2000; Kincheloe & Steinberg 2008). In Indigenous knowledge systems, the knowledge held by individuals and families is considered personal and always correct. At a broader level (e.g., community or nation), for knowledge to have social validity across individuals and families, it

must be authenticated through collective debate that leads to a high degree of consensus. Knowledge is also thought to express an important relational character in that meaning derived is always contextualized through one's relationship with one's community and the immediate environment. As Holmes (2000, pp. 42-43) writes, "Knowledge is a gift from a higher power, revealed and contextualized through relationships. [In other words,] knowledge is validated not through the notion of truth value but rather [is affirmed] through connection." A key definition of decolonizing and Indigenous methodologies is offered by Evans and colleagues (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009, p. 894) who write that such approaches "can be defined as research by and for Indigenous people using techniques and methods drawn from the traditions and knowledges of those people." Incorporating this into critical social science research, scholars have advocated for a decolonized Western academy.

However, the use of Indigenous knowledge can be problematic. As Indigenous scholars, we often hear the critique that the theories we use to develop and guide our research are "inherently Western, are nonindigenous, and [...] insufficiently grounded in the needs of Native communities" (Simpson & Smith, 2014, p. 1). It has long been recognized that "epistemologies have material consequences" (Simpson & Smith, 2014, p. 3; see also Smith, 1999 and Smith, 2014) in ways that link with and support the continued expansion of the colonial project. This idea embodies the need for Indigenous scholars to critically use

decolonizing methodologies to shift Western theory (Grande, 2004; Grande, 2008). In describing Indigenous knowledges in decolonizing research contexts, scholars generally highlight several common features across diverse Indigenous knowledge systems. Critical social science methodologies that are grounded in Indigenous knowledges are thought of as preformative (Denzin & Lincoln, 2008a; Grande, 2004; Grande, 2008; Smith, 1999; Smith, 2014; Swadener & Mutua, 2008). Intertwined with a key precept of Indigenous knowledge, decolonizing and Indigenous methodologies are thus best viewed as transformational social action grounded in praxis. They are also considered approaches that tend to emphasize Indigenous community participation in conducting research (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009; Hall, Dell, Fornssler, Hopkin, & Mushquash, 2015), that commit to acts of cultural reclamation and healing (Smith, 1999; Smith, 2014), and that guide research processes in ways that leave the approaches used by researchers accountable to the Indigenous peoples represented in the research.

The development of Indigenous knowledges for use in decolonizing research processes involves “methodologies and approaches to research that privilege indigenous knowledges, voices, and experiences” (Smith, 1999, p. 87). Drawing inspiration from critical race theory, interpretative, post-modern, and feminist approaches, these relatively new ways of engaging in research with Indigenous peoples have been reimagined through Indigenous epistemologies

(Evans, Hole, Berg, Hutchinson, & Sookraj, 2009; Grande, 2004; Grande, 2008; Smith, 1999; Smith, 2014). What all these approaches have in common is a core set of unifying themes that include a commitment to social justice. Nonetheless, it is important to acknowledge that decolonizing approaches in a critical social science context are relatively new and some Indigenous scholars remain troubled by approaches that draw on Western foundations. No matter how much we indigenize Western methodologies and methods, the fear is that they will continue to embody colonizing influences (Grande, 2008). In other words, while critical social sciences may appear congruent with and supportive of efforts to end colonialism, the use of indigenized Western approaches remains problematic. As Grande (2008, p. 240) notes, “It is important to recognize that revolutionary critical [approaches] remain rooted in the Western paradigm and they’re in tension with Indigenous knowledge and praxis.” For some Indigenous scholars, the requirement to conform to Western academia feels like “an imposition on [one’s] intellect and creativity because [the] focus is shifted from *doing and living* to *talking about* or *explaining*” (Simpson, 2014, p. 113). Unlike the static edges of objectivity embodied by some Western approaches, “creating [Indigenous knowledges] are embedded within a larger epistemological framework that values emergence, vision, flux, and dynamic relationship with both human and non-human entities” (Simpson, 2014, p. 112).

My Journey Using Indigenous Knowledge in Decolonizing HIV Research

Long before my introduction to decolonizing and Indigenous methodologies, as a member of the academy, I'd always felt like I'd been asked to make a choice. I sensed that I was being asked to choose between identifying as an *Anishinaabe* person or submitting to Western training as a scholar of HIV research. As an undergraduate student in the early 1990s, little of what I was taught reflected Indigenous knowledges. As a graduate student, despite opportunity to learn about and use Indigenous knowledge, I often continue to question whether I'm being asked to make a similar choice. In terms of softening the edges of Indigenous consciousness, am I being asked to simply adapt Western research approaches, use their methods, their ways of creating meaning? As Grande (2008, p. 234) noted, "One feels compelled to choose between retaining his or her integrity (identity) as a Native person or doing research." Despite advances made by Indigenous and allied scholars and the acceptance of Indigenous ways of knowing by some Western scholars, the pressure to conform to Western standards of truth and validity are considerable and, in some ways, Indigenous knowledge remains firmly marginalized in the Western academy. It is exceedingly difficult to untangle, to not only understand deep-seated emotional reactions, but to respectfully negotiate and claim space at the Western research table. According to Grande (2008, p. 234), in examining our own roles within the academic industrial complex, our personal journeys are primarily characterized by

“vacillation between wholesale adoption of Anglo-Western theories and the stance that Indigenous scholars need nothing outside of themselves or their communities to understand the world or their place within it.”

