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Getting the Canadian HIV epidemic to zero: Valuing indigenous cultures through holistic research

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ABSTRACT

This paper was orally presented at the Canadian Aboriginal AIDS Network, Wise Practices IV – Community-Based Research Gathering on September 25, 2013 in Saskatoon, Saskatchewan, Canada as the LaVerne Monette Memorial Lecture. The objectives of this paper are: (1) to describe the HIV epidemic among Aboriginal people living in Canada; and (2) to examine the value of incorporating indigenous cultures into research within the context of holistic research perspectives. The methodology used to address the objectives was an integrative review (i.e., structured review) of the literature. The major results of this review revealed that while Aboriginal people make up 3.8% of the Canadian population, they represent 12.2% of all new HIV infections in 2011. In 2011, a full 81% of newly diagnosed HIV cases in the Province of Saskatchewan were of Aboriginal ethnicity. Although there are diverse approaches to conducting research involving Aboriginal populations (e.g., critical social paradigm, indigenous research paradigm, and critical indigenous pedagogy vis-à-vis critical, indigenous qualitative research), each has its unique challenges. This paper concludes that Aboriginal people are overrepresented in the Canadian HIV epidemic and that valuing indigenous cultures through holistic research perspectives has the potential to get the Canadian HIV epidemic to zero.

I orally presented this paper at the Canadian Aboriginal AIDS Network, Wise Practices IV – Community-Based Research Gathering on September 25, 2013 in Saskatoon, Saskatchewan, Canada.

It's a great honour for me to deliver the LaVerne Monette Memorial Lecture here at Wise Practices. LaVerne Monette (1953-2010) was a leader in the Aboriginal HIV movement.

Before I begin, I would like to acknowledge the Plains Cree, Saulteaux, and Dakota/Sioux Nations whose traditional territory we are on today. There are many other groups and individuals I would like to recognize, but in particular the Canadian Aboriginal AIDS Network; my PhD thesis committee, Dr. Ted Myers, my supervisor, Dr. Cameron Norman and Dr. Kue Young; SHARE, which stands for the Saskatoon HIV/AIDS Research Endeavour; and the funders who are supporting my research: the Canadian Institutes of Health Research (CIHR) Fellowship Program – Priority Announcement in Health Services/Population Health HIV/AIDS Research, and the University of Toronto-based CIHR Social Research Centre in HIV Prevention Student/Trainee Award Program.

The objectives of my presentation are twofold: (1) to describe the HIV epidemic among Aboriginal Peoples living in Canada; and (2) to examine the value of incorporating indigenous cultures into research within the context of holistic research perspectives.

HIV, ABORIGINAL POPULATIONS AND CANADA

According to the 2006 Canadian Census, Aboriginal people make up 3.8% of Canada's population (Statistics Canada, 2006). The Aboriginal population grew rapidly over the previous decade and continues to grow. It is comprised of First Nations (59.5%), Metis (33.2%) and Inuit (4.3%) (Note: Other Aboriginal responses account for the remaining 3%).

There is an increasing burden of HIV infection among Aboriginal populations. Although the first AIDS case in Canada was diagnosed in 1979, it was not until the 1990's that the HIV epidemic noticeably affected the Aboriginal population (Archibald, Sutherland, Geduld, Sutherland, & Yan, 2003). By 2011, Aboriginal people accounted for 8.9% of the estimated 71,300 people living with HIV in Canada (Public Health Agency of Canada, 2012c). Furthermore, in 2011, Aboriginal people accounted for 12.2% of all incident HIV infections in Canada at a point estimate of 3,175 with a range of 2,250 to 4,100 (Public Health Agency of Canada, 2012c). From 1998 to 2008, in comparison to the non-Aboriginal population, HIV exposure categories in the Aboriginal population were more likely to be injection drug users (60% vs 23.4%), women (48.8% vs 20.6%), people under the age of 40 years (69.5% vs 57%), and people between the age of 15 and 29 years (32.5% vs 20.6%) (Public Health Agency of Canada, 2010).

There is a unique health risk contributing to the HIV epidemic. The development of HIV drug resistance is associated with sub-optimal antiretroviral (ARV) therapy and non-adherence to ARV therapy (Little et al., 2002; Public Health Agency of Canada, 2012a; Wainberg & Friedland, 1998). In Canada, from 1999 to 2008, 9.8% of newly diagnosed, treatment-naïve people were HIV drug-resistant (Public Health Agency of Canada, 2012a). "Some of the increase observed for the time period 2004-2008 [in Canada] was likely due to an increase primarily in the Province of Saskatchewan during each of those years" (Public Health Agency of Canada, 2012a, p. 18).

Given that my current research concentrates on the Province of Saskatchewan (and specifically, the cities of Saskatoon and Prince Albert), I would like to highlight the HIV epidemic within this

province. For the one-year period of 2011, the HIV diagnosis rate for the adult population of Saskatchewan as a whole (non-Aboriginal people and Aboriginal people) was 19.6 per 100,000, which was 2.5 times the national HIV diagnosis rate of 7.6 per 100,000 for the same period (Public Health Agency of Canada, 2012b). There was an increased trend in HIV drug resistance from 1999 to 2008 (p < 0.0001) with an overall transmitted drug resistance in Saskatchewan estimated at 15.1% (Public Health Agency of Canada, 2012a). In 2011, a full 81% of newly diagnosed HIV cases (150) in Saskatchewan were of Aboriginal ethnicity (Saskatchewan Ministry of Health, 2012).

In Saskatchewan, "[t]he median length of time between being tested positive for HIV and being diagnosed with AIDS in 2011 was 16 months (range 0 to 14 years)" (Saskatchewan Ministry of Health, 2012, p. 6). Also in 2011, 24 AIDS cases were reported in Saskatchewan, and nearly half of them (11/24) died in the same year (Saskatchewan Ministry of Health, 2012). According to the Saskatchewan Ministry of Health (Saskatchewan Ministry of Health, 2012):

> *six of 24 AIDS cases in 2011 had their initial HIV test at the same time they were diagnosed with an AIDS defining illness. Three who were first tested for HIV and diagnosed with AIDS in 2011 passed away the same year (p. 6).*

Aboriginal people living in Canada are overrepresented in the HIV epidemic. HIV among Aboriginal people is an important research problem which needs to be further studied, particularly given the high burden of HIV among Aboriginal populations as well as the emergence of drug-resistant strains of HIV.

I believe that valuing indigenous cultures through holistic research perspectives is instrumental in getting the overall Canadian HIV epidemic to zero. However, it is important to ensure that holistic research perspectives incorporating indigenous values are focused and have manageable parameters. To this end, I believe that such research should be supported by theoretical frameworks that are consistent with indigenous cultures.

HOLISTIC RESEARCH PERSPECTIVES

One framework that can support research valuing indigenous cultures is critical, indigenous qualitative research. Essentially, critical, indigenous qualitative research is a holistic research perspective that acknowledges the theoretical underpinnings of a critical social paradigm (which is related to decolonizing methodologies) but pays explicit attention to the indigenous axiology (or the study of values) that is central to an indigenous research paradigm. To explain what a critical, indigenous qualitative research paradigm is, I must first explain what both a critical social paradigm is and what an indigenous research paradigm is in terms of their theoretical and philosophical foundations. And because their foundations are defined by ontology and epistemology, I will start with two quick definitions.

Ontologies, according to one serviceable definition, "are beliefs about the basic entities that make up reality" (Giacomini, 2010, p. 129). As a philosophy of the nature of existence (Abercrombie, Hill, & Turner, 2006), ontology considers the nature of values and how such

values relate to a phenomenon in question (Giacomini, 2010). But if ontology concerns the relation of values to phenomena, it also concerns the potential of values, whether good or bad, to prompt action that affects social phenomena (Giacomini, 2010). In other words, "How does one's way of being potentially effect social change?" Now, if I am to understand the essential phenomena of my substantive research topic based upon the socially constructed ontological beliefs of my study participants, then I must not only generate knowledge but I should understand the nature of that knowledge.

To understand phenomena, researchers use epistemologies (Giacomini, 2010) that can be thought of colloquially in the form of the question: How do we know what we know? Asking ourselves how we know what we know about a research phenomenon is a necessary precursor to generating a good research question because epistemology will influence our research methodology (Carter & Little, 2007). The simple fact is that an ontological stance—the researcher's own belief system and the belief system of research participants—flows into a researcher's epistemological approach—the way the researcher ask questions and conducts research with study participants.