I’ve found a resonance, however, in written accounts by other Indigenous scholars, their stories, and their journeys, when considering my own. Before returning to studies, I was employed by a national Indigenous non-profit organization focused on HIV and AIDS in Indigenous communities. As we built our own internal research capacity, we partnered with trusted Western academics and shared leadership on a variety of projects, that explored deficiencies in the provision of health services to Indigenous people living with HIV (Jackson & Reimer, 2008), the impacts of HIV-related stigma and discrimination in accessing health services by people living with HIV (Mill, et al., 2009; Mill, et al., 2011), experiences and responses to depression among Indigenous peoples living with HIV (Cain, et al., 2011; Cain, et al., 2013; Jackson R. , et al., 2008), and HIV testing and diagnosis of HIV infection among Indigenous youth (Mill, et al., 2008; Mill, et al, 2011; Prentice, et al., 2011). Although these earlier projects drew on participatory methodologies and were mindful to meaningfully include Indigenous participation, they were not projects that were shaped by Indigenous knowledges. As research teams, for example, we did not consider Indigenous knowledge (e.g., relational connection of participants’ stories to the environment) in ways that might differentially inform our interpretation. Rather, consistent with

participatory research approaches, the roles I primarily assumed on these research teams were responsibility for promotion and recruitment, contributing to analysis, and community knowledge dissemination activities.

As our research capacity as an organization grew, and once we acquired the opportunity to hold research funding, we also began to understand that research could be made more congruent with Indigenous world views (Smith, 1999; Wilson, 2008). We began by designing research that drew on a range of cultural assets of Indigenous communities. Indigenous Elder participation in research, for example, is considered pivotal to the success of our research because Elders are respected as cultural knowledge keepers, are ethical and cultural consultants that help shape research approaches, are mindful of the spiritual needs of both researchers and participants, and can conduct ceremonies as part of research (Flicker, et al., 2015). More recently, we have also worked to develop ways of meaning-making that are carefully grounded in Indigenous world views. Across several projects—e.g., resiliency among two-spirit men living long-term with HIV (Jackson, Brennan, Georgieski, Zoccole, & Nobis, 2017); cultural understandings of home in the context of living with or at risk of HIV infection (Greene & Jackson, 2015)—meaning making has evolved to where we have drawn on the traditional teachings of the Medicine Wheel.² This work has been

² The Medicine Wheel, a symbol of *Anishinaabe* culture, expresses health and wellness as balance and harmony among four aspects of self (physical, emotional, mental, and spiritual) and one's relationships with one's family, community, nation and universe (Isaak and Marchessault, 2008). Used in research, it

carried out at a number of levels: to gather and organize data and generate interpretations that are relationally embedded in the communities from which knowledge has been derived (Isaak & Marchessault, 2008). The Medicine Wheel can be used in focus groups to stimulate dialogue among participants. Key quotes found in interview or focus group data selected and assigned an unique letter/number combination; quotes are then mapped to the area of the Medicine Wheel that matches the meaning expressed by the quote. Connections among coded data are then grouped into themes. This approach to data gathering, analysis, and interpretation is meant to maintain the relationship of data to Indigenous peoples. As Wilson (2008) advocates, Indigenous scholars must remain accountable to Indigenous communities and cautiously consider the research topic, methods of data collection, forms of analysis and ways information is being presented. These more recent research projects highlight the promise of Indigenous HIV research in contributing to social change, emancipation, and the use of liberatory and strength-based language. In short, these approaches to Indigenous scholarship suggest a move away from the pathologization of Indigenous peoples to a way of being with, thinking, and writing about Indigenous peoples who, despite structural challenges that give rise to health

provides a conceptual tool meant to facilitate close connection between the themes generated in research with Indigenous ontologies.

disparities, as cultural beings are fully capable of achieving health and wellness through embodiment of Indigenous values and beliefs.

In exploring use of Indigenous knowledge, I have also become deeply interested in how stories represent theory and how storytelling can be viewed as a culturally dynamic intervention. It is a position that is taken up by Simpson & Smith (2014, p. 7) who ask, “How we can critically and intelligently theorize current conditions in diverse spaces inside and outside the academy, and how can we theorize our responses to these conditions.” In the context of PhD studies, and towards this end, I’ve also become increasingly interested in Indigenous methodology as a theory of inquiry that draws on Indigenous methods—poetry, drama, storytelling, critical personal narratives—as performative practices that represent and make Indigenous life more visible. Specifically, I’m interested in how stories represent Indigenous theorizing and how the process of storytelling can affect healing trajectories for Indigenous communities confronting HIV and AIDS. Unlike the Western narrative approaches, Indigenous stories convey embodied meaning not through content but by making visible the context in which the stories originally occurred (Simpson, 2014). As Million (2014, p. 31) writes, “The stories, unlike data, contain the affective legacy of our experiences. They are felt knowledge that accumulates and becomes a force that empowers stories that are otherwise separate to become a focus, a potential for movement.” Over the last decade, I’m convinced that Indigenous people might locate their

own empowerment through stories and therefore finding some healing from the ravages of colonialism. As a qualitative researcher, who uses an indigenized narrative inquiry in HIV research, like Million (2014, p. 33), I'm buoyed by the prospect of the "power of our everyday stories, the theory of stories as theory, and Indigenism as theory." My interest in Indigenous stories and storytelling springs from a desire to more closely align my scholarship with my tribal genealogy and to work to forge new ground for Indigenous theorizing. As Simpson (2014, p. 110) similarly writes, "I want my writing and my creative work to do the same thing for others—to pull people into my consciousness" and make the beauty of Indigenous peoples' world views and ways of knowing more visible to outsiders.

The Challenge of using Indigenous Knowledge in HIV Research

Despite the promise of Indigenous knowledge systems that potentially offer "compelling insights into all domains of human endeavor" (Kincheloe & Steinberg, 2008, p. 135), the use of these approaches remains, as Connell (Connell, 2008, p. ix) suggests, "a fragile project." Similarly, Smith (2005, p. 87) describes this space as "tricky ground" competing within "internal relations of power, as in any society, that exclude, marginalize, and silence some while empower[ing] others." Although decolonizing and Indigenous methodologies are being widely used in Canadian research (Chambers, et al., 2017), their uptake in Canadian HIV research among Indigenous communities isn't reflected to the same degree (Peltier, et al., 2013). This has serious implications for designing

HIV prevention and other HIV-related health services for Indigenous peoples. Perhaps part of the challenge is that it is difficult to raise one's voice, to upset the status quo, and to work to gain legitimacy (Briggs, 2005; Kovach, 2009; Million, 2014). Three critical questions are outlined below: 1) the question of the master's tools, theoretical overlap, and building confidence to challenge dominant ways of conceptualizing research; 2) questions about two-eyed seeing as a potentially useful construct to alleviate tensions between Indigenous and Western ways of knowing, and; 3) what makes a critical decolonizing and Indigenous social science an Indigenous science?

The Master's Tools: Theoretical Overlap and Building Confidence

It has never been easy being Indigenous in the academy. It requires operating within systems of power that Indigenous scholarship helps to critique and transform. The burden of responsibility placed on Indigenous scholars is considerable. Can an Indigenous scholar be both Indigenous and of the academy? As Million (2014, p. 34) acknowledges, "The struggle of our generation has been to honour our own paradigms, concepts that arise from our lives, our histories, and our cultures while knowing that they are often inextricably mixed with concepts growing from our subjugation." Yet many Indigenous scholars remain troubled by using the tools of the empire to mount resistance to the Western academic project (Briggs, 2005; Grande, 2004; Grande, 2008; Million, 2014; Smith, 2014). Many express the reasonable fear that if we draw on Western

theories and rearticulate them through the lens of Indigenous knowledges, we'll always remain guarded by the possibility that we may “unwittingly recapitulate colonial and capitalist assumptions” (Simpson & Smith, 2014, p. 7). In some ways, it looks and feels like a paradox: to critique Western research as colonial, while at the same time, draw on these same theories in Indigenous research towards establishing intellectual sovereignty. The tension is palpable and it reaches back into a shared history of colonialism, is ever present, and is a site of intense academic interest. It raises other types of questions: If not the master's tools then whose tools can we use? Do we further develop Indigenous methodologies? It is these kinds of questions that are important to raise, as Grande (2008, p. 234) adds: “Is it possible to engage the grammar of the empire without replicating its effect?”