CRITICAL SOCIAL PARADIGM

A critical social paradigm (CSP) has an idealist ontology that is based upon historical realism and it has a subjectivist/transactional epistemology where findings are ultimately agreed upon by weighing the values of people in a particular time and place (Giacomini, 2010; Guba & Lincoln, 2005). This paradigm creates new knowledge by interpreting qualitative data ideologically or creatively (Giacomini, 2010). The reality of the interpreted data exits in the mind of the person who creates the interpretation. The philosophy of *idealism* posits that reality is not independent from the mind (Schwandt, 2007). But it is also the responsibility of the researcher practicing such subjective idealism to understand that "the external social reality cannot exist independently from the everyday interactions and subjectivity of social actors" (Abercrombie et al., 2006, p. 189). The ontology of idealism dictates that the world has qualities which relate to our own ideas and "that we have direct access only to our ideas and subjective experiences, and no empirical access to the world beyond, except through these ideas" (Giacomini, 2010, p. 131).

From a CSP perspective, the research findings that result from interpreting data according to the standpoint of marginalized parties have the capacity to create more equitable power relations (Giacomini, 2010). Researchers using a CSP "assume that hegemonic interests have constructed the prevailing accounts of reality" (Giacomini, 2010p. 133). In order to counter these prevailing assumptions, researchers challenge the social, economic and political agendas behind hegemonic accounts of reality (Giacomini, 2010). However, in an Aboriginal context, notwithstanding the potential of a CSP to combat paradigms that favour colonialist perspectives, it has failed "to address how indigenous cultures and their epistemologies were sites of resistance and empowerment" (Denzin & Lincoln, 2008, p. 9). In response to this negative consequence, indigenous people as a group have often resisted research that uses a CSP and instead only engage in research that meets their best interests (L. T. Smith, 2005). In this case, indigenous people as a group "can be defined as the assembly of those who have witnessed, been excluded from, and have survived modernity and imperialism" (L. T. Smith, 2005, p. 86) and include

those "who identify their ancestry with the original inhabitants of Australia, Canada and other countries worldwide" (Wilson, 2008, p. 34).

One Aboriginal research initiative that seems to build upon a CSP is the Kaupapa Maori research (Bishop, 2005). Specific to New Zealand, this research challenges the dominant discourse and preferences "the need to recognize and address the ongoing effects of racism and colonialism in the wider society" (Bishop, 2005, p. 128). Kaupapa Maori research privileges practices with an indigenous viewpoint by focussing values within an indigenous-centred research paradigm as opposed to translating them from, or disguising them within, a dominant discourse of Western methodologies such as collaborative research (L. T. Smith, 1999). Promising as this approach is, one must always heed the caution of Kovach (2009) that such research risks being sublimated in the Western colonizing perspective.

Kovach (2009) has argued that an indigenous-centred research paradigm that is incorporated into a CSP is characterized in relation to its approach to decolonizing methodologies, and is thus still consistent with the theoretical underpinnings of Western critical approaches because such indigenous frameworks are still based within a critical theoretical perspective. Decolonization speaks to "the reevaluation of the political, social, economic, and judicial structures themselves and the development, if appropriate, of new structures that can hold and house the values and aspirations of the colonized people" (Burgess, 2000, p. 155). This conceptualization of *decolonization* is not restricted to governance but transcends all sectors including culture, language and psychology, in order to divest colonial power (L. T. Smith, 1999). "Kaupapa Maori is a 'local' theoretical positioning which is the modality through which the emancipatory goal of critical theory, in a specific historical, political and social context, is practised" (L. T. Smith, 1999, p. 186).

To summarize, neither a CSP in general nor a CSP incorporating an indigenous framework to understand phenomena experienced by indigenous people, adequately explain some of the most pressing social issues faced by indigenous people (Denzin & Lincoln, 2008; Kovach, 2009; L. T. Smith, 2005). So it is important to examine a second research paradigm in more depth.