Although the debate about these ideas—i.e., using the master's tools—is largely a public one, I believe that for many Indigenous scholars it is also a deeply personal journey that is not widely shared. For me, my interest in decolonizing and Indigenous methodologies is hinged to Indigenous personhood and it is this that both informs and complicates my research. I bring a beautiful and vibrant culture to research—and it comes from a deeply cultivated sense of connection to Indigenous identity, to a clan system, to a community and nation, to ceremonies, and to customs and protocols. As I described above, I draw on and incorporate Indigenous culture in my research. I also bring some baggage by virtue of having

almost been assimilated. My experiences of colonialism, the damage it has caused, make me highly suspicious, sceptical and fearful that somehow, no matter how carefully I tread, that I'll be seduced "into the colonial abyss with [the] promise of [academic] empowerment" (Grande, 2008, p. 234). For me, untangling and understanding the ways I'm impacted by colonialism remains a life's project. This project—to decolonize oneself—begins with me acknowledging that I'm enmeshed in colonialism but choose to mindfully act in ways that draw on Indigenous consciousness to build Indigenous renaissance.

Decolonizing research, when championed with Indigenous knowledges, can uncomfortably stretch Western scholarship by directing practitioners to embody the research process—to involve one's physical being, the emotional self, spiritual energies and our intellect (Simpson, 2011). My research experience suggests that doing so is an uncomfortable process when inside the academy. Yet, I also understand that the angst I experience is necessary if Indigenous knowing is to flourish within the academy. According to McIsaac (2000, p. 100), "for those of us who participate in producing knowledge, there exists a moral imperative to become resituated as learners, and to engage in a process and relationship of learning that is based on indigenous knowledge" (see also Brant Castellano, 2000; McLeod, 2007). In a project, described earlier, focused on the resiliencies of two-spirit men living long term with HIV, we struggled with the idea of internal consistency among our various methodological and epistemological approaches

(interpretative, participatory, decolonizing/Indigenous). Using the Medicine Wheel as a tool to code our data, we were concerned with the idea of internal consistency. Did Indigenous knowledges as a methodological approach fit with how we gathered (i.e., focus groups) and understood the data (i.e., grounded theory)? We also struggled with the idea of diversity in Indigenous knowledges and whether it represented our study participants' diverse Indigenous cultures. Similarly, we questioned matters of validity, whether the relational in Indigenous knowing could adequately counter our assessment of the rugged individualism we feel is embodied in Western science. Although we'd been trained to resolve tensions in research, we were also cautiously optimistic that such tension might, in fact, be a site of positive and productive methodological development. In attempting to better understand, we began the process of reframing some important ontological, epistemological, methodological and axiological implications with ideas that these four aspects often have material, discursive, and transformative qualities. In terms of ontology, for example, we reframed our process as embodied and experiential (i.e., drawing on our cultural understanding of health that we shared with our non-Indigenous allied team members); acknowledged the shared epistemological underpinnings in our methodological approaches (i.e., critical, interpretative, empirical); and we came to a place that supported the idea that our decolonizing methodology speaks also to our shared experiences of colonization; and finally that our research could be guided by an

ethic that privileged the idea of “retraditionalization” of research (Walters, et al., 2009) with the *Anishinaabe* principle of *mamowenchike* (i.e., mutual respect and responsibility for one another).

Although I’m buoyed by the notion that Western science has helped me develop the skills to resist Western colonialism in research, I recognize that if I’m not acting in ways consistent with my culture these efforts will be stymied and bound to fail. I’ve reached a place that is supportive of what Simpson & Smith (2014, p. 9) have labeled “intellectual promiscuity”—the Indigenous project for intellectual sovereignty need not occur in isolation from the West. In fact, there is much common ground. The development of decolonizing research, for example, has been influenced by the family of participatory methodologies and post-colonial, feminist, postmodern, and critical race theories, etc. (Cannella & Manuelito, 2008). What all these approaches have in common are a core set of unifying principles that include a commitment to social justice. The resulting dynamic, according to Denzin and Lincoln (2008a), is a focus on performance, interpretative pedagogies, and the development of theories of power, truth, and ethics. Taken together, some have argued that this is what makes Western theoretical approaches useful, if not congruent, with decolonizing and Indigenous methodologies. Nevertheless, tensions between Western and Indigenous methodologies remain and one promising strategy is the development of two-eyeing as a way of learning to live with methodological angst.

Two-Eyed Seeing: Solution or Red Herring?

A critical social science perspective embraces the idea that there are many ways of knowing the world. Widely considered a new research approach, principles of two-eyed seeing are gaining popularity among health researchers investigating a range of Indigenous health issues (Hall, Dell, Fornssler, Hopkin, & Mushquash, 2015). Two-eyed seeing in research contexts elevates the idea that “diverse perspectives might work together to answer our most pressing questions about the health of Indigenous people and communities” (Martin, 2012, p. 22). First developed as an approach to providing culturally grounded education for Indigenous students in Western academic settings, two-eyed seeing refers to seeing and understanding the world “from one eye with the strengths of Indigenous ways of knowing, and from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together” (Hatcher & Bartlett, 2010, p. 16; see also Barlett, Marshall and Marshall, 2012; Hall, et al., 2015; Iwama, et al., 2009; Martin, 2012; Marsh, et al., 2015). According to Hall and colleagues (2015, p. 5), use of two-eyed seeing in research reflects efforts of health researchers to apply “the tools of Western science from within an Indigenous worldview.”

Ultimately, the promise of two-eyed seeing rests on the potential it holds as a research approach towards supporting Indigenous identity as grounded in culture that is tied to the land and to language. Importantly, this framework is

used as a strategy to mitigate, manage or respond to tensions researchers experience when weaving Indigenous and Western research processes (Hall, Dell, Fornssler, Hopkin, & Mushquash, 2015). Similarly, Martin (2012) recognized that two-eyed seeing promotes critical appraisal about ways knowledge gets created and inspires approaches that uphold Indigenous world views in research contexts. Indeed, when coupled with reflexivity, use of two-eyed seeing can promote ‘intellectual promiscuity’ and draw on the strengths of both Western and Indigenous research traditions (Simpson & Smith, 2014). Two-eyed seeing can ultimately work to ground research in the perspectives, values and world view of those who originally experienced these phenomena (McLeod, 2007). In doing so, another goal in using two-eyed seeing relates to blending disparate forms of Indigenous and Western ways of knowing and investing in and developing research “relationship[s] of mutual cultural respect, wherein the benefits of both world views are acknowledged as beneficial in healing processes” (Marsh, Cholic, Cote-Meek, & Najavits, 2015, p. 5).

Initially, like scholars before me, I was excited by the promise of two-eyed seeing to assist in resolving what I experienced as tensions between Indigenous and Western ways of knowing. In fact, across a range of projects, we often write two-eyed seeing into our grant applications and use two-eyeing as a conceptual device that allows for inclusion of Indigenous knowledges. In the resiliency project described earlier, for example, we used grounded theory (i.e., open, axial,

and selective coding) to assist with mapping data to the Medicine Wheel. Once mapped, themes and meaning were generated consistent with Indigenous knowledge (Jackson, Brennan, Georgieski, Zoccole, & Nobis, 2017). Although the approach proved fruitful and allowed for diverse expertise across Western/Indigenous knowledge systems (Rowan, et al., 2015), earlier I had been questioned by a community member about whether I was selling out by ignoring the power of Indigenous ways of creating knowledge. As much as two-eyed seeing provides some direction about the use of Indigenous knowledge in research contexts, it also raises these kinds of uncomfortable questions: Does use of two-eyed seeing make Indigenous scholars less Indigenous and more likely to favour Western approaches despite rearticulating them through an Indigenous lens? My experience suggests that tensions remain—between the desire to conduct Indigenous research fully within Indigenous knowledge systems, with community expectations that often express a realistic need for culture to be woven into the research process, and with use of Western ways of conducting research. Despite troubling questions, I am supportive of efforts to use two-eyed seeing in research. However, I feel that it needs to be cautiously adopted with continued focus on the goals of decolonizing methodologies that challenge research as a colonial practice.

What makes Indigenous Scholarship, Indigenous?

For me, as I've pointed to earlier, the use of Indigenous knowledge in social science research is not easily travelled and several critical questions can be raised: How do we assess authenticity, validity, or verify that Indigenous knowledge has been used in good ways? Does Western science offer anything practical in terms of affirming Indigenous identity in research? Do principles of two-eyed seeing offer some way of mediating the tensions associated with using Western approaches or is use of Indigenous knowledge made more problematic? Although Western academia is gradually recognizing Indigenous knowledges as a system of philosophy that can be used to know the world (Rheault, 1999), bringing the social science research into relationship with the lives and experiences of Indigenous peoples remains extremely challenging. “‘Talk[ing] back to’ and ‘talk[ing] up to’” to borrow from Smith (Smith, 2014, p. 2), “implies [...] having confidence in and deploying Indigenous knowledge, among other things, to bring about economic and social progress” (Briggs, 2005, p. 100). Part of the challenge is embracing Indigenous knowing and using that knowing knowledge? to address the questions posed above. According to Castellano Brant (2000, p. 30):

The holistic quality of knowledge implies that isolating pieces of experience and trying to make sense of them apart from the environment that gave rise to them flies in the face of reality and is

bound to lead to frustration. This does not mean that analysis of parts of the circle of life is to be dismissed; it simply means that analysis must be balanced with synthesis—placing the part that we come to know [in] close analysis in the context of all its relations, which will continually impact that which we thought we knew, and thereby transform it.