INDEGENOUS RESEARCH PARADIGM

An indigenous research paradigm (IRP) is considered to be non-Western in terms of its ideologies (Wilson, 2008). Researchers who employ an IRP can be described as Indigenists (Denzin & Lincoln, 2008). From a methodological viewpoint, "Indigenists resist the positivist and postpositivist methodologies of Western science because these formations are too frequently used to validate colonizing knowledge about indigenous peoples" (Denzin & Lincoln, 2008, p. 11). Unlike a CSP, which interprets data in order to level the playing field of power relations between marginalized and hegemonic groups, an IRP uses interpretative research strategies such as testimonies and personal performance narratives that are specifically appropriate to the lived experiences, including the culture, language and traditional values, of indigenous people (Baskin, 2005; Denzin & Lincoln, 2008). The challenge here is to avoid having these strategies exploited by researchers unfamiliar with their unique interpretive strength. As Battiste (2000) writes: "the heritage of an Indigenous people is a complete knowledge system with its own concepts of

epistemology, philosophy, language, and scientific and logical validity that needs protection from Eurocentric exploitation" (p. 195). Eurocentrism describes the preferencing by Western academics of European ideologies over non-European standpoints (Henderson, 2000). An IRP is not rooted in a dominant discourse in the way that a Western paradigm such as the CSP is, and it should not be compared to non-indigenous ideologies as a way of validating its legitimacy (Baskin, 2005; Wilson, 2008), especially considering that indigenous ways of knowing predate the participatory and narrative approaches recognized today by the dominant discourse as legitimate forms of research (Baskin, 2005).

Wilson (2008) explains that the ontology and epistemology of an IRP is specifically defined by Aboriginal cultures. It has both a relational ontology and a relational epistemology (Wilson, 2008). Unlike the idealist ontology and historical realism of the CSP, the nature of reality in indigenous research paradigms is based upon sets of physical, mental, emotional and spiritual component relationships (Baskin, 2005). "Therefore reality is not an object but a process of relationships, and an Indigenous ontology is actually the equivalent of an Indigenous epistemology" (Wilson, 2008, p. 73).

Battiste (2008) claims that the epistemology of an IRP is based upon the immediate ecology of indigenous peoples and requires drawing from:

> *experiences, perceptions, thoughts, and memory, including experiences shared with others; and from the spiritual world discovered in dreams, visions, inspirations, and signs interpreted with the guidance of healers or elders. Most Indigenous people hold various forms of literacies in holistic ideographic systems, which act as partial knowledge meant to interact with the oral traditions (p. 499).*

The epistemology of an IRP involves the dynamical interaction of variables which are forever changing. Indigenous knowledge then is a "relationship within the global flux that needs to be renewed, kinship with the other living creatures and life energies embodied in their land, and kinship with the spirit world" (Battiste, 2008, p. 500). As Wilson (2008) proposes, the epistemology of an IRP is derived from multiple relationships interacting with one another, including personal, interpersonal, structural and, most importantly, spiritual relationships. Spirituality is an integral part of an indigenous worldview (Baskin, 2005).

An IRP has a methodology that is accountable to these relationships. And it has an axiology and value system that is based upon respectful, reciprocal and responsible relationships (Baskin, 2005; Wilson, 2008). This is relational accountability that has local relevance to a specific indigenous community (Baskin, 2005; Wilson, 2008). The methodology and axiology of an IRP as proposed by Wilson (2008) is consistent with the call by Denzin and Lincoln (2008) "for a collaborative social science research model that makes the researcher responsible, not to a removed discipline (or institution) but rather to those studied" (Denzin & Lincoln, 2008, p. 15). When researchers and the methodologies they employ are accountable to the research participants and the local indigenous community, then research ceases to objectify indigenous people and their knowledge (Baskin, 2005; Wilson, 2008).

An IRP, like a CSP, favours views that have been marginalized. Yet an IRP appears to be more relevant to a study of social phenomena experienced by indigenous people, given its unique concept of relational accountability. Although an IRP is not commonly used in the academy of health sciences, it is gaining some traction (Baskin, 2005; Lavallee, 2009; Rothe, Ozegovic, & Carroll, 2009). Unfortunately, when it comes to accessing the IRP epistemology with a methodology, such methodologies are not fleshed out enough in the existing literature.

Notwithstanding the limitations of both paradigms (i.e., a CSP and an IRP), I believe that a discussion can take place between the CSP and the IRP that will both aid social change in a way that is more culturally centred to indigenous people and that will support the further articulation of a dedicated IRP. I believe that a critical indigenous pedagogy vis-à-vis critical, indigenous qualitative research can offer strong support for ethical research involving Aboriginal populations.