In asking questions about whether research uses and reflects Indigenous knowing, perhaps we've committed a Eurocentric error (Cannella and Manuelito 2008). In other words, the questions may reflect a Western bias we need to “challenge, discard, or transcend” (Strega, 2005, p. 211). Rather, any evaluation of decolonizing and Indigenous methodologies is best when it is grounded and embedded in an Indigenous world view. In terms of self-evaluation, we ask whether the work we've accomplished reflects Indigenous knowing and experience in all phases of the research, from design to dissemination. Here, the idea of “all my relations”³ proves helpful. In what ways does the research refract Indigenous knowledges? We are extremely interested in evidence of its use in all stages of the research process. In what ways are the participatory aspects of research participatory (i.e., involvement of Elders and community investigators,

³ The notion, “all my relations,” expresses the sentiment that all things (people, plant life, wildlife, spiritual realm) are interconnected. As researchers, “all my relations” reminds us of our accountability and responsibility to consider this broad context as we develop our research approaches, methods and analysis.

etc.)? Is participatory involvement supportive of decolonizing efforts to challenge colonialism? Given the cosmological orientation of Indigenous knowledge, if we accept that the development of knowledge is a sacred pursuit, in what ways have we incorporated ceremony into the design of data gathering and analysis? And finally, are findings supported by Indigenous peoples? In virtually every project I've been involved in we've established validity through member-checking processes. We do this with participants and the broader Indigenous community—asking whether we've got it right. Efforts made to valid Indigenous knowledge from within Indigenous knowledge systems is critical toward producing new knowledge that is entirely consistent and supportive of Indigenous identities.

Discussion and Conclusions

In reflecting on my research experience as central to the notion of a critical disposition, I'm reminded that reflexivity is a 'journey' and not an 'end goal'. Ongoing reflexivity in Indigenous research contexts is meant to assist with problem solving, and encourage the use of critical reasoning to help untangle and move forward. It is as others have also pointed out: that without reflexivity we may inadvertently "become fixated on a simplistic [decolonization] of Western knowledge and [its research practices]" (Nakata, Nakata, Keech, & Bolt, 2012, p. 120). Reflectivity pushes scholarship in new directions, potentially generates new understanding, and creates new Indigenous knowledges that are grounded in the

world views, beliefs, perspectives and values of Indigenous peoples. As Nakata and colleagues (2012, p. 120) aptly summarize, such an approach “encourage[s] openness to further inquiry and productive ways of thinking in and through complex and contested knowledge terrains.” Reflexivity in Indigenous science matters. Continual assessment of the ways Indigenous scholars apply their craft to complex health and social problems can potentially open space to also consider the ways lived experience, and more importantly, how the meaning of experiences is culturally mediated in ways that consider the value of understanding the interconnectedness with all other things.

Critically focused Indigenous HIV research is not a simple matter. Embracing Indigenous HIV research involves navigating complex theoretical tensions between Western and Indigenous approaches, the deft use of two-eyed seeing to address the pull towards sole use of Western theoretical foundations, and challenging issues about assessing validity in the use of Indigenous knowing in social science research. Like Swadener & Mutua (2008, p. 36), I too have “confronted the likelihood that decolonizing research is messy, complex, and perhaps an impossible endeavor—yet have affirmed that attempting to decolonize one’s work is a project worth pursuing.” As much as learning about Indigenous research and decolonization has been about professional development, it has also inspired personal growth and healing. I’ve learned that the notion of ‘intellectual promiscuity’ is important but is likely best practiced when coupled with two-eyed

seeing that embeds the values of sensitivity, humility and respect, as much maturity, skill, and knowledge (Smith, 1999; Simpson & Smith, 2014). Having noted this, however, I will not say that I have answers to all my critical questions about the Indigenous research endeavour, but I do believe I have gained as much as I offer. Despite tensions, for example, decolonizing, participatory and Indigenous research can be a catalyst for real change and the meaningful involvement of Indigenous knowing in research. As Brant Castellano (2000, p. 33) writes, “The ultimate test of the validity of knowledge is whether it enhances the capacity of people to live well [and whether] new formulations of old wisdom can best be tested in the crucible of everyday life.”

Chapter Six

A Research Note

Western ways of knowing are powerful in terms of its ability to construct Indigenous identity—and if we aren't careful—it is an approach that describes Indigenous people in ways that prescribe to us who we are and how we understand and experience life. Western ways of knowing—and particularly the language of Western research—often ignores the power and beauty of Indigenous cultures to bring healing and wellness. It is often done in ways that pathologize Indigenous people (Reading & Nowgesic, 2002) and in ways that have negative material consequences for Indigenous peoples. It is this—through this dissertation—where I hoped that I might add my voice and experience with other Indigenous scholars who are actively resisting.

In a presentation at the Ontario HIV Treatment Network conference (Peltier, Jackson, & Nowgesic, 2012), colleagues and I quoted a Haudenosaunee Elder, who wrote the following:

“My people never knew or had any position in life except the face of the earth—stretching away from them in all directions forever. And they lived there laterally—on one level with each other and all things. They looked up only to trees and eagles ... [and] by reading our own footprints we could

always tell where we had come from. In fact, we had no future. In our language, the closest word we had to future was sort of an arc or circle. Our going was part of the arc of a circle. So was our coming.”

Although I’m Anishinaabe, and this writer is Haudenosaunee, when I first read his words, there was a resonance that for me grounded in my own cultural identity. It had an orienting effect, particularly when we consider the poor history of research that has been conducted ‘on’ and not ‘with’ Indigenous peoples in Canada. It helped me build an argument that goes something like this—that attending to and including one’s cultural identity in research contexts, is not only an ethical, but a moral imperative that we as researchers have when learning about our lives as Indigenous peoples. To be clear, when we include who we are as a people to shape research, when we include our languages to describe our knowledges, we are committing to and supporting the act of cultural continuity. In short, we support our own health, our own well-being, and the health of Indigenous communities. To be useful, beneficial, and supportive of cultural identity in research, we need to carefully attend to the way in which research is planned and conducted. But more importantly, and closer to the idea I want to share here, when we embed Indigenous culture in what we do as researchers, we potentially shape a more holistic and powerful image of who we are as Indigenous peoples. Certainly, it is far better to produce research and findings that highlight our strengths and beauty as Indigenous peoples, even in contexts where we may

live challenging lives. This dissertation attempted to share a more rounded story about Indigenous peoples' experience of HIV and depression than more normative and Western approaches simply focused on our pathologies that were produced through the operation of colonialism.

The earlier quote also reminds me how vitally important it is to say a bit about myself. My way of knowing has always been directly and indirectly related to my own position in the stories I shared as part of this dissertation—as a person who lives with HIV and has in the past experienced depression. I've been impacted by the ways Western science has documented how we as Indigenous have been made vulnerable by colonialism through poverty, poor housing, inequitable employment opportunities, negative early childhood experiences, et cetera. I think it is important that we as Indigenous scholars collectively resist these representations. We must consider them, as I hope I've done in this dissertation, as partial stories about who we are as Indigenous peoples. This statement is not made lightly—as I and other Indigenous scholars make clear—Western science has also produced a wealth of valuable knowledge that has helped our communities to respond. Like other cultural groups, and although the gap still needs to close, many Indigenous people are living longer and healthier with HIV. In fact, it is this point that provided the impetus for the focus of this dissertation. It was important to focus not solely on the violent operation of continuing colonialism, but it was more important to open and create space for Indigenous

knowledge to shape and share research findings. In other words, I framed much of the work I did do in this study with what I'm been taught as an *Anishinaabe* person growing up in southwestern Ontario. In fact, the geography of this place is stunningly beautiful—a land ripe with Indigenous teachings. Related to the story of the Thunderers and Water Serpents, for example, my community is known for its unusual spherical rock formations that erode from the underlying shale beds along the shore of Lake Huron. These rock formations, also known locally as “kettles”, are unique to only three locations in the entire world, and wise storytelling Elders in my community might say—this is our traditional land and it a place where the Thunderers come to lay their eggs. I was taught and live my life firmly connected to this place and the knowledge it contains—and it is an experience, reflecting on this now, that I now understand as largely responsible for any health and well-being that I experience in my life today. I'm rooted in this place, it is where I belong, where I was born and raised, and it provides me a firmly rooted sense of Indigenous identity embedded in culture and its traditional teachings—it is something I wanted to draw on and use in this dissertation as something that even colonialism failed to sever.

In using story and storytelling in this research, I was also heavily influenced by Thomas King's take on stories (King, 2003). As part of a *Massey Hall Lecture Series*, he shared several principles about stories that I found instructive in terms of how we might begin to understand research stories told

about us as Indigenous peoples. King (2003) shared, as part of this lecture series, that the truth about stories is that is all we are, that you cannot understand the world without telling a good story, and that if you want to change the world—or at the very least, our lives in it—then we need to tell different stories. He also wrote about how stories can be wondrous things and dangerous at the same time.

Take, for example, the material story about the power of Western knowledge to shape Indigenous identity. Up until recently—in the last fifteen plus years or so—Canada had an appalling history of researching Indigenous peoples. To borrow a statement from Smith (1999, p. 1), “the word ‘research’ is probably one of the dirtiest words in the Indigenous vocabulary.” Complaints about research often centred on several arguments that include, for example, the notion that Aboriginal people have been “researched to death,” that research is often initiated by and carried out by non-Indigenous people, and that it is consequently driven by pure academic interest with little or no attention to notions of community relevance. Indigenous communities too, have historically been treated merely as convenient sources of data. Researchers, for example, have often simply “helicoptered” or “parachuted” into communities and focused solely on individual and community deficits. They did little to no meaningful community engagement or knowledge transfer and exchange, so that Aboriginal communities could benefit from their work. Consequently, many Indigenous scholars and

people believed that research was simply used as a tool to justify racist and assimilation policies.