CRITICAL INDIGENOUS PEDAGOGY VIS-À-VIS CRITICAL, INDIGENOUS QUALIATIVE RESEARCH

Critical indigenous pedagogy (CIP) is a term used by Denzin and Lincoln (2008) to describe the connection between critical methodologies and indigenous methodologies. CIP appreciates that research is political and moral and aims to attain social justice (Denzin & Lincoln, 2008). Although CIP seems similar to the purpose of a CSP, it actually gives greater value to indigenous, subjugated knowledge and its ability to transform social structures to support indigenous people (Denzin & Lincoln, 2008). As posited by Denzin and Lincoln (2008), a CIP "embraces the commitment by indigenous scholars to decolonize Western methodologies, to criticize and demystify the ways in which Western science and the modern academy have been part of the colonial apparatus" (p. 2). Decolonizing methodologies is a term used to describe the connection between an indigenous perspective and a Western ideology (L. T. Smith, 1999; Wilson, 2008). However, according to Smith (2005), to realize such a paradigm shift within the academy, it is important that indigenous researchers, other researchers, and indigenous communities work together to educate the wider academic community. This is the pedagogical aspect of critical indigenous pedagogy. Without such a connection, the dominant discourse of a colonial ideology leads to the continued destruction of indigenous culture (L. T. Smith, 2005).

According to Denzin and Lincoln (2008), critical, indigenous qualitative research connects indigenous and critical methodologies. When practicing critical, indigenous qualitative research, the investigator always needs to be aware of how research can and should advance the self-determination of indigenous people (Denzin & Lincoln, 2008). Critical, indigenous qualitative research should not be legitimized using neocolonial paradigms as a standard (Denzin & Lincoln, 2008). Furthermore, the researcher should be aware of the challenges associated with entering into any dialogue between indigenous and critical non-indigenous discourses. According to Denzin and Lincoln (2008):

> [f]irst, the legacy of the helping Western colonizing Other must be resisted…. Second…critical, interpretative performance theory and critical race theory, without modification, will not work within indigenous settings….Critical theory must be localized, grounded in the specific meanings, traditions, customs, and community

relations that operate in each indigenous setting…. [Third, c]ulturally responsive research practices must be developed. Such practices would locate power within the indigenous community (pp. 5-6).

As previously mentioned, the ontology of idealism concerns the nature of values. According to Giacomini (2010), "[r]esearchers who work with ideas-as-facts (idealist) cannot step outside their personal, social, or cultural perspective to view those ideas objectively" (p. 134). However, as a researcher who collects ideas-as-facts from my study participants, I must also contextualize them. In other words, whereas facts deal with "questions of what is….[v]alues, in contrast, concern questions of what ought to be" (Giacomini, 2010, p. 133). Investigation using critical, indigenous qualitative research "holds that values are inherent in all facts….[and that] values motivate researchers to ask certain research questions (and not others), so values drive the research enterprise" (Giacomini, 2010, p. 134). Consequently, epistemology, which is axiological or value bound, guides methodology (Carter & Little, 2007). In my own research, I value the subjective experiences of my study population as they are socially constructed, recognizing that my study participants' realty is what they perceive it to be and that it also has a reality within their environment, a socially constructed environment I am responsible for interpreting. The research implication here is that the realities of my study participants will be constructed by the subjectivist epistemological foundations of my study. The focus of my research is to understand HIV among Aboriginal populations from a holistic perspective.

CONCLUSION

Today, I presented the epidemiological data illustrating that Aboriginal people are overrepresented in the Canadian HIV epidemic. I showed how key concepts such as ontology, epistemology and methodology, could be used to conduct research with serviceable theoretical frameworks and I raised critical questions about theoretical design that is consistent with indigenous cultures. "Epistemology, methodology, and method are fundamental concepts…. However, qualitative research reporting is frequently insufficient in all three areas….[with methods generally being] the best reported. Articles are often silent and, worse, sometimes internally inconsistent with regard to epistemology" (Carter & Little, 2007, p. 1319).

My central argument stressed the value of using holistic research perspectives to address the HIV epidemic in Canada among Aboriginal people, while valuing indigenous cultures.

Given that the focus of this paper addressed the congruence between the theoretical and methodological frameworks of research addressing the HIV epidemic, I would like to end this paper by saying that such internal consistency between ontology, epistemology, values, theory, methodology and methods speaks to the overall issue of quality in qualitative research vis-à-vis meaningful coherence (Tracy, 2010). I believe that, by continuously and unfailingly valuing indigenous cultures through holistic research perspectives, we can genuinely strive to get the Canadian HIV epidemic to zero.

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