Not only can Western scientific discourse justify continued paternalism and colonialism—but it can and has been used to ignore suffering in dispassionate, rational, objective ways. If we contribute to this, if we allow it to continue, perhaps we unwittingly ally ourselves to the interests of those in power—that is—we help maintain scientific power and privilege at the cost of doing continued violence to Indigenous peoples. In fact, as O’Neil, Reading and Leader (1998) share with us, portraits of Indigenous sickness and misery can and often act as powerful social instruments for the construction of Aboriginal identity. Epidemiological knowledge—knowledge about incidences and distribution diseases—constructs an understanding of Indigenous society that reinforces unequal power relationship. It is language that can, perhaps, support the notion, “I’m only here to help you, that you are unable to help yourselves.” In fact, when we are taught through Western science that strife and challenges are the only thing of value to explore about Indigenous peoples—it blinds us and it becomes the only thing we can see about Indigenous peoples. The beauty of our essence, as Indigenous peoples, becomes blurred or hidden from view. In other words, perhaps through the language of science, we only ever get to see images of sick and disorganized communities that can be used to justify continuing patterns of paternalism and dependency. This dissertation—although not a goal or

objective—was shaped by the following question: When it comes to Indigenous peoples who live with HIV and depression, who gets to decide what this means? Is it researchers who have the authority to define us through our illnesses? Is it ourselves? Perhaps I already had the answer to these questions. According to Cook-Lynn (2008), scientific research is the dominant master narrative and its ability to powerfully shape Indigenous lives is based on ‘an arrogance that is unremitting’ and that this often ‘leads to distortion.’

It is this that needed, through this dissertation, to be interrupted. In attempting to think through, this dissertation I was also inspired by Vizenor’s “Manifest Manners” (1994) and particularly, his ideas of “survivance” and the ‘post-Indian warrior.’ As I understand these terms, they express a form of resistance and a form of self-determination. Survivance merges survival with endurance by inserting, as a form of resistance, new images of Indigenous peoples that are decidedly post-Indian; in other words, to be a post-Indian warrior is to challenge dominant colonial representations of Indigenous peoples. In resisting, through this dissertation, it was important to do, as McKegney (2007) suggested, to ‘touch ourselves into being with words’, and to begin to resist the Western scientific language of research from a place of cultural strength.

In drawing on *Anishinaabeowin*, a language I consider powerful as well as beautiful, and embedding this throughout this dissertation, I hoped to touch the

spirits of Indigenous people and to use research findings in ways that enabled a new way of seeing and being—perhaps in ways our ancestors and Elders imagined we would do. As I was working on this dissertation, my colleague and friend—Doris Peltier (2012)—introduced me the idea of *n'ginaajiwimi*. Roughly translated, it refers to the essence of Indigenous peoples as beautiful. It is this idea that I wanted to reflect in my dissertation. My desire was to give readers with a felt sense of Indigenous experience—I hope you too, the reader, discover the beauty of our cultures. Take another word, learned as I moved through this preparing this dissertation, *debewin*. Again, roughly translated, it is a word that refers to ‘expression from the heart’ or the ‘truth as we know it.’ When we speak from the heart, it means our spirit is speaking with you. It is our way of bridging mind and heart knowing. And so, lastly, I hope this dissertation has conveyed some this ‘heart knowing’ to you as a reader.

Prior to returning to school a few years ago—after I had worked for several years as a community investigator examining HIV/AIDS in Indigenous communities—there are a couple of lessons I’ve learned that grounded me as I wrote this dissertation. The first is that it is essential that I interrogate and critically evaluate research that is shared with me. It is important, in other words, to ask whether Indigenous lives have more meaning, does the research support the kind of Indigenous identities they want for themselves, does the research reveal the ways they are connected to land, living meaningfully, contributing to

community health, etc. As I wrote this dissertation, I often found myself moving out of my comfort zone in sharing a bit of my own story. But—by inserting ourselves into the research that we do, “we assume responsibilities—responsibilities that are not necessarily bestowed upon us by the collective, but that we take on these things we do, our tasks and our involvement” in Indigenous scholarship, and we do so “according to our own gifts, abilities and affiliations. We place these things we know about the world in the context of own personal lives, in an emotional, physical, spiritual and intellectual way” and we reciprocate and give back (Simpson, 2011). It is my hope that this dissertation imparts a bit about Indigenous experiences of HIV and depression through Indigenous eyes—how it can be understood, how it unfolds, how I take care of myself by continuing to reclaim and live my culture and bring that into research, and how I try to give back for all that I’ve received. In as much as I experienced the rigors of PhD studies, it has also been absolute honour and joy!

